

R E V I E W

Right to be forgotten: European instruments to protect the rights of cancer survivors

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Abstract. *Background and aim:* Cancer survivors, even many years after their illness, are often excluded or discriminated against when they apply for loans, insurance coverage, child adoptions, and other aspects of social life. *Methods:* The authors conducted a search on the PubMed database using the keywords “cancer survivor” and “right to be forgotten,” also accounting for national and international legal, judicial and regulatory sources. The aim of the study is to analyze the scope of the phenomenon and identify suitable tools to counteract this discrimination. *Results:* Several European countries, including France, Belgium, Luxembourg, the Netherlands, Portugal, Romania, and Italy, have implemented laws specifically addressing the “right to be forgotten” for cancer survivors. This legal recognition stems from advancements in scientific research that have reduced cancer mortality and morbidity. These laws grant individuals the right not to disclose their past illness after a certain period of time after recovery, even when applying for financial and insurance services. The European Union has encouraged other states to enact similar legislation to ensure uniform protection for cancer survivors. *Conclusions:* The regulations that are put in place by some European countries currently provide essential support to cancer survivors, by facilitating access to insurance and financial products otherwise unavailable. However, relying on the expectation that scientific advances in cancer research will go forward, it is possible to envisage a future in which, regardless of regulations, the market itself will adjust and no longer discriminate against cancer survivors. (www.actabiomedica.it)

Key words: cancer survivors, cancer patient rights, right to be forgotten, discrimination, access to financial instruments, access to adoption, European laws, EU law

Introduction

In Europe, over 3 million new cases of cancer occur annually, affecting approximately 1.6 million men and 1.4 million women. A cancer diagnosis can have a devastating impact: treatments are demanding and often debilitating, the patient’s life is heavily affected, and the prognosis is not always favorable. According to the International Agency for Research on Cancer (IARC), nearly 4.5 million new cases of cancer occurred in Europe in 2022, accounting for 22% of the global figure, including nearly 2.5 million in men and just over 2 million in women (1).

The EURO CARE-6 study (2) estimated that by early 2020, 5% of the population in Europe had been diagnosed with cancer at some point in their lives, totaling 23.7 million individuals (12.8 million women and 10.9 million men). In Italy, according to the IARC, there were 436,242 new cases of cancer in 2022, considering both sexes, with a slight male predominance. The three most diagnosed types of cancer were breast, colorectal, and lung cancers. The number of cancer-related deaths amounted to 193,706 (3).

However, thanks to the advancements made in scientific research over the past three decades, a cancer diagnosis no longer amounts to a death sentence.

Especially when diagnosed early, cancer has a higher likelihood of being successfully treated. It is estimated that within the European Union, about 40% of cancers can be prevented, and there are more than 12 million cancer survivors (4).

Studies indicate that over half of cancer patients are still alive years after diagnosis, with an average increase of 20% compared to the 1990s (5-7). Thirty-five percent of these patients fall into the category of “long-term survivors,” i.e. those who were last diagnosed at least 10 years ago and have since experienced no relapse or recurrence. Such individuals reportedly have the same life expectancy as cancer-free individuals of the same age and similar sociodemographic characteristics (8). In Western countries, the number of cancer survivors increases by about 3% annually (5).

In Italy, the National Day of Cancer Patients was established in 2006, in order to raise awareness as to the impact of cancer in the lives of millions. During the latest edition, the 17th National Day of Cancer Patients celebrated on May 21, 2023, the 14th FAVO Report (Italian Federation of Voluntary Associations in Oncology) on the care condition of cancer patients was released. This report highlighted statistical data in Italy and emphasized that cancer survivors face discrimination at the socioeconomic level, particularly regarding access to banking and insurance services. Despite recovery, such individuals continue to be viewed as “cancer patients”, which entail an element of discrimination constraining their rights, even decades after recovery (9). Financial institutions often do not seem to deem cancer as a curable disease, hence risk assessment frameworks are not updated based on the individual’s current medical conditions. Therefore, according to a recent study conducted by the Irish Cancer Society (10), financial institutions consider the patient as a high-risk customer, and therefore require additional documentation and a health-centered survey before deciding whether to grant funding. Such a procedure requires the applicant to disclose any serious, current or past illnesses, compromising not only their right to privacy but also their likelihood of being granted the loan compared to applicants with no such a history. This occurs because financial institutions do not objectively and scientifically calculate risks, and insurance premiums fail to account for improvements

in patient survival rates. If the client/patient fails to disclose their illness, insurance companies may deny compensation, thus negatively affecting the lives of 75% of cancer survivors (10), who, according to the same study, believe they have not been treated fairly with respect to financial services.

Cancer survivors often face difficulties in simpler situations as well, such as enrolling in a gym, being issued a certificate of good health for sports activities, which are physically and mentally beneficial, and even more so for competitive activities. Similar challenges arise when they apply to renew their driver’s license or boating license, a firearms permit, and most importantly, when they seek to adopt a child. As far as adoption is concerned, it should be noted that cancer survivors may not have had the opportunity to undergo fertility preservation prior to cancer treatments (11-16). Such hurdles may therefore pose a major hardship for such patients, and like other forms of discrimination, they need to be addressed (16).

These are just a few examples of past illness which can still impair the recovered person’s ability to carry out daily activities. For these reasons, some countries have enacted laws to uphold the rights of cancer survivors (17), in order to guarantee non-discriminatory treatment and, above all, fair and equitable access financial services.

Materials and methods

The authors conducted a PubMed search using the keywords “cancer survivor”, “oncological oblivion” and “right to be forgotten” as search strings. National and international legal, judicial and regulatory sources were accounted for as well, limited to European countries. The study aims to assess the extent of the phenomenon in order to identify suitable tools to counter any discriminatory dynamics.

Results

The fundamental principle of the right to be forgotten for cancer patients, also known as the ‘right to oncological oblivion’, encompasses the notion of

‘medical oblivion’. Such a right enables individuals who have overcome cancer to refrain from disclosing their past condition after a certain period after remission. The notion of oncological oblivion is crucial for the preservation of mental and social well-being of cancer survivors, which is often jeopardized by unfair treatment in the workplace and in financing due to their past disease. Indeed, the World Health Organization defines health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’ (18). From this perspective, oncological oblivion aims to protect the mental and social well-being and viability of survivors, which may otherwise be compromised when their past illness leads to discriminatory treatment. Several studies stress how dealing with cancer, especially during childhood, can significantly damage quality of life, and is akin to a stressful event such as physical trauma, violence, or, to mention a more recent one, the COVID-19 pandemic (19, 20).

Oncological oblivion could help to prevent the dissemination of personal health records, thereby guaranteeing the same treatment and opportunities for cancer survivors as for anyone else. To claim this right, a certain number of years need to pass after recovery, which will naturally be determined and set based on scientific standards, e.g. survival rates of individuals at 5- and 10-years post-illness and last treatment. The right to be forgotten is therefore strongly influenced by factors such as disease type and scientific innovations (21).

The legislation in some European countries

Seven European states have already codified the right to be forgotten (Table 1) in order to eliminate any barrier which may constrain the freedom and rights of cancer survivors.

In recent years, France (22), Belgium (23), Luxembourg (24), the Netherlands (25), Portugal (26), Romania (27), and Italy have enacted legislation recognizing the right to oblivion for cancer survivors. Such pieces of legislation stipulate that the period within which banks and insurance companies can demand medical information cannot exceed ten years from the end of treatment. For cancer conditions arising before the age of eighteen (in Luxembourg)

Table 1. RTBF in European Countries

| Country | Legislation |
|-------------|---|
| France | Law No. 2016-41 amended by Law No. 2022-270 |
| Belgium | Law V 2019/40,839 |
| Netherlands | Decree enacted on November 2, 2020 |
| Portugal | Law No. 75 enacted on November 18, 2021 |
| Romania | Law 200/2022 |
| Luxembourg | Agreement between the Ministry of Health and the Association of Insurance and Reinsurance Companies |
| Italy | Law No. 193 of December 7, 2023 |

or twenty-one (in France, the Netherlands, Portugal, and Italy), banks and insurance institutions can only request information within five years after the end of active treatment, in the absence of recurrence within the same period (28). In Romania, Law No. 200/2022 prohibits the disclosure of any cancer condition, provided that seven years have elapsed since the successful completion of the treatment protocol, and only five years if the diagnosis was made before the age of eighteen. Based on proposals from cancer research institutes, the Ministry of Health establishes terms shorter than seven years, based on the age and types of conditions of cancer survivors, as well as scientific data regarding the types of diseases and therapeutic progress (27). France was therefore the first European country to recognize this right in 2016 (29) by ensuring that no information about their past oncological condition needs to be disclosed when the patient seeks insurance coverage (30). In Belgium, however, the law does not specifically provide for such a right, but rather recognizes a right not to be discriminated against based on information regarding one’s clinical history (23). In Italy, the latest country where a law for the right to be forgotten has been enacted, the debate has been moved forward thanks to national oncology associations, such as AIOM or LILT (31). An Italian piece of legislation enacted in 2023 (32-34) prohibits requesting information about a previous oncological condition after 10 years from the end of treatments, in the absence of disease recurrence during this period. For patients diagnosed before the age of 21, this limit is reduced to 5 years. Additionally, the Italian law is

currently the only one that stipulates that individuals who have been cured of cancer for more than ten years should not suffer discrimination when applying for adoption (33). The assessment of health status must be made on a case-by-case basis, taking into account a host of factors that vary significantly according to cancer types and individual features. With such an approach, not only is the cancer survivor protected, but the interests of minors and families are upheld as well (35). For example, there is a wide variety of breast neoplasms, some of which are less aggressive. Not surprisingly, national laws enacted so far also include a list of exceptions for tumors with “excellent” prognosis. In such cases, individuals may exercise the right to oblivion with even shorter time limits. The 2023 Italian legislation charges the Minister of Health with identifying, through a decree, the diseases for which different deadlines should be applied, to be updated every two years based on the therapeutic progress of the disease and new scientific data (32).

European scenario

As of this writing, the European Union has not yet enacted specific legislation to uphold the Right to be Forgotten, hence Articles 114.3 and 169 of the Treaty on the Functioning of the European Union still apply (36). Article 114.3 is part of Chapter 3 on the approximation of legislation, while Article 169 is part of Title XV on consumer protection. These articles are designed to provide for the obligation of a high level of consumer data protection, by relying on suitable measures based on new developments founded on scientific evidence (37). Furthermore, the European Union also refers to Article 9 of the GDPR, which explicitly prohibits the processing of health data outside the cases provided for by the regulation (37). Additionally, the European Union has sought to address the needs of citizens with the “Beating Cancer Plan,” which reaffirms the need to regulate the right to oncological oblivion to ensure that no one within the Union territory is discriminated against for their clinical history, and thus improve the quality of life of cancer survivors by removing unreasonable obstacles, such as those arising by the exclusion from access to

financial services (38). The European Parliament has also emphasized the need to introduce legislation on the “right to oncological oblivion” in EU countries (39, 40) to reduce healthcare inequalities and injustices and the social and economic costs of the disease (41).

The European Parliament thus calls for:

- all Member States to ensure the right to be forgotten by 2025 for all European citizen patients after ten years from the end of treatment and up to five years after treatment completion for patients diagnosed before the age of 18;
- the framing of common rules for the right to oblivion, in order to overcome the uneven nature of national legislative frameworks and ensure equal access to financing for cancer survivors.

Conclusion

In Europe, the number of people surviving a cancer diagnosis grows by about 3% each year (42, 43). This means that many individuals can return to normal life, with the same rights and opportunities recognized as other citizens. With such a high population of cancer survivors and, in cases of childhood cancer, a long-life expectancy, it is necessary to implement economic and social policies aimed at improving the quality of life of survivors. Cancer survivors face major difficulties, especially regarding access to financing and insurance services. It is therefore necessary not only to provide medical support during the illness but also to implement psychological support programs in the years following the illness for these individuals. Furthermore, it seems reasonable to ensure that medical history does not continue to influence the individual’s life as a sort of stigma (37). This would constitute a disproportionate invasion of the citizen’s private life if recovery and a ten-year course without relapse were not sufficient to consider the former patient as a healthy person, with the same rights as a healthy individual (44).

It is worth noting that in several countries, the laws on the right to be forgotten enacted so far address the same need with largely similar solutions. The chief limitation seems to be the lack of a European law

codifying the right to be forgotten, which should be considered a priority. The harmonization of legislative frameworks at the EU level should be viewed as a common goal, through a shared set of standards serving as guidance for national legislative interventions.

An important aspect for cancer survivors is the number of years necessary for the right to be forgotten to be enforced. Currently in place legislation calls for a period of 5 or 10 years, depending on cancer type and level of aggressiveness, with some exceptions for diseases with an excellent prognosis. Predictably, scientific research will offer elements in the future to further reduce or even eliminate mortality rates, the frequency of recurrence, and the healing time for each type of cancer, allowing for a better quality of life for patients and cancer survivors. After all, medical progress is undoubtedly essential to make such legislative innovations viable, and therefore remains crucial for any subsequent determination. Without further advances in terms of scientific evidence, it is difficult to imagine that the right to oblivion could arise more rapidly. It will therefore be crucial to prioritize cancer research, both in terms of prevention and treatment. Furthermore, social sciences must also provide guidance to eliminate any additional profiles of discrimination against former cancer patients, as it is the case with child adoption. The legislative overview herein outlined points to significant progress in the field of citizen rights. Nonetheless, the goal of preventing cancer survivors from being unduly stigmatized has not yet been achieved: first as patients, then due to social penalization after recovery. Ultimately, cancer survivors should not be discriminated against in their basic rights and aspirations based on their past illnesses. Rather, they should be entitled to fully and freely live their lives, previously undermined by the disease and just reclaimed, and to freely decide whether or not to share their cancer experience without being forced to disclose their personal data and medical history, as any other citizen does. Even the insurance and financial sectors should take into account the fact that a large group of individuals, now free from disease and with a long-life expectancy, could constitute a valuable client base.

Study limitations

Our study has limitations that we want to bring to the reader's attention to make our work clearer and more accessible. The right to oblivion is a highly relevant issue, but as already mentioned, jurisprudence on this matter is lacking. The first limitation is represented by the initial use of a single search engine, which provided data from different parts of the world, but which we nevertheless extended. The second limitation lies in the undefined time frame, but this choice was deliberately made to emphasize how recently the issue began to be discussed. One of the most comprehensive scientific search engines (PubMed) confirmed the relatively recent emergence of this issue: the first article dates back to 2017. The same time frame was found in Google Scholar. Another limitation is represented by the choice to analyze only the data from European countries, where the debate on this issue has intensified in recent years, naturally focusing particularly on Italy for reasons of belonging and greater familiarity. Despite these limitations, the present study can hopefully make a contribution to a more comprehensive debate, for the ultimate purpose of identifying corrective legislative interventions most befitting the clinical conditions, rights, and dignity of these citizens.

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Authors Contribution: GN, LDP and GMV designed the study and outlined the article's structure; GMV analyzed the data, all three authors equally contributed to writing the manuscript.

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