



A right to be forgotten for cancer survivors: A legal development expected to reflect the medical progress in the fight against cancer



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ABSTRACT

The aim of the article is to draw attention about cancer survivors and the challenging obstacles to tackle, once the cure is declared. In particular, one of the most neglected issues for cancer survivors concerns the financial toxicity and specifically the possibility to get access to mortgages, loans or life insurances.

The issue concerns more than 12 million cancer survivors in Europe. The practices of creditworthiness assessments are mostly self-regulated by private actors, including the collection and the evaluation of health information and data related to the applicant.

In 2016, France adopted a law on the Right to Be Forgotten in this purpose. The same initiative has been implemented later on by Belgium and Luxembourg.

The article analyses the content of these legislative initiatives, to disseminate their objectives and promote further perspectives of development to avoid any risk of discrimination for cancer survivors throughout EU.

The goal of this study is to promote political solutions, taking into consideration the progress of Medicine and the implementation of legal principles and social values. The article will also provide the opportunity to spread the debate about the social needs of cancer survivors, highlighting the attention about the necessity to provide them with a specific status in the national and European policies, avoiding discrimination and financial toxicity.

The study is part of a broader investigation on the right to be forgotten into the EU Area, still ongoing. For this article, the analysis is limited to the three EU Member States that recently adopted a specific legal framework on the issue, underlying the importance to regulate this aspect marked by the increasing success of therapies of cancers.

1. Introduction

In 2040, data predict an increasing number of oncological diseases among the European population, with more than occurring before the age of 69 [1].

According to the most recent scientific research and data, cancer survivorship increases progressively, and these patients acquire a comparable life expectancy than other people of similar age and socio-demographic characteristics with no cancer diagnosis. Data shows that proportions of cancer survivors are increasing by 3 % on a yearly basis and in 2018 more than 12 million cancer survivors have been estimated in Europe [2].

Based on these considerations, a growing number of cancer survivors should be able to return to a normal life, like other people of similar age with no cancer diagnosis. However, to be able to get back to an appropriate quality of life for former patients may prove to be a

neglected issue. Survivors of cancer across Europe are experiencing several obstacles, in particular when looking for access to financial services, such as mortgages, loans and life insurances.

In this respect, three EU Member States (France, Belgium and Luxembourg) adopted specific legislative initiatives, recognizing a Right to Be Forgotten for cancer survivors. The provisions state that in the context of the mentioned financial instruments, the period beyond which no medical information relating to the previous cancerous disease can be collected by insurance organisms may not exceed ten years after the end of treatment or, for cancers occurring before age eighteen years of age, five years after the end of treatment. The laws also include a list of exceptions for cancers with an excellent prognosis having shorter delays to exercise the Right to Be Forgotten.

The goal of this study is to advocate for a deeper examination of the issue, promoting political solutions and legal initiatives that take into consideration the progress of Medicine, the fundamental rights and

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social values for cancer survivors.

The analysis will encourage a wider debate about the social needs of cancer survivors, highlighting the necessity to provide them a specific status in the national and EU policies, with appropriate prerogatives of which the right to be forgotten is an integral part. In this aim, the article will analyse and disseminate the content of the legislative initiatives implemented, promoting them as a successful practice to avoid the risk of discrimination for cancer survivors.

2. Why is important to address the specific needs of cancer survivors?

A lack of consensus persists surrounding the definition of “cancer survivorship” and “cancer survivor”.

A number of different definitions of “cancer survivor” have been considered over the past several decades [3]. In particular, the World Health Organization considers them those patients who, having had cancer, are, following treatment, now cured of the disease. The cure is defined as the attainment of normal life expectancy and has three important components: (1) recovery from all evidence of disease (complete remission); (2) attainment of a stage of minimal or no risk of recurrence or relapse; (3) restoration of functional health (physical, developmental, and psychosocial) [4].

For this article, the analysis provided is based on the definition above mentioned of a cancer survivor, considering the 5-year prevalent cancer cases as defined by the International Agency for Research on Cancer [5].

The importance to define and classify cancer survivors is a key-issue to differentiating a specific group of patients. It is also a preliminary step to identify them as a new specific social group in terms of interests to be protected and promoted.

As an example, in the last decades, persons attained by different functional limitations have been progressively protected through international and national legal instruments, affirming their rights and promoting their wellbeing at all levels. In particular, in 2006 the United Nations adopted a Convention on the rights and privileges of persons with disability [6]. Following the same approach, at EU level, the European Charter of Fundamental Rights states that “the EU recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community” [7]. It also prohibits any discrimination based on disability [8].

Against this background, cancer survivors are not legally recognised as a particularly disadvantaged group with special needs in this matter, and the implementation of special programs focused on their complete reintegration is not performed by all EU Countries.

According to statistics and previous researches, the process of full rehabilitation and restoration of functional health is hindered by several sorts of challenges that former cancer patients have to deal with. Part of these latter ones includes late side effects of the cancer treatments, added to psychological issues, difficulties in finding or keeping a job or being promoted and also discrimination in applying to access for financial instruments as loans, mortgages or life insurances [9].

The mentioned issues represent the key aspects for the empowerment of a specific group of cancer survivors, providing appropriate support to the implementation of the survivorship care programs and the development of social and legal measures to strengthen inclusiveness and avoid discrimination [10].

Cancer survivors’ risk to be a neglected group, and to forward in our understanding and ability to determine meaningful intervention targets and outcomes for cancer survivorship care, a general consensus should be reached regarding evidence-based definitions of cancer survivors and cancer survivorship.

More specifically, in the European Union, a key role should be played throughout the development of an European health policy, providing healthcare models and implementing practices of collecting

and sharing information among the Cancer National Registries.

The importance to endorse the category of cancer survivors could mark a new era in cancer advocacy and realise the implementation of legal provisions for the promotion of cancer survivors’ rights.

3. The denied access to financial instruments

As anticipated, having a history of cancer often represents an obstacle for former patients to obtain access to financial instruments, such as loans, mortgages and life insurances. According to the experiences reported by cancer survivors, the main issues noticed rely on the denial directly from the bank, or the need to contract a life insurance to ensure the credit¹¹. Also in this case, it can occur that no insurer agrees in providing a contract, other than through charging an additional insurance premium or the warranty exclusion provision.

Bankers and insurers have difficulties assessing the risks associated with such a complex disease and its risk of relapse. Adopting a precautionary approach in the interest of their business, insurers often applied a principle of caution and denied cancer survivors’ applications in order to maintain their solvency. As the progress of cancer treatments are rapidly improving the prognosis of many patients, up to date information is still often lacking and risk assessments are made on outdated data or models.

The issue concerns the practices of creditworthiness assessment and the criteria to calculate the risk rely on the applicant. Article 18 of Directive 2014/17/EU on credit agreements for consumers relating to residential immovable property (*Mortgage Credit Directive or ‘MCD’*) requires that, before concluding a credit agreement, the creditor makes a thorough assessment of the consumer’s creditworthiness, taking appropriate account of factors relevant to verifying the prospect of the consumer to meet his/her obligations under the credit agreement. Article 20(1) MCD provides that the assessment of creditworthiness shall be carried out on the basis of information on the consumer’s income and expenses and other financial and economic circumstances which is necessary, sufficient and proportionate.

The lack of specific criteria uniformly applied by private actors contributes to generating a fragmented assessment practice, mainly self-regulated by the same companies, with a lack of transparency and monitoring control.

The exclusion of cancer survivors to contract life insurances and the other financial instruments, make property ownership difficult or even impossible in some countries. This situation is leading to a feeling of a double penalty for cancer survivors, hindering many of them from coming back to a normal life. Beyond successful treatment, social and professional reintegration is important to restore a sense of normalcy after surviving cancer, which is key to a patient’s remission.

In this regard, further studies and investigation should be performed to investigate the impact of those denials as indirect issues connected to the financial stress faced by cancer survivors and their families.

4. The implementation of the Right to Be Forgotten to ensure access to financial instruments for cancer survivors

In the last years France, Belgium and Luxembourg adopted the legislative initiatives, recognizing a Right to Be Forgotten for cancer survivors. The three initiatives have in common the principle to ensure the access to financial instruments for cancer survivors, facilitating the access to this instrument for the oncology pathologies having a good prognosis.

4.1. The right to be forgotten in France

The provision on the right to be forgotten has been introduced in the French regulation in 2016, as part of the Law on the modernisation of the National Health System [12].

Thanks to the reform, France endorsed the article 190, now article

L1141-5. The rule states that in the context of insurance or loan contracts, the period beyond which no medical information relating to cancerous pathologies can be collected by insurer organizations may not exceed ten years after the date of the end of the therapeutic protocol or, for cancerous pathologies occurring before age eighteen years of age, five years from the end of the therapeutic protocol. Indeed, former cancer patients have the right, after the mentioned deadlines, of not declaring it when taking out a borrower insurance contract and, as a result, not to be subject to any exclusion of guarantee or excess due to the previous cancerous diseases.

The content of the provision needs to be integrated by the standards in the AERAS Convention (*S'Assurer et Emprunter avec un Risque Aggravé de Santé/Insuring and Loaning with Aggravated Health Risk*) and the other norms in the French Public Health Code (as L. 1141-2) [13].

The AERAS Convention represents a national protocol concluded between the State, the professional organizations representing the credit institutions, the finance companies, insurance companies, mutuals and provident institutions as well as national organizations representing patients and users of the health system or representing disabled people. The Convention aims to facilitate access to insurance and loaning for people presenting an aggravated risk due to their state of health or a handicap with. It ensures that credit institutions and finance companies take full account of guarantees alternative to insurance, defining also appropriate procedures for informing applicants, investigating their files and mediating.

The Convention applies, under certain conditions, to consumers, real estate and professional loan insurance. It fixes for mortgage loans (estate and professionals), the maximum amount of 320,000 euros and any condition of the loan duration is removed when the borrower is not more than 70 years old at the end of the loan. For consumer loans, the maximum amount of the loan granted without a health questionnaire is 17,000 euro.

A "reference table" incorporated into the AERAS Convention defines, for each pathology, the period after which former patients can take out an insurance policy without any cover exclusions or having to pay an extra premium, under the same conditions as people who have not suffered from one of these illnesses. According to the law, the terms and time frames are yearly updated in line with advances in treatment and scientific data.

A monitoring committee ensures the proper application of the provisions of this Convention and respect for the commitments of the parties. Alongside this organism, it has been established also a Committee for studies and researches, responsible for collecting and studying the available data on mortality and morbidity caused by the main pathologies. A mediation committee is in charge of the examination of the individual complaints from loan applicants.

At the beginning of 2017, France adopted a new decree (*Decree 2017-147*) to implement the obligation of information for insurers [14]. By law, the insurer is responsible for giving an "information document on the right to be forgotten" to applicants for credit repayment insurance, at the same time as the normal risk declaration form.

The regulation has been implemented by Decree no. 2017-173 of 13 February 2017, that relates to the penalties applicable to any insurers that do not conform to the legal time limit for the collection of medical information.

Since July 2019, kidney cancer, leukaemia, prostate cancer, cystic fibrosis, hepatitis C and HIV infection are among the new types of pathologies included in the referred table of the AERAS Convention.

4.2. The right to be forgotten in Belgium

Promulgated in April 2019 and entered into force in February 2020, the Law no. C – 2019/40,839 modified the Insurance regulation (*Loi relative aux assurances, C – 2014/11239, 4 Avril 2014*) and reformed article 61.

The provisions are applicable to insurance contracts concerning

mortgage and professional loans.

The new provisions in the article 61/2 state that persons who are or have been suffering from any type of cancerous disease and who wish to take out insurance as referred to in article 61/1 shall declare that disease to their insurer in accordance with article 58. However, the insurance undertaking shall be prohibited, on the expiry of a period of ten years after the end of successful treatment and in the absence of relapse within that period, from taking that cancerous condition into account in determining the current state of health, as provided for in article 61. The provisions are applicable to the contracts concluded from the 1st February 2020.

The end of a successful treatment means the date of the end of active treatment of the cancerous pathology, in the absence of a new onset of cancer.

The insurance undertaking may not exclude this cancerous pathology from the insurance contract or refuse insurance on the grounds of this cancerous pathology. After the expiry of the time limits, the insurer cannot refuse or impose an additional premium because of this condition.

In May 2019, according to the provisions in article 61/3, the regulation has been implemented through the adoption of a reference table (*Doc. No. C – 2019/12,990*). This latter entered into force from April 1st, 2020, determining a reduced time limit to access to the right to be forgotten for specific cancer pathologies.

Every two years, the Belgian Health Care Knowledge Centre (*KCE*) assesses the reference table based on the medical progress and the available scientific data relating to the pathologies referred. The Belgian monitoring office of pricing (*Bureau du suivi de la tarification*) is in charge of the disputes relating to the application of the concerned provisions.

The Belgian regulation does not provide a limitation related to the amount covered by loans or insurance contracts.

4.3. The right to be forgotten in Luxembourg

Since the 1st January 2020, Luxembourg has introduced the Right to be forgotten to facilitate insurance access for cancer survivors. The initiative has been formalized through a Convention between Luxembourg's Ministry of Health, the Luxembourg Insurance and Reinsurance Association (*ACA*) and eight insurance companies [15].

The Convention applies only and exclusively to the balance outstanding insurance for a loan or estate loans for the acquisition of the main residence or professional facilities and whose maximum amount does not exceed 1,000,000 euros. It applies only within the limit of the maximum amount of 1,000,000 euros of cover and not for the acquisition of a second home or rental investments.

According to the provisions of the Convention, the applicant cured of cancer is entitled not to declare the cancerous pathology when the therapeutic protocol has ended for 10 years (end of active treatment of cancer by surgery, radiotherapy, chemotherapy); or the therapeutic protocol relating to this cancerous pathology has ended for 5 years, for cancer diagnosed before the age of 18. During the mentioned time-frame, the absence of relapse is needed.

Apart from this specific condition, the right to be forgotten is supplemented by some exceptions, related to the Right to be forgotten with the obligation to declare, without additional premium.

When applying for balance outstanding insurance for a mortgage loan, the applicant cured of specific cancers (10 specific types of cancer) or viral hepatitis C, must declare his pathology, but if certain conditions are met, the insurer cannot exclude the insurance candidate or request a premium.

The Convention provides the establishment of a monitoring committee, made by experts from the insurers, patients and national cancer institute and direction santé, to ensure its proper application of the provisions and the respect of the commitments of the parties. For this, it has the competence to examine the individual complaints addressed to

it by the applicants.

5. Conclusion and recommendations

This article aims to highlight the societal challenges faced by cancer survivors (5 years after the end of treatment) from a political and legal perspective, relying on the impact of full rehabilitation and restoration of functional health due to the obstacles to access to financial instruments to buy a house or finance the work activities.

The legislative initiatives taken by France, Belgium and Luxembourg are the proof that a solution exists in these contexts and Member State have the possibility, other than the obligation, to repair to these discriminations' practices limiting the "marge of appreciation" of insurers and banks. The importance to proclaim a Right to Be Forgotten throughout EU is also a way to initiate the dialogue with the science, and more specifically with the progress made by Medicine in this domain and ensure by law the equality of cancer survivors to all the other citizen.

Considering this recognition should be a key steps, but many challenges remain and the most important is the possibility to have similar regulations between the European countries, minimizing the discrimination, promoting social equality and regulate the market for all EU citizens being cured of cancer.

The article would like to be an instrument to promote and support researchers at all levels on cancer survivorship, in order to have data and stimulate a holistic approach to improve the process of health and the social rehabilitation of former cancer patients.

In this regard, an important step forward is the inclusion of the Right to Be Forgotten as a measure of best practice to ensure the best possible quality of life for cancer survivors in the roadmap for the EU Beating Cancer Plan, promoted by the EU Commission in February 2020 [16].

Cancer patients should not have to pay twice.

Declaration of Competing Interest

The authors whose names are listed immediately below certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

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