



Rights of People with Cancer in the Context of Health Bioethics in Brazil

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Commentary

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The right to health is guaranteed by the Constitution of the Federative Republic of Brazil [1], in addition to the Unified Health System (Sistema Unico de Saude, SUS in Portuguese) created in 1990 is the framework of public health based on the principles of universality, equity and integrality. These three basic principles aim to ensure access to health services for all people, regardless of any social or personal characteristics. Thus, health services must respect the individuality of each person, recognize differences, and reduce inequalities so that people receive treatment according to their needs. However, what we perceive in practice is that people do not always receive adequate treatment and, as a result, other legal provisions have been created in an attempt to ensure comprehensive care and the strengthening of public policies for the promotion and prevention of diseases.

In Brazil, the increasing incidence of cancer in the population follows the global trend and, according to estimates by the National Cancer Institute [2], predicts 700 thousand cases per year for the period 2023-2025. Considering this panorama, it is essential to point out and discuss the Rights of People with Cancer based directly on the Rights of Health Users and the Statute of People with Cancer, knowing that these rights permeate several others, including issues of Bioethics in Health. All health legislation must respect the principles of bioethics, which include the concepts of beneficence, non-maleficence, autonomy and justice.

In light of these principles, in 2009, the National Health Council approved the Charter of the Rights of Health Users

[3], an important milestone for all people to know their rights and ensure a fair, egalitarian and quality health system. In order to achieve this goal, the Charter is based on six principles:

1. Every citizen has the right to orderly and organized access to health systems.
2. Every citizen has the right to adequate and effective treatment for his or her health problem.
3. Every citizen has the right to humanized, welcoming care free from any discrimination.
4. Every citizen has the right to care that respects his or her person, values and rights.
5. Every citizen also has responsibilities to ensure that their treatment takes place properly.
6. Every citizen has the right to the commitment of health managers so that the previous principles are fulfilled.

The law states that all people have the right to access goods and services in an orderly and organized manner in order to guarantee the right to comprehensive health promotion, prevention, protection, treatment and recovery.

Access to health services will be preferred by the services offered in the primary care of the municipalities, that is, in the health posts and centers, as well as in the family health units and basic health units closest to their place of residence. However, the major problem of the public health network in Brazil is the lack of speed in care, whether in primary care or in units of greater complexity, which harms the health of the population. It is at this point that the Rights of People with Cancer are inserted, since cancer is a progressive disease that must be diagnosed and treated early to preserve health and life.

Other important issues are pointed out in the Charter of the Rights of Health Users, such as agile care, the use of appropriate technologies, humanized care provided by a trained multidisciplinary team, adequate care conditions, the provision of clear, objective and understandable information about their health status, as well as the confidentiality of this information. In cases of need to use high-cost drugs for their treatment, these must be guaranteed by the Ministry of Health.

The law highlights that it is the right of all people to receive care in the health network, whether public or private, in a respectful, welcoming manner, without any type of discrimination, restriction or denial due to age, race, color, ethnicity, sexual orientation, politics, socioeconomic conditions and especially related to their health status. This care should respect the limits of medical ethics and bioethics in health, so that no patient will be forced to participate in studies or research developed in health or research establishments. If by any chance they choose to participate in the research, which may or may not involve some type of experimental treatment, this patient will be given complete information that guarantees their freedom of choice, observing the ethical aspects and integrity of the participants' health by signing the Free and Informed Consent Form (ICF). In addition, it should be made clear that the patient is allowed to refuse to participate in research or experimental treatments without causing embarrassment, punishment or sanctions by health services.

Despite being a comprehensive document, the Charter of the Rights of Health Users was still incipient with regard to the Rights of People with Cancer in our country, which motivated legislators to institute by Law No. 14,238 of November 19, 2021, the Statute of People with Cancer [4], aimed at ensuring and promoting, on an equal basis, access to appropriate treatment and the exercise of the fundamental rights and freedoms of people with cancer, and thus ensuring respect for dignity, citizenship and their social inclusion. To this end, the Statute has 12 principles and 20 objectives that complement each other and form the basis for guaranteeing the rights of people with cancer.

The essential principles of this Statute emphasize respect for the dignity of the human person, equality, non-discrimination and individual autonomy; universal and equitable access to appropriate treatment and, as mentioned earlier, the guarantee of early diagnosis. In addition to these first principles, it will be important that health systems are prepared to promote health and stimulate cancer prevention throughout the population by providing clear and reliable information about cancer and its treatment. It will be necessary for this information to be transparent and to comply with process protocols, deadlines and flows, also

including the provision of systemic and referenced treatment, in accordance with the guidelines proposed by the competent health agencies. With the high demand of cancer patients, it is essential that the health network is expanded in its service capacity and infrastructure, while promoting the training and specialization of health professionals. It is necessary to stimulate the population's awareness about the risk factors of cancer, and their forms of prevention, strengthening education and family support, in order to enable the patient to have sustainability of the treatments that are necessary, including decision-making about which treatments can prevent the worsening of the disease and maintenance of a humanized support network.

The essential objectives to ensure the application of this Statute are to guarantee and enable the exercise of the social rights of people with cancer, once again emphasizing the need to promote adequate mechanisms and means for the early diagnosis of the disease, as well as its adequate treatment as recommended by Laws No 8.080 of September 19, 1990 and 12.732 of November 22, 2012. This last legal provision recommends that the patient diagnosed with malignant neoplasm will be guaranteed free care by the SUS in order to offer the necessary, standardized and updated treatment according to scientific knowledge and new proven treatments will be made available. The greatest innovation refers to the duration of treatment, because by law, the cancer patient must have started the first treatment (surgical therapy, radiotherapy or chemotherapy) in the SUS within 60 days from diagnosis, and is known as the Law of Sixty Days. Failure to comply with this deadline will subject health managers from the three governmental spheres to administrative penalties directly and indirectly, which in practice has not been observed. Compulsory notification and registration by both public and private health services should be carried out throughout the national territory, but most health units do not have trained personnel and/or infrastructure to carry out this registration properly.

Also, regarding the objectives of the Statute of Persons with Cancer, the need for actions that guarantee communication, publicity and awareness about the disease, its prevention, its treatments and the rights of people with cancer is highlighted, as well as the guarantee of transparency of information from bodies and entities in their processes, deadlines and flows and access to essential information about the disease and its treatment by patients and their family. In order to guarantee the rights of people with cancer, it is essential that the competent bodies enforce current legislation to reduce the difficulties that people with cancer face, from the time they receive the diagnosis of the disease to the completion of treatment. It is important that the public and private health systems support actions that can promote instruments to enable the implementation of the National

Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases. This means that health managers should encourage the creation and strengthening of public policies to prevent and combat cancer, also promoting the articulation between countries, agencies and entities on technologies, knowledge, methods and practices in the prevention and treatment of the disease.

In order to operationalize all these objectives, it will be essential to create conditions for the training, qualification and specialization of human resources involved in the process of cancer prevention and treatment, also enabling methods and systems to estimate the number of people affected by the disease and reduces the incidence of the disease through cancer prevention actions.

The promotion and prevention of cancer aim to reduce mortality and disability caused by the disease, but there is a need to correctly apply financial resources to encourage the creation, maintenance and use of special national, state and municipal funds for the prevention and fight against cancer. With the creation of this special fund for cancer, it will be possible to stimulate the continuous, sustainable and responsible expansion of the care network and its infrastructure. Some initiatives are being processed in the National Congress for this purpose, such as the taxation of prices on sugary drinks, alcoholic beverages and tobacco products and derivatives, which together account for a large part of the cancers caused worldwide.

It is necessary to build a dialogue in society with a view to combating misinformation and prejudice, as cancer is a stigmatized disease. By combating prejudice, it will be possible to contribute to improving the quality of life and treatment of people with cancer and their families, offering education and support to patients and their families.

With the increase in childhood and adolescent cancer, it is necessary to create actions aimed at this public with cancer or suspected cancer, ranging from ensuring differentiated care and treatment in all its phases, ensuring universal and comprehensive treatment for children and adolescents, to prioritizing prevention and early diagnosis, stimulating the humanization of treatment and providing differentiated attention to the patient and his family.

The fundamental rights of people with cancer must be preserved, and in cases where obtaining early diagnosis and access to treatment in a universal, equitable, adequate and less harmful manner is not being respected, these patients must be guaranteed the means to receive social and legal assistance as a priority.

Social assistance will provide patients and their families

with access to information in a transparent and objective manner regarding the disease, their treatment and their social rights in order to protect their personal, social and economic well-being. Cancer patients should have the right to the presence of a companion during care and the treatment period, as well as to be welcomed, preferably, by their own family, to the detriment of a shelter or long-term institution, except for those people in a state of vulnerability who lack conditions to maintain their own survival. Cancer patients are guaranteed prioritized home treatment, educational care in a hospital class or home regime, according to the interest of the person with cancer and their family, under the terms of the respective education system.

The rights of people with cancer to social assistance should be provided in an articulated manner, based on the principles of the guidelines of the Organic Law of Social Assistance, harmonizing with other policies in the social sphere, preserving and respecting other pertinent legal norms. It is important for people with cancer to be aware that the government should promote the access of people with cancer to the Public Prosecutor's Office, the Public Defender's Office and the Judiciary in all its instances. The government should stimulate, through legal assistance, knowledge and access to tax incentives and subsidies due to people with cancer. No less important will be the role of the State, which should formulate policies aimed at people with cancer who are in a situation of social vulnerability, in order to facilitate the progress of diagnostic and treatment procedures.

The right to priority of people with cancer must respect and reconcile the rights of priority conferred on the elderly, pregnant women and people with disabilities so that the right of one does not supplant the right of another. Thus, people with cancer will be assured preferential care, respecting the precedence of the most serious cases and other legal priorities, care in public services, in public and private agencies that provide services to the population, also respecting the precedence of the most serious cases and other legal priorities, priority in access to mechanisms that favor the dissemination of information related to the prevention and treatment of the disease and finally priority in the judicial and administrative proceedings.

No right can be provided or guaranteed without respect for the duties, and in the case of people with cancer it is important to establish that it is the duty of the family, the community, society and the public authorities to ensure that people with cancer are fully realized as a priority the full realization of the rights related to life, health, food, social and legal assistance. family and community life, among others arising from the Federal Constitution and laws. Therefore, no person with cancer shall be the object of any kind of

negligence, discrimination or violence, and any violation of their rights, by action or omission, shall be punished in accordance with the law. It is important to emphasize that discrimination against people with cancer is considered to be any distinction, restriction or exclusion based on the disease, through action or omission, which has the purpose or effect of harming, impeding or annulling the recognition of the rights guaranteed by the Statute of Persons with Cancer. Everyone is responsible, as each citizen has a duty to report to the competent authority any form of violation that he or she has witnessed or is aware of. We must not forget the responsibilities of the State, which must develop specific public health policies aimed at people with cancer, which include, among other measures:

- promote preventive actions and campaigns against the disease;
- ensure universal, equal and free access to health services;
- promote periodic evaluation of the treatment offered to cancer patients in the public health network and adopt the necessary measures to reduce existing inequalities;
- establish technical norms and standards of conduct to be observed by public and private health services in the care of people with cancer;
- stimulate scientific and technological development to promote advances in the prevention, diagnosis and fight against the disease;
- promote continuous training processes for professionals who work directly in the prevention, diagnosis and treatment phases of people with cancer;
- train and guide family members, caregivers, assistance entities and self-help groups for people with cancer;
- organize a screening and diagnosis program that favors the early initiation of treatment;
- promote awareness campaigns about the rights and benefits of people with cancer who have social security, tax, labor, procedural and health treatments, among others.

Finally, the Statute of People with Cancer makes it clear that the right to health of people with cancer will be ensured through the implementation of public social policies that can promote their physical, psychological, emotional and social

well-being with a view to preserving or recovering their health. Comprehensive and mandatory care to maintain the health of people with cancer should be provided by the SUS or private health units, and comprehensive care is understood as that provided at the most different levels of complexity and hierarchy of care and medical specialties, according to the special and individual needs of cancer patients, including medical and medication assistance, psychological support, specialized care and, when possible, home care and hospitalization. It is important to ensure that comprehensive care offers appropriate pain management, multidisciplinary care, and palliative care.

In a country of continental dimensions such as Brazil, with great sociodemographic diversity, and considering the pockets of misery and poverty scattered in the metropolitan regions of the cities, it is not possible to guarantee the health of everyone, especially the most vulnerable. Brazilian public health is facing several lawsuits, either to guarantee care and medicines, or to enforce the Statutes created by the legislature. It is necessary for the public and private sectors to invest in health, financing actions to promote and prevent chronic diseases, including cancer. The principles and guidelines of the SUS, the Charter of the Rights of Health Users and the Statute of People with Cancer form a background for respect for ethical principles in health, but this theoretical framework alone has been shown to be insufficient to reduce cancer cases in Brazil.

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