July 05th, 2018

UN General Assembly - High Level Meeting on the Prevention and Control of Non-Communicable Diseases

Brazil/Latin America - Civil Society Demands

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people.

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

In 1948, this UNITED NATIONS GENERAL ASSEMBLY have proclaimed that THIS UNIVERSAL DECLARATION OF HUMAN RIGHTS as a common standard of achievement for all peoples and United Nations Universal Declaration of Human Rights all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.
According to the International Agency for Research on Cancer (IARC/WHO), the cancer incidence in 2012 is estimated ins 14.1 million new cases in the world, it is estimated that the mortality was 8.2 million cancer deaths in 2012.

In relation to the new cases in Brazil it is estimated +/- 600 thousand new cases of cancer per year for the biennium 2018-2019, cancer is already the leading cause of death in 516 (10%) Brazilian municipalities. The data shows that most cities where cancer is already the leading cause of death are located in more developed regions of the country, in 2015, 209.780 cancer deaths were recorded, compared to 1998 data, showing a 90% increase in cancer deaths. The estimatives in Brazil are that if nothing is done to change the public policies on câncer, in 2029 it will become the first cause of death in the country.

About 75% of the population is included in the Public Health System, through the Unified Health System (SUS), which is financed by federal, state and municipal resources. The Ministry of Health's spending on cancer treatments has grown by 66%, jumping from R$ 2.1 billion in 2010 to R$ 3.5 billion in 2015. Also in the analyzed period, the number of patients being treated in the public health system has increased from 292,000 to 393,000.

The final consumption of health goods and services in Brazil increased in 2015 and reached R$ 546 billion, equivalent to 9.1% of the Gross Domestic Product (GDP). Of this total, R$ 231 billion (3.9% of GDP) corresponded to government consumption expenditures and R$ 315 billion (5.2% of GDP), expenses of families and non-profit institutions serving households.

Total health expenditure in Brazil as percentage of gross domestic product (GDP) (%) is below the world average and the private sector (insurance, out-of-pocket and others) accounts for more than 50% of total expenditure on health. According to World Health Organization (WHO), in Brazil, the general government health expenditure (GGHE) as percentage of general government expenditure (GGE) is decreasing along the last ten years. In 2006, GGHE was as 9.0% of GGE and in 2015 it was 7.7%
The Brazilian National Policy of Cancer Prevention and Control is very comprehensive and covers the main points related to the prevention, diagnosis and treatment of cancer, but its implementation is still deficient, and cancer care faces several difficulties, patients access to adequate is still a huge obstacle and this is reflected in the poor treatment outcomes of the country:

- Decreased healthcare capacity in health facilities due to the lack of updating of procedures and sub-financing costs;
- Lack of specialized professionals for interdiscipline attention;
- Concentration of the service network of high and medium complexity in few main cities;
- Lack of access to early diagnostic and curative procedures, especially those resulting from technological innovation;
- Failures in strategic planning for certain policies by investing in preventive actions that minimize costs;
- Lack of access to new treatment technologies for SUS patients, accentuating the existing social gaps;
- Discontinuity in the production and distribution of essential medicines, due to lack of economic interest on from the multinational industry, without the necessary measures of the sanitary authorities and the incapacity of the national industry to absorb the production;
- Need for modernization of management, ensuring greater social participation in decision-making processes and transparent process.
All Together Against Cancer Movement

The All Together Against Cancer Movement (TJCC) is a initiative created in 2014 of the Brazilian Lymphoma and Leukemia Society in partnership with more than 100 organizations among the main stakeholders of oncology in Brazil - patient advocacy organizations of all types of cancer, Government Instances, Oncologists, specialized Media, Medical and multidisciplinary Societies, hospital managers, economists, layers and other interested parties - to address and collaborate in common purpose: to broaden the cancer patient access to proper therapies across the country and improve the national treatment outcomes. TJCC strategy is to strengthen the Brazilian Oncology network to impact and monitor the public policy, by having the National Policy of Cancer Prevention and Control as backbone reference.

TJCC strategy is to strengthen the Brazilian Oncology network to impact and monitor the public policy and have the National Policy of Cancer Prevention and Control as backbone reference. Every year TJCC Movement congregates all members in a 3 day Congress held in São Paulo, SP, Brazil to debate the implementation of the National Policy of Cancer Prevention and Control, developing strategies to improve the articulation between the entities and the public sector stakeholders. In the framework of the TJCC, 18 task forces were created, covering 8 areas of discussion: General Principles, Prevention, Promotion, Monitoring and Evaluation, Comprehensive Care, Science and Technology, Communication in Health and Education.

Approximately 9,000 leaders of the segment participated in the 4 Congresses organized since 2014, including health managers, physicians, health professionals, scientific societies, NGOs, activists, lawyers and media organizations. This year we are organizing the 5th Congress and we expect to have more than 3,500 participants.

The innovations listed below come from the needs mapped by the "Declaration for the Improvement of Cancer Care in Brazil" developed in the context of the 1st Congress of the TJCC (2014), which became a guideline framework for the network actions. All actions are developed by several partners that compose the TJCC movement:

- Oncology Observatory: [http://observatoriodeoncologia.com.br](http://observatoriodeoncologia.com.br)

The Oncology Observatory is an online and dynamic platform for monitoring open data and sharing relevant information from the oncology area in Brazil. All data used comes from governmental open data sources. The main databases are the Ministry of Health, the National Cancer Institute.

Fernandes Coelho Street, n° 64, 13° Floor, São Paulo – SP – Brazil - CEP 05423-040
☎ +55 (11) 3149-5190 | www.abrale.org.br | abrale@abrale.org.br
(INCA) and the Brazilian Institute of Geography and Statistics (IBGE). The data cover four dimensions: demographic, epidemiological, health care and care network. Data on the incidence of cancer, outpatient visits, hospitalizations and mortality are mainly used.

- Oncoensino: [http://www.oncoensino.org](http://www.oncoensino.org)

  The Oncology Teaching Project is an initiative by ABRALE in the context of TJCC that has developed a platform of free online courses based on distance education, through the National Oncology Support Program of the Ministry of Health, that proposes the training and updating of doctors and health professionals involved in cancer care in Brazil. With the aim of stimulating prevention and early diagnosis, disseminating successful practices in the treatment and rehabilitation of patients, palliative care, and the multidisciplinary care model.

- TJCC Radar: [https://todosjuntoscontraocancer.com.br/](https://todosjuntoscontraocancer.com.br/)

  Built by more than 50 entities, the TJCC Radar maps actions to combat cancer in Brazil. Actions can be registered by the population or entities. Filters help you search for stocks in your city or region by selecting diseases, National Cancer Prevention and Control Policy guidelines, or sectors of society. The data collected gives a more accurate view of the fight against cancer to develop more effective actions.

**Alianza Latina**

Alianza Latina is a network of patients organizations founded in 2006 and composed by more than 120 patient advocacy organizations. We operate in 18 countries in Latin America, the United States of America, Spain and Portugal, and we represent more than 12 million patients from 29 different pathologies.

The project is leaded by the Brazilian Lymphoma and Leukemia Association - ABRALE and aims to offer its members several programs such as the Commitments Program, Alianza Latina Forum and Award, and Coaching Leadership Program. The purpose of the network is to develop its members, stimulate the exchange of experiences and to empower latin american patients.

We also provide management tools to empower, qualify and develop our members, encouraging expertise and best practices exchange that can be replicated across organizations to improve impact of initiatives;
Every year we award two organizations for an innovative project implementation aiming to improve treatment outcomes and we produce educational materials and toolkits that help organizations.

**Universal Health Coverage**

The Universal Declaration of Human Rights in it’s Article 25, says:

> “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

As civil society representative organization, we demand the governments to respect their international and human rights compromise guaranteeing the right of all their population to have the same opportunities, access to prevention methods, promotion, education, diagnosis infrastructure, the best treatment available, rehabilitation and palliative care without distinctions on the private and public health systems.

**Financing**

Health financing systems are critical for reaching universal health coverage. We must ensure adequate funding for the training of human resources, public infrastructure, social protection system and reduction of regional inequalities in cancer care. Stimulate the engagement of civil society and public sector to achieve the goals proposed in the national and international frameworks in health policies.

**Education**

Work with the Governments in the promotion of training and specialization of human resources, as well as the qualification of the assistance through the permanent education of the professionals involved in the prevention and control of cancer in the health care networks at the different levels of attention. Stimulate the training of multidisciplinary teams in the humanized care in the areas of diagnosis, treatment, rehabilitation and palliative care in Oncology, providing online platforms and capacitation programs, free of charge, permanent and open resources and contents, to enable training and continuous updating of cancer care teams.
Surveillance System

Measuring the performance of the National Policies for Cancer Prevention and Control is the first step towards producing coherent action. Knowing the efficiency and effectiveness of public policies enables strategic management of managers and improvements in service to society. Monitoring the quality and quantity of health services is essential for planning activities to increase access to treatments and improve clinical outcomes.

The elaboration and revision of indicators should be elaborated by mechanisms that guarantee the interaction of the open data with representatives of the government, organized civil society, universities and the private sector.

Prevention

Control, tax raise and banning of substances known to cause cancer and other chronic non-communicable diseases. Constant media campaigns to raise awareness about healthy eating, exercise, and potentially carcinogenic substances. Governments should plan education and prevention campaigns within public and private education systems.

Diagnosis

In Brazil, 60% of cancer patients are diagnosed with advanced disease. Every patient has the right to receive an adequate diagnosis and a timely treatment, respecting the established times, as well as respecting and guaranteeing the right to a second opinion. The public planning must consider the implementation of regional centers for the early diagnosis of cancer.

Treatment

We are concerned about the growing inequality of access to universal healthcare and treatment for patients in Brazil and Latin America, especially the access to high cost treatments. We have also identified the lack of specific national health policy plans for chronic non-communicable diseases in most Latin American countries. The patients must be empowered in the decision making process with the doctor, disseminating the rights and guarantees of patients.

Transparency, security, surveillance and regulation in medicines and supplies demand strict official regulations in order to guarantee quality, efficiency and safety of medicines used in health systems.
Multi-Stakeholders Dialogue and Social Participation

Increase the participation of patients in the public policy design, making available new spaces for effective citizen participation in health should be promoted and maintained, in order to ensure that the voices of health professionals, patient and patient organizations are listened in the different analysis, discussion, agreement and decision-making in relation to the formulation of prevention, diagnosis and treatment policies. Collaborative actions with different stakeholders and civil society are essential for the design of better public policies for patients.

Conclusions

Cancer is today the second cause of death in Brazil, and if nothing is done, in 2029 it will be the first, surpassing the cardiovascular diseases that today occupy the first place. The increase in incidence is related to a higher life expectancy of the population as well as a greater exposure to risk factors.

The impact of cancer on society is extremely high. In addition to the emotional impacts on patients and their families, there is also a major financial impact. The treatments are complex and expensive, both for the public and private healthcare system, and the new technologies that promise more effectiveness come with increasingly high values. In addition, young people are withdrawn from the productive chain, failing to generate wealth for the country. (About R$ 15 billion a year, according to the IARC study, published in the BBC Brazil, 18/02/2018)

Primary prevention may decrease the incidence of cancer in Brazil and Latin America, and early diagnosis and follow-up of clinical outcomes may reduce treatment-related costs. In this scenario, it is very important to involve everyone, especially the authorities, to prevent cancer from becoming a serious Public Health problem in the very near future.