

The Chilean experience with national cancer plan and law: a cooperative bridge between the civil society and the government.

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Abstract

In Chile, like in other Latin American countries, cancer incidence is rising rapidly with a massive social and economic burden, and this situation has worsened after the COVID19 outbreak. In 1986 the Chilean government created two antineoplastic drugs for adults (PANDA) and children (PINDA). Later, several cancers, cancer prevention plans and palliative services were covered by the GES/AUGE plan. However, the lack of a national cancer register, disparities in coverage and centralisation of specialists and oncologic infrastructure made the creation of a new National Cancer Plan necessary. Civil society, particularly non-governmental organisations (NGOs), pushed for a National Cancer Law as the legal framework for the National Cancer Plan. Their role is crucial to expose the patient perspective. Likewise, the collaborative work with clinic specialists, scientific societies, government and stakeholders is essential to face a multifactorial disease such as cancer. In this article, we analyse the role of civil society, particularly NGOs, in developing the Chilean National Cancer Plan and the National Cancer law. Through public consultation (including the Massachusetts Institute of Technology-COLAB platform, telephone and online surveys), we show that the community's main concerns were treatment financing, coverage, transparency of public policies, integral cancer care, health promotion and prevention. Historically, NGOs have played an assistant role; however, this is changing towards a more preponderant role in public policies, as seen in other developed countries, giving the strength to the civil society to collaborate in the construction of patient-centred cancer policies.

Key words: Cancer policies, Cancer law, NGO, Chile, civil society.

Introduction

During the last decades, South American economies have grown, pushing countries to cultural and political changes and increasing the life expectancy of the population(1, 2). How fast we adapt to a new scenario depends on the ability of each society to recognise, understand and act on these changes. Countries, therefore, depend on their culture to solve problems. One of the main threats for South American countries is the increasing burden of chronic and non-communicable diseases such as cancer (3, 4). These diseases

impose overwhelming pressure on the country's health systems, and how fast they control health threats will depend on prevention and public health programs.

In South American countries, the health system is composed of public and private schemes that coexist to provide care. However, in many cases, the public health system is not adequately funded, leading to massive out-of-pocket spending to cover care or treatments(4). An excessive dependency on private schemes to assure health care results in social inequalities; most of the resources (infrastructure, equipment and specialist availability) benefit specific privileged populations, while the poor are provided with fewer and lower-quality services and must wait on long waiting lists for medical attention (5). As a result, health outcomes and the success of prevention plans strongly depend on socio-economic and cultural status. Unfortunately, during the last two years, the COVID-19 pandemic has worsened the situation, leading to attention and referral delays and an important reduction in cancer diagnosis. Particularly, in Chile, it is expected to have more than 3500 deaths compared to a no- COVID-19 pandemic situation in five of the most important cancers for the next nine years(6).

Chile has developed the *Regimen de Garantías Explícitas en Salud* (GES - Guaranteed Health Treatments) and the plans for access to antineoplastic drugs for adults “Drogas Antineoplásicas para adultos” (PANDA) and children (PINDA) to improve public health care plans and coverage. PINDA financed treatments for all childhood Cancers, but the success of this program was not replicated by the adult program PANDA, since several adult cancers were not covered. The GES plan assures treatment and deals with waiting times, but unfortunately, not every disease is covered by GES. Indicators such as incidence and mortality rates, availability of effective treatments, and costs will determine whether GES or other public health plans can cover a disease. In countries that are moving towards more sustainable economies, non-governmental organisations (NGOs) and patient groups, as representatives of civil society, have held a crucial role in the construction and implementation of different health-associated laws and strategies. In Chile, patients are more aware of their rights and duties(7) and are moving forward to an active role in health decisions, promoting the patient perspective and transforming the health services into a “patient-centred care” health service(8-11). Several social movements, NGOs and patient associations have claimed to increase the coverage for cancer and other diseases, provide more healthcare specialists, decentralisation of their services, waiting-lists reduction, and expand the expenditure on public health, which has resulted in two crucial laws (Ricarte Soto and the National Cancer Law). Thus, the civil society's role in health policies has been crucial for developing strategies to assure patient’s social rights and duties. In the present article, we analysed how Chilean NGOs and oncologic patient associations have contributed to public health policies such as the National Cancer Plan and the National Cancer Law.

Methods

Quantifiable data

Analysis of NGOs participation and cancer burden

Cancer plans, strategy programs, and years of implementation were extracted from the Chilean Ministry of Health (MINSAL). Cancer incidence and mortality data were collected from the “*Departamento de Estadísticas e Información de Salud*” (DEIS) derived from MINSAL(12).

The information of the NGOs directly involved in the Ricarte Soto law (law N° 20850) was assessed from “*Alianza de pacientes*” (Patients alliance) group and cancer NGOs that participated in the process and consultation.

The information of the NGOs directly involved in the National Cancer law (law N°21258) was assessed from the Cancer law movement and from the national consultation through the Massachusetts Institute of Technology (MIT)-COLAB platform. Likewise, members of the civil society involved in the National Cancer plan were obtained from the Cancer plan list of authors (13).

Questionnaires and surveys

Public-opinion, data was collected from three different quantitative studies. Firstly, during May 2019 Ipsos-Chile conducted a telephone survey about cancer topics using the CATI (Computer Assisted Telephone Interviewing) system (14). The telephone numbers for the survey were randomly selected, covering all Chilean regions. The sample was stratified by geographic area, age and gender, including 500 men and 500 females over 18 years old.

Secondly, to analyse the public participation and suggestions in the MIT-COLAB platform (Massachusetts Institute of Technology, MIT), each comment was read and grouped in relevant thematic areas. The

suggestions frequencies in each thematic area were calculated using STATA software version 14. Finally, we used an online survey, distributed through social media from the 24th of October to the 7th of November of 2019, to establish which cancer topics were most relevant for the community and whether the information was clear regarding the National Cancer Law and the National Cancer Plan. The survey was open for two weeks. In all studies, the samples included people over or equal to 18 years of age.

Results and discussion

Cancer is a pathologic condition that includes several diseases and imposes a high economic burden (direct healthcare costs and indirect costs such as productivity loss) for all of the Latin American region (4, 15). Patient management involves diverse therapeutic interventions of different complexities, including palliative care in advanced cases(4). Patients often present severe comorbidities, and cancer treatment is associated with several side effects. To face the ever-increasing number of patients, Chile created, in 1986, the National Commission on Cancer (16). In 1987, the cervical cancer program was developed, and in 1988 the PANDA and PINDA programs emerged. In 2005, the *Plan de Acceso Universal de Garantías Explícitas* (AUGE) health plan, currently known as *Garantías Explícitas de la Salud* (GES), arose as a public health initiative for financial coverage for treatments of several diseases, thereby fixing the interval times for emergencies and regardless of the type of health insurance (private or public). This plan covered several cancers, including all cancers in patients under 15 years old, and for patients older than 15 years old covers cervical cancer, gastric cancer, breast cancer, prostate cancer, colorectal cancer, lung cancer, testicular cancer, epithelial ovarian cancer, the central nervous system primary tumours, leukaemia, lymphoma, osteosarcoma, bladder cancer, thyroid cancer, kidney cancer, multiple myeloma, preventive cholecystectomy for gallbladder cancer (for symptomatic people between 35 to 49 years old) and palliative care and pain relief for advance cancers. To analyse how NGOs promote cancer policies, we identified NGOs actively participating in cancer-related policies during the last years. Chile presents vast and complex geography (4,329 km long). Therefore, firstly, we analysed the distribution of the patient's association or NGOs that promoted the law 20.850, also known as the Ricarte Soto law or the National Drug Fund law "*Ley de Fondo Nacional de Medicamentos de Alto Costo*". This law appeared in 2015 due to massive mobilization and social pressure. The Ricarte Soto law so far includes coverage for gastrointestinal stromal and pancreatic neuroendocrine tumours and HER2+ breast cancer. The participation of cancer NGOs and oncologic patient associations in the movement that promoted the Ricarte Soto law was reduced compared to NGOs or patient associations representing other diseases (Figure 1). Furthermore, 65% of the NGOs and patient aggrupation were from the central part of Chile, including only a minor representation of cancer NGOs (Fig 1A).

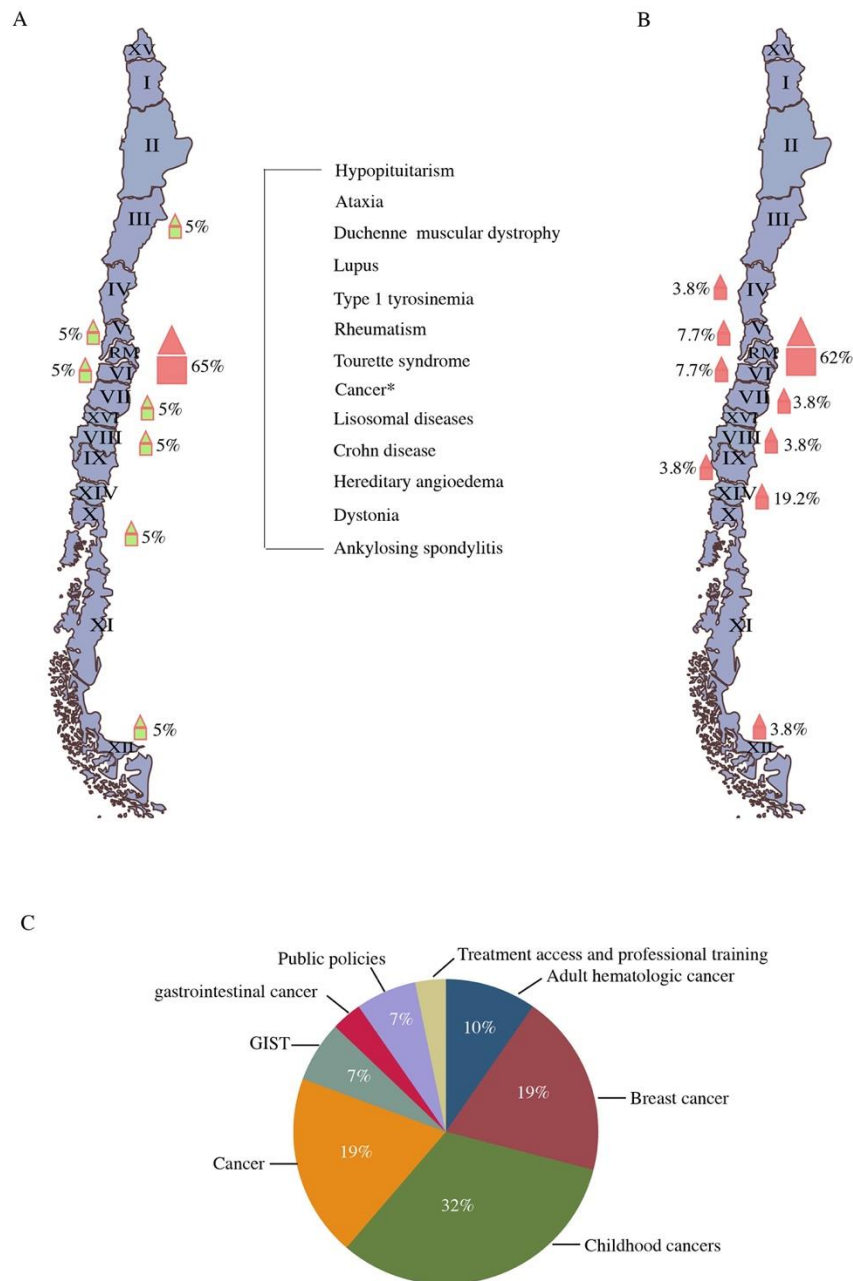


Figure 1: NGOs and patient aggruppation's involved in the Ricarte Soto law. The Ricarte Soto law (20.850) is a national drug fund law. (A) Distribution throughout Chile of NGOs and patient aggruppation's that represented the need of patients affected by different diseases during the implementation of the Ricarte Soto Law. (B) Distribution throughout Chile of cancer-related NGOs or patient aggruppation's involved in the National Cancer Law. (C) Cancer represented by NGOs or patient aggruppation's during the implementation of the National Cancer Law. Of note, most of the organisation represent patients of the central part of Chile, suggesting a centralisation problem.

National Cancer Law and National Cancer plan: collaboration is the key.

Since cancer incidence has been rising dramatically, a new national cancer plan was proposed. The correct implementation of the National Cancer Plan would allow facing challenges such as equal distribution of oncology services, a national cancer register, treatment coverage and cost-effective strategies for cancer prevention, early diagnosis, information, specialists training and education. However, to assure the long-term function of the National Cancer Plan, NGOs, patient associations, expert institutions and scientific societies were actively claiming for a National Cancer Law, which was presented as a project to the Chilean congress in 2018. The idea of a cancer law was to provide the legal framework for the National Cancer Plan. To identify and include patient-centred care strategies in the National Cancer Law, the Chilean authorities collaborated with several oncology experts, oncology intuitions, patients, caregivers, scientific societies and

NGOs. Thus, our next step was to analyse the type and distribution of the registered cancer NGOs involved in the national cancer law promotion (Fig. 1B). Childhood cancers represented 32% of the non-governmental institutions, followed by breast cancer NGOs (Fig.1C). 62% of the NGO and patient groups were localised in Santiago (Chilean capital). However, since the national cancer law was a general concern and the decentralisation of oncologic services was a critical issue, oncologic organisations throughout Chile actively participated in this endeavour (Fig 1B).

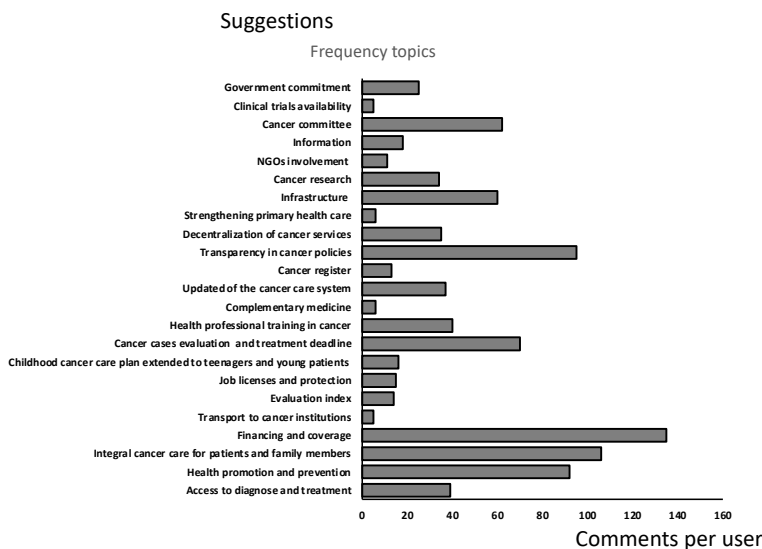


Figure 2: Frequency of user comments and suggestions on the MIT-COLAB online platform. Financing and coverage are the most important issues for civil society, followed by integral cancer care for patients along with families and transparency in cancer policies (mostly how decisions are made in cancer policies).

The National Cancer Law was built following a novel participation method, which included the community in the elaboration of the law. An online platform provided by MIT was used to ensure participation and collect suggestions from different NGOs, cancer institutes, oncology experts and the general community. The most urgent topics were categorized and grouped by comments per user. The frequency analysis showed that the most urgent topic was treatment coverage (financing and coverage), followed by integral cancer care for patients and family members and transparency in cancer policies (Fig. 2).

The evidence indicates that the government and authorities are responsible for promoting and implementing policies to improve cancer care. However, civil society should collaborate with local authorities and government departments to develop these plans(17, 18). NGOs bring patient perspectives and expose patients and caregiver’s real needs, which mainly depend on the social and geographical contexts. Furthermore, NGOs expose the resources available for cancer care. Breast cancer NGOs are an example of raising awareness and promoting early detection campaigns (19).

In Chile, civil society actively promoted the Ricarte Soto law (15.000 civilians participated in two organised demonstrations). However, most of the NGOs that participated in this movement belonged to the central part of Chile, which shows a territorial disparity and suggests an underrepresentation. For the National Cancer Law, the innovative virtual platform (MIT-COLAB) for public consultation improved NGOs participation. MIT-COLAB allowed suggestions for each article of the law, exposing the main problems from a community, institutional and academic perspective. As shown in figure 2, the main topics were financing and coverage, transparency in public policies related to cancer, integral cancer care for patients and caregivers, and health promotion and prevention. Other important topics were clear deadlines for case evaluation and interventions, infrastructure (decentralization), cancer research and professional training.

Public perception of the National Cancer Law and National Cancer plan.

We performed a public opinion survey to evaluate the community and popular perception of the National Cancer Law. A sample of 1000 people (500 males and 500 females over 18 years old) were randomly

interviewed over the telephone, covering the country's 16 regions. The results showed that 31% were well-informed about the National Cancer Law. When the interviewees were asked about the most crucial measurement that the law should include, 71% agreed that treatment coverage was the most crucial issue (Fig. 3A). However, only 20% of this population had cancer insurance of some kind (Fig. 3B).

We performed a second survey (from October 24th to November 7th) on a small group of 156 patients and caregivers to understand whether patients or caregivers understood the difference between the National cancer plan and the National Cancer Law. The results showed that only 31.7% knew the difference between the National cancer plan and the National Cancer Law (Figure 3C), and 69.1% considered that access to treatments and drugs (costs) was the most crucial issue (Figure 3D). Likewise, 53.5% of the interviewees experienced a delay in diagnosis or treatment initiation (Figure 3E).

Although the sample included in our survey was small (1000 surveyed), it showed the same tendency as the National Cancer Law consultation results. However, the community was unable to distinguish between them, which suggests an information limitation.

The NGO's campaigns promoted treatment coverages for more cancers, which resulted in the inclusion of myeloma, thyroid, kidney and lung cancer into the AUGE/GES plan. NGOs further promoted the enactment of the National Cancer Law during the COVID-19 pandemic resulting in its final enactment on August 26th, 2020.

During the current COVID-19 pandemic, the Chilean government has actively collaborated with civil society to identify problems and delays in cancer care, and this work should continue after the COVID-19 pandemic is over. Civil society's involvement in the public health policies-decision process has been strongly recommended by the World Health Organization and the International Union Against Cancer (UICC) (17, 20).

Our work suggest that the collaborative framework also needs to include stakeholders and the health and scientific community. Coordinating between these active groups is crucial to efficiently implement a cancer strategy and avoid unnecessary costs(21).

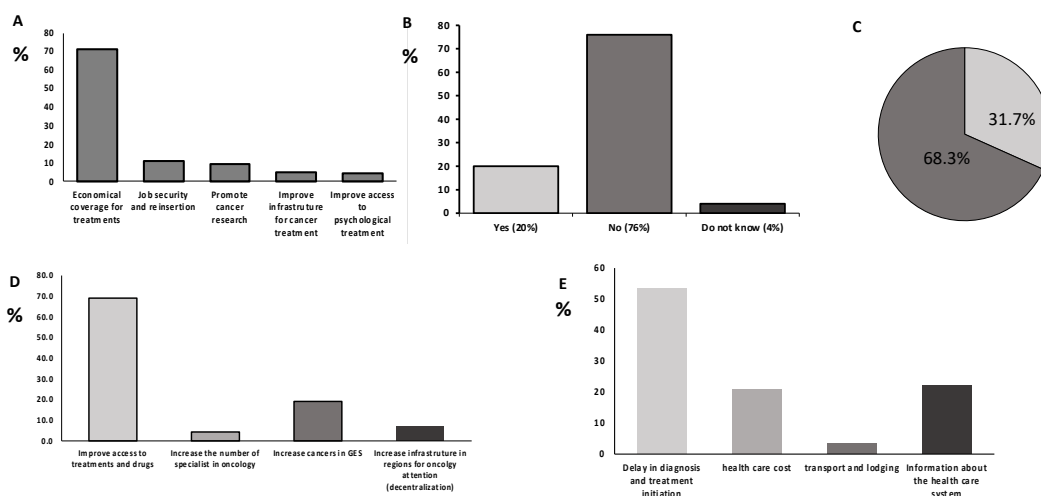


Figure 3: Most important issues in oncology according to public opinion surveys. A to B, the survey consisted in a random sample of 1000 people over 18 years old interviewed over the telephone, covering all country's 16 regions. C to E the survey consisted in a random sample of 156 patients and caregivers. (A) Most important issues that the National Cancer Law should include. (B) Percentage of interviewed people coverage with a cancer insurance (public or private). (C) Percentage of interviewed patients and caregivers that distinguished the difference between the National cancer plan and the National Cancer Law. (D) Most relevant issues in oncology for patients and caregivers. (E) Most important problems detected by patients and caregivers during the patient's disease journey.

Conclusion

In Latin America, NGOs have not been strongly involved in cancer policy creation, but instead, this type of organisation has displayed a more assistant role in medical services, spiritual counselling, information and cancer awareness (22). However, as part of civil society, NGOs and patient associations are slowly moving

towards a more preponderant role in research, advocacy and legal rights, as seen in developed countries(15, 19).

In Chile, to face cancer, different strategies have been implemented. Firstly, more types of cancer have been added to the AUGE/GES plan. Secondly, a National Cancer plan has been designed under the legal framework of the recently approved National Cancer Law. Thirdly using an online public consultation platform, civil society has been directly involved in creating the National Cancer Law, establishing a novel way of including public opinion in cancer policies. Our study showed that the main challenges are access to treatment, financing treatments (coverage), transparency of public policies, integral cancer care, decentralisation of specialised services, health promotion and prevention. All these challenges have been covered in the National Cancer plan and law.

The patient and caregiver perspectives are crucial to successfully implementing the National Cancer Plan and the National Cancer Law. To ensure the right direction of cancer policies, we need strong collaboration between NGOs, the government, health professionals and the scientific community.

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