Barriers along the continuum of cancer patient's care in Argentina: a preliminary qualitative exploration

EXECUTIVE SUMMARY:

In 2018, Argentina had an incidence rate of cancer of 212 cases per 100,000 inhabitants (for both sexes and excluding non-melanoma skin tumors), which places it among the countries in the world with medium-high cancer incidence and seventh in Latin American and the Caribbean countries. Within the framework of the international initiative ALL CAN, a preliminary qualitative exploratory trial was conducted in order to identify potential barriers or aspects to be improved in the course or continuum of patients care, including any factors that have discouraged prevention and/or early detection, as well as others that make it difficult for providers to provide an efficient health service. Fifteen cancer-related stakeholders were interviewed: four oncologists, an oncology nurse, a psycho-oncologist, a pathologist, a thoracic surgeon, two patients/survivors, a caregiver, a family physician, a palliative care physician, a director of a patient's association, and a health economist. Based on the analysis of the interviews, the author identified 42 barriers related to generic deficiencies in the system, the State and health organizations; the performance of the physicians themselves; patient's behavior; the pharmaceutical industry; and the social and occupational environment, even though "responsibilities" are often shared.

If immortality is our aspiration,
it is also, in a rather perverse
sense, that of the cancer cell.

Siddhartha Mukherjee, "The Emperor of All Maladies".

Cancer includes diseases in which abnormal cells multiply uncontrollably and invade nearby tissues. But cancer is also a process, an experience that re-signifies life, an ominous sounding word, an industry, a pressure for health systems, a prevention project that was never efficient, a destiny's fate, a succession of battles, a network of specialists, a population statistic, and a singular non-transferable biography. A territory where genetic markers and spiritual disquisitions; euphemisms and protocols; science and lies; agonies and hopes; anger and resignation; verdicts, uncertainties and outcomes are all interwoven.

Oncological diseases are part of the repertoire of "things that fear does not mention”, as one political columnist once said. In Paul Auster's novel Mr. Vertigo, the young protagonist prefers to deny his worst assumptions when one morning he finds his master Yehudi with a “horrific attack” and vomiting in the bathroom, the sign of a stomach cancer that would mean few months of life for him. “The idea that the master was a victim of a terrible illness frightened me too much to even consider it,” he evoked.[i] “I am tortured by the tenacious suspicion that it all began when I uttered those words: the creature was born when I called it by its name,” said the Hungarian poet, journalist and novelist Frigyes Karinthy (1887-1937) in his book *A Journey Round My Skull*,[ii] where he describes in detail the surgery he underwent to treat a brain tumor.

Scientists suspect that genetic events eventually leading to cancer may occur several decades before the symptoms.[iii] The turning point is always diagnosis, the zero-kilometer point of the new journey the patient will have to go through. The American essayist Susan Sontag reflected: “Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”[iv] The protagonist of a 1967 novel by the Russian Nobel Prize winner Alexander Solzhenitsyn, *Cancer Pavilion*,[v] feels that the disease confines him to a medical gulag without borders and even more oppressive than the Soviet state he already suffered from.

When the British debater Christopher Hitchens (1949-2011) was diagnosed with advanced esophageal cancer, he felt he was being deported “gently but firmly” from the land of the well to the land of the sick: a land that has its own language, medical gestures, condescending smiles of encouragement, and topics that are discussed and omitted.[vi] We could add: its own bureaucracies; its emotional rollercoasters; its occupational, economic and family challenges; its face-to-face encounters with the palpable finitude of existence.

According to the International Agency for Research on Cancer (IARC) data collected by the National Cancer Institute,[vii] in 2018 Argentina had an incidence rate of 212 cases per 100,000 inhabitants (for both sexes and excluding non-melanoma skin tumors), which places it among the countries in the world with a medium-high cancer incidence and seventh in Latin American and the Caribbean countries, following Uruguay, Puerto Rico, Guadeloupe, Martinique, Barbados, and French Guiana. The ranking of more than 125,000 incident cases in men and women listed in the table is leaded by breast (17.2%), colon-rectum (12.6%), prostate (9.3%), lung (9.3%), kidney (3.9%), pancreas (3.9%), and cervix (3.6%) cancers.

Regarding mortality, in Argentina, around 60,000 people die each year from malignant tumors, a number equivalent to a standardized rate of 118 and 87 deaths per 100,000 men and women, respectively.[viii] This number represents 1 out of 5 deaths per year (over 300,000) and cancer is the leading cause of death among 35-64 year old people. Cancer types (by location) with the highest death rate in both sexes are lung (15.1%), colon-rectum (12%), breast (9.7%), pancreas (6.9%), prostate (6.0%), and stomach cancers (4.8%). According to the former Health Secretary, Adolfo Rubinstein, "probably, in less than 10 years" cancer will outnumber cardiovascular diseases as the first cause of death,[ix] as is the case already in high-income countries.[x]

However, statistics show the beginning (diagnosis) and the end (death) of the journey, and do not reflect the different instances of the patients' journey. A very simple comparative analysis shows that every year twice as many cases of cancer as compared to deaths from the disease "occur" in the country, which implies a progressive increase in the burden or prevalence of the disease. *The Cancer Atlas* estimated that in 2018, in Argentina, there were 587.1 cancer survivors per 100,000 people of both sexes,[xi] i.e., more than 260,000 living Argentinians diagnosed with a malignant tumor in the previous 5 years. The number increased 25% in the last decade. This is the highest rate in South America, following French Guiana and Uruguay.

Of course, different types of cancer contribute different numbers of survivors. Data from the 2010-2014 period of five Argentinean population-based registries from the CONCORD-3 study[xii] reveal that only 16.4% of patients with esophageal cancer, 21.5% of patients with stomach cancer, and 12.6% of patients with liver cancer manage to live 5 years or more after diagnosis. In contrast, the rate rises to 54.4%, 84.4%, and 87.6% for colon, breast and prostate cancers, respectively. For many tumors, advances in early detection and/or new treatments have significantly improved prognosis. In acute lymphoblastic leukemia, for example, between 1958 and 1967 only 1 out of 100 patients in Argentina survived for more than 4 years;[xiii] at present, long-term leukemia-free survival and overall survival is around 70% for children and 30-40% for adults.[xiv]

As with other chronic diseases, cancer is already one of the most common, the experience of cancer patients can be described as a "travel" or a "journey."[xv] In the 2016 documentary *The C Word*,[xvi] director Meghan O'Hara says that the surgeon who informed her that she had the most aggressive form of breast cancer warned her: "Now you're going to *embark* on a wild adventure."

A journey or an adventure that nobody chooses and that, as another patient tells in the same documentary, puts the patient on a kind of conveyor belt that goes through tests, appointments, consultations, treatments, paperwork, meetings with peers, financial challenges, and personal and family adjustments to the new situation, with unequal levels of control over decisions.

ALL CAN is an international initiative that brings together multiple stakeholders to improve the efficiency of cancer care by focusing on aspects that matter most to patients.[xvii] Within this framework, in order to get a better understanding of the patient’s journey in Argentina, the circumstances conditioning this journey to the destination and all the obstacles to overcome, it was considered relevant to add patients perspective, as well as that of oncologists, nurses, psychologists, pathologists, surgeons and caregivers, among others.

The aim of this paper was to identify the different barriers faced by cancer patients in Argentina along the course or continuum of patients care, and also to include those factors that have discouraged prevention and/or early detection, as well as others that make it difficult for providers to provide an efficient health service. The research was intended to identify all instances that precede, accompany and follow the disease and that could be improved through intervention, either to reduce the incidence or to optimize clinical outcomes, as well as to increase quality of life levels.

Methodology

A preliminary qualitative exploration was conducted to gather the perspective of 15 cancer-related agents or stakeholders (9 women and 6 men). For this purpose, the author, a journalist specialized in science and medicine, conducted 15 individual, semi-structured face-to-face interviews with an average duration of 40 minutes, between September and December 2019.

The selection of the people to be interviewed for the sample was not probabilistic and was aimed to include the heterogeneous insight of patients, caregivers/family members, and people with different professional profiles associated with cancer. All of them reside or work in the City of Buenos Aires, Greater Buenos Aires, or La Plata and Greater La Plata.

The interviews were recorded and later transcribed for further review. All the barriers identified in the disclosures obtained from the interviewees were categorized and, for the presentation of the results, illustrative textual quotations or *verbatim disclosures* were included. We preferred to take a more scientific approach and omit the attribution of the textual quotations to specific sources, so as to prioritize the content over the identity of the interviewee.

The list of barriers serves as a checklist or enumeration, but no attempt was made to rank or order them according to a criterion of importance. Neither were them weighted according to the number of interviewees mentioning them: when a certain barrier appeared in the Disclosure of only one individual, it was recorded, even when there were other sources that might not coincide with that perspective.

Barriers identified

Based on the interviews, it was possible to identify and categorize 42 barriers or obstacles interfering to different degrees in the prevention, diagnosis and effective treatment of cancer, including the assistance of patients already treated and/or cured. Below each one, textual quotes from the sources that referred to that aspect are included.

1. Lack of campaigns and other public policies for prevention and early detection

Deficits in the implementation of public campaigns or other measures, such as the ratification of the World Health Organization’s Framework Convention on Tobacco Control or more active policies against obesity, affect primary or secondary prevention and early detection.

There is a lot of work to be done as regards policies: if the WHO Framework Convention is not signed, the measures are schizophrenic. You cannot have primary prevention of cancer without actively fighting tobacco. […] 70% of cancers are preventable, and tobacco is responsible for 45 different types of tumors. Lung, head and neck, and bladder cancers might be significantly reduced, up to 90%. (Disclosure 1)

There are no campaigns. The other day, in the subway, I saw posters against violence... Why not making a strong campaign at least in October [on breast cancer screening]? It's a public policy. The State has to do it. With many agents. (Disclosure 2)

2. Unequal access to screening tests

The socio-economic stratum influences the degree of access to screening tests, leading to both excesses and deficits.

The common situation is the "reverse care law" described in 1971: people who need medical services the most have less access, and people who need it the least have more access. In this context, there are women who have a Pap smear or a colposcopy every six months and others who die of cervical cancer who have never had a Pap smear in their lives. Both groups coexist. The same happens with breast cancer: in this context, there are some women who get mammograms at the age of 35 when they are most at risk of being damaged by the system, when they think they can be protected, and women who have no access in time and form to everything they should. (Disclosure 4)

Prevention should be universal, i.e., those who have a social security service, those who do not have, those who have a prepaid health insurance, those who have whatever... should have to access and receive messages inviting them to screening and early detection. (Disclosure 13)

The State should implement screening [tomographies for early detection of lung cancer] for patients at risk. This is being done worldwide, the problem is the cost-benefit issue. [...] I ask for these tests for all my patients at risk. (Disclosure 8)

The problem is access, not information. We did some very interesting work with the residents on the issue of cervical cancer... everyone knows about the Pap, even women in the shantytown. 95% knew about it. And we compared the data from the hospital population and from the population of 3 or 4 private clinics; everyone knew, but there was a great difference in the results... Why people do not do screening? Low income women didn’t because they didn't have time, they couldn't leave their children, they had other priorities in life. (Disclosure 3)

Middle class people have all the means. Why don't they screen? Because they don’t want to know. Or, in the case of colon cancer, because they don’t want to have the colonoscopy... there's still an apprehension about the method, it’s annoying. A rejection. For breasts, cervical, male PSA, they just do not want to know: “I’ll go later, next month”. (Disclosure 3)

3. Disruption of screening strategies

Resources and trained personnel must be available to act in a coordinated and timely manner when a positive test result requires additional studies or procedures.

There must be someone to make sure that the people who are tested are the ones who can really benefit, and that someone then will read the results and make the appropriate *referral. If you screen for colon cancer using fecal occult blood tests, then you must be able to offer video colonoscopy. You have to organize the system at all levels for that to happen, and that's not always the case. The same goes for mammography. (Disclosure 4)*

4. Unequal access to genetic and molecular marker tests

Patients in the public care sub-sector or members of certain social security services have more difficulty accessing molecular or genetic tests that can guide the selection of innovative treatments, so they often have to bear the costs or start classical chemotherapy, and thus they "burn out" the possibility of benefit from new drugs as a first line therapy.

Because of this current characteristic of precision medicine, you have to ask for the tests. But nowadays the capacity that Argentina has for testing is not ideal, it's quite limited, and it depends a lot on who assists you: if you belong to the public sector you're not going to get very far. (…) There, it takes a long time, maybe months, to get a diagnosis. (Disclosure 5)

To me, at present, this information is very important for diagnosis and for guiding subsequent treatment, and it is totally prohibitive for most people. It should be covered by now, and it is not currently covered. […] In fact, we cover it with personal savings [...] This is about 5,000 dollars approximately. (Disclosure 9)

5. Unequal access to specialists

Patients belonging to the public sub-sector or specific social security services or prepaid health insurance companies have fewer opportunities to access certain reference specialists for consultation, as well as limited chances for inter-consultations, or to change their treating professionals.

Patients should be able to change their treating physicians to get a second opinion and not lose their medical information. Doctors often compete for patients, because they know they are losing money. Patients with a certain social security service for whom doctors are not paid as they would like to, will have less time for the consultation. Some doctors are specialized exclusively in treating people covered by a specific social security service and not others. (Disclosure 5)

6. Under-reporting

The lack of population-based records and the fact that reporting of cancer diagnoses is not mandatory in general practice result in under-reporting.

This prevents an immediate coordinated approach to patients and makes it difficult to plan prevention or early detection strategies according to the incidence of the different tumors.

Cancer has been reportable since 1961, but it has never been implemented. Where should it be reported? Anatomical pathology services should report all cases, because cancer is an anatomical-pathological diagnosis. [...] And that report should trigger that the patient is given access to the health system: oncological surgery, clinical oncology, radiation therapy, and palliative care. (Disclosure 1)

Cancer records should be reported by pathologists. They should, but they don’t. The pathologist will notify you easily and may then notify the registries. But if he finds cancer in a biopsy... and the patient never goes get his report, or gets it and stays home... that's a cancer case under-reported. (Disclosure 7)

7. Delays in care after diagnosis

In the public sector or social security service, delays in the first consultation with the oncologist and/or surgeon after the cancer diagnosis are more frequent.

We have quite accessible appointments schedules, but they are not immediate anyway. (...) There is quite a delay. Appointments are more than a month delayed; however, we try to make the first appointment to be the closest as possible, and there are many patients who, because of their characteristics, are referred from the emergency department. (Disclosure 6)

She tried to make an appointment [with the surgeon] through the social security service and she got an appointment date much later than the time she was already operated on and at home. So, if she hadn't been fortunate enough to meet a surgeon who took care of her [privately] and told her "this has to be done as quickly as possible," she would have been waiting for her first consultation with a surgeon long after [the surgery]. (Disclosure 9)

8. Obsolescence of mammographers, poor training of staff, or inefficient use

Other barriers to breast cancer screening are inefficient use of mammographers, outdated equipment, and unequal distribution of staff trained to read and interpret the results.

In the country there is an adequate number of mammographers per number of inhabitants, but their use is inefficient: many acquired mammographers have no maintenance awarded; the ratio of professional mammographers, technicians and radiologists is 1 to 1, when the reasonable ratio would be 9, 3 and 1. In public hospitals, the time of attention is limited only to the morning, so the use of the resource available is inefficient. (Disclosure 1)

There is idle mammography capacity [...] many pieces of equipment are outdated, in fact, there is a National Cancer Institute program intended to upgrade all equipment. And not only that: the technician performing the test, and the one reporting the results, have to be trained people. There is a lot of manual expertise to get tests better done or not so well done, but then, images require a report... Regarding that information, the trend is that chances of specialists issuing better reports is increasing, because they see thousands of mammograms, as compared to those reported by a Dr. Smith from a small town who sees two mammograms per month... (Disclosure 2)

9. Unequal or late access to imaging equipment for diagnosis and staging

Especially in the public sub-sector, access to CT scans and other imaging techniques for diagnosis and/or staging of patients is harder. Equipment are usually overloaded or out of service and patients have to be transferred to other care facilities, resulting in a delay in the assignment of appointments.

As far as health is concerned, everything is difficult. We don't have the scan results overnight, there are insufficient equipment, sometimes these few scanners become out of service, we lack the appointments and tests we require. (Disclosure 6)

Times are not the same. In a private institution, you get the PET in a week, and at PAMI (social security service for advanced age people), you get it in 20 days... However, that doesn't change the equation. (Disclosure 8)

10. Delays in delivering results of biopsies and cytological studies

In the public sub-sector, the results of pathological anatomy, which are decisive for the diagnosis of cancer, may take longer to be delivered.

When we see a patient, histological diagnoses are also delayed. With a lot of luck, you get the diagnosis after 20 or 30 days, not before (Disclosure 6)

Common biopsies without cancer, or some with cancer, are delivered in 4 days. Those requiring other techniques take longer. Some hospitals take one month and a half to deliver results. In the private sector, you get lynched... (Disclosure 7)

11. Non-mandatory and non-systematic review of biopsies by a second pathologist

When biopsies are not reviewed by a second pathologist, the chances of false positives and negatives increase.

[Mandatory and codified reporting from pathological anatomy should require] that the first action be the revision of the pathological anatomy result by another pathologist. To avoid diagnostic errors. In other words, the standard should be mandatory reporting and mandatory review. Two pathologists matching on the results should be required to avoid diagnostic error. (Disclosure 1)

There are always false positives and false negatives, the former quite minimal, and false negatives are a little more... [...] When there are more pathologists who can consult each other, the percentage of false negatives is reduced. (Disclosure 7)

12. Disarticulation or lack of coordination or integration of the professionals involved

The multidisciplinary approach to assist all aspects of treatment requiring attention often seems to be more an illusion than a reality.

You see with great sorrow that patients do not choose their own path, in fact, they cannot choose another one. Are oncology services, radiation therapy, medical clinic, surgical oncology, palliative care services integrated to work together? This is so in very few institutions. How many institutions have palliative care services? How many have psycho-oncology services? Very few institutions. There's a lot of talk and little practice. (Disclosure 1)

I've heard this: "I don't send patients to the oncologist because he steals them from you." Or "I'm not going to give my information [to a colleague], he should call me". Knowledge must be shared. (...) Today, the doctor behind the desk doing what he wants with the patient does no longer exist, that kind of medicine is retrograde... The paradigm shift involves a multidisciplinary approach. (Disclosure 8)

A patient with breast cancer requires a mastologist, an oncologist, and if needed, a nutritionist or a psychologist... a lot of professionals should work in a coordinated way. Even in the private sector they don't work like that: although the trend is on that direction, reality shows other aspects. (Disclosure 2)

Everyone knows someone who can help you with one thing, so that makes a little noise. And maybe it's unnecessary, because it might be approached through the oncologist and a team, that is, the oncologist supported by a specialized care team, which doesn't even necessarily have to be formed only of oncologists, instead it should address all the aspects that the patient or the family are interested in knowing about. (Disclosure 5)

She was seeing a regular gynecologist who I remember did not give her any solutions. The same oncologist recommended her a surgeon who could treat her. But she wanted her gynecologist to advise her [about the surgeon]. I remember that was a disappointing problem and it is even more so in situations where everything is urgent. (Disclosure 9)

13. Disconnection between different service providers

The lack of coordination between the different sites that care for a patient is aggravated by the non-existence of a single electronic medical record, which is still in the early stages of implementation.

At present, all health care centers should be linked. For example, a person from Jujuy was examined in Mar del Plata. There he was diagnosed with an illness and was treated in a community hospital. When he returns home in Jujuy, he should continue the treatment, his information should not be lost. But everything is lost, so there are no links. And not only between Mar del Plata and Jujuy, but also within 10 kilometers in the suburbs. There is no inter-connection. (Disclosure 5)

14. Unequal or irregular access to medication and other treatments

The private sector or certain social security services appear to have more possibilities or resources to access medication in shorter periods or even to receive certain innovative high-cost treatments. On the other hand, prolonged cycles of radiotherapy require better articulation between centers for patient’s referral when services have to be discontinued or suspended for various reasons.

There is an enormous dispersion of human, diagnostic, therapeutic resources... there are patients with no access to the health system and others who access robotic surgery and image-guided intensity-modulated radiotherapy and state-of-the-art systemic treatments. (Disclosure 1)

In the private sector, there is medication that people get in 48 hours, and in a public hospital, this takes 20 days. You can schedule treatment in the same week you see the patient. (Disclosure 6)

We conducted a study and found that there is an important difference in the initiation of treatment according to the sub-sector of care. Is that clinically relevant? We don't know, because we require a huge sample to complete a serious work. (Disclosure 3)

Ultimately, patients assisted at that [private] sub-sector have the chance of being told the type of cancer, and whether or not they can benefit from certain treatments, but for public sector patients, that does not happen. And not only it does not happen, if it did, it would be bad news, because you would know that you are a candidate for a drug that you know you are not going to get. It's tragicomic. (Disclosure 5)

You can get the medication included in the Mandatory Medical Program (PMO) (100% covered) without major problems... In general, the public system provides for them. The problem is the high cost of innovative drugs: there barriers become walls. We are talking about high cost drugs, USD 30,000, you need to be a millionaire. And these drugs are appearing more and more. (Disclosure 2)

I am sure that, in our country today, all curable patients have access to the medication that can cure them. It is difficult for patients with tumors with certain molecular profiles to access very expensive specific treatments for molecular targets that may have other benefits, such as symptom relief and increased longevity. (Disclosure 1)

There are medications approved by the FDA, EMEA and ANMAT. If they are available in Argentina, and you are going to prescribe them to Argentine patients, why, some will have access to them and others will not, depending on their social security service? I cannot understand that. (Disclosure 3)

The relationship between doctors and auditors in general is not good. First, because there are some auditors who do not have the necessary training, and sometimes they have economic objectives rather than health ones. Then they are practicing the profession and depriving the patient of medical indications made by their doctor. (Disclosure 13)

They started [the radiation therapy] and it was a disaster. The device broke down once, and I understand because these devices are complex, but there came a time when they stopped working: there were personnel conflicts or financial problems and treatment was suspended. It was December 2016 and in the middle of the treatment they told him: “Well, find some other center.” "But I don't even know what dose they gave me, how to continue with this when you discontinue therapy for one day or 4 days or 6 days?” She doesn't know because she does not know the cumulative dose. (…) Finally, she ended up somewhere else where she had a new dose determination that doctors made with the information she brought from the other site. (Disclosure 9)

15. Insufficient or inadequate psychological support and contention during the course of disease

Anxiety, fears and uncertainty often accompany both cancer patients and their families, although they do not always receive the necessary professional assistance and support.

In oncology, patients already come with the diagnosis of the clinician, or the gynecologist, with very high diagnostic suspicion. They already come with the "earthquake or tsunami moment", which is a disruptive moment. And from then on, they would need support, which is not always psychotherapy. Interviews to moderate anxieties, with the patient and family (so they know what to do). 75% of patients would need that. (Disclosure 10)

Oncology patients are very special because of the diagnosis. Although there are many more specific treatments at present, diagnosis is still very frightening. It always meant death. I believe that the patient and his family need a very important support provided by the whole team. Our patients need more support than anyone else. (…) Many times, it is observed that the patient is very scared, very worried, very negative, very distressed... we talk to the doctor and ask him for an inter-consultation with psychology. (Disclosure 11)

I think the system should provide some kind of psychological support. I had been in therapy before and I continued, and it was very important for things like "You decide; you make the decisions.” (Disclosure 12)

And there [in the diagnosis] the issue of time comes into play, which kills your brains, the anxiety... What you have to do, what you don't have to do, work, family, food, physical activity... (Disclosure 5)

16. Insufficient psychological support and contention after treatment

The eventual need for psychological assistance after treatment is completed is often overlooked or ignored.

Many patients consult after finishing the treatment and have to assume the daily life. The family and social environment that had to make changes are waiting for the moment to say: "that’s it". And the patient who had to put things aside has to start thinking: "Am I cured or not?" […] The doctor's advice that you may need psychological support [after treatment] can be very powerful, and it can help you not to feel that intense sense of loneliness when everyone is celebrating and you are more distressed than before. (Disclosure 10)

In the United States, it was found that patients with breast cancer who went through six cycles in the 90's, after those six months, showed a depressive profile because they stopped getting the support that meant being in contact with their doctor every other week, and the assistance support, and "I fight", "I can"... They got depressed after finishing the treatment. (…) The same as happens with a woman after delivery, after giving birth she is no longer important, the baby is what matters now. Human mind is very complicated. (Disclosure 3)

When I finished chemo, I felt like I had taken off the raincoat, like I had no protection... "Now that I'm not doing chemo, what do I do?” On the one hand, an enormous joy of not having more chemo sessions, but, also, you feel kind of empty. (Disclosure 12)

17. Lack of longitudinal follow-up by the general practitioner, clinician or gynecologist

When cancer is dominant in the scene and the general practitioner (family doctor, clinician, gynecologist) is set apart by the oncologist, the opportunity for a more all-encompassing approach to pre-existing or new concomitant diseases is lost.

However, some patients do not have a general practitioner and others had one and their relationship with this physician prior to diagnosis was not very strong.

General practitioners or gynecologists do not accompany the patient with cancer diagnosis; patients remain with the oncologist. They see the patient from time to time... they have no day-to-day evidence of patients who are well, who heal... they lose sight of the patient. They have no follow-up. […] For any other intercurrent disease, [patients] tend to call the oncologist. (Disclosure 10)

I didn't have a family doctor at that time and I never had one. So, that's a point, who did you talk to about non-specific issues? That’s when I basically transformed my oncologist into my family doctor, I get a headache and I call my oncologist... But this has to do with the health system in general. (Disclosure 12)

The important point is the kind of link you had with the patient at the time you gave the diagnosis. If you got on well with the patient, they won't leave you. (Disclosure 4)

18. Shortage of non-medical oncology specialists and palliative care training

There is not enough academic degree training in palliative care or oncology nurses and psychologists integrated into multidisciplinary teams to provide the specific assistance required by the increasing flow of patients.

Nursing needs special training, nurses require knowledge about drug types, development of the disease, the different kinds of treatment, chemo, radiation... The nurse must know what specific care means. They should specialize as the doctors specialize in oncology. But specialization courses or training in oncology nursing are expensive. (Disclosure 11)

Hospital oncology services, where outpatients or inpatients are treated, should have at least one psychologist in the team. It has a great impact on the concept of the patient support network. And a net is better the more knots it has. (Disclosure 10)

Of the 50 medical schools in the country, only 6 have specific training in palliative care. (..) And it is understood that a doctor should have training in this subject when they graduate. It's getting better, but there’s a lot missing. (Disclosure 15)

19. Access barriers to reconstructive surgeries

Longer delays in the appointment with the surgeon, the suggestion of obtaining prostheses not covered by the health insurer or the State, or the need for psychological assistance at that time often affect the population with fewer resources disproportionately.

The issue with prosthesis [for breast reconstruction], you have to request it to the provider, and (if) the doctor asks for one type that is not the national one, you have to pay the difference. In breast reconstruction, the issue of symmetry matters, however, the social security service covers it *(whether through an appeal) and (...) the mammary areola (tattoo) too. It is part of the recovery process, it is not only aesthetic, it also impacts muscle issues. It's an obstacle race and personal imprint is more prevalent. (Disclosure 2)*

There are a lot of treatments in addition to medication. If a woman with breast cancer does not have the opportunity for breast reconstruction, she gets even sicker, if a patient with colon cancer cannot have the colostomy repaired or reconstructed and is kicked forward, a lot of circumstances will affect the patient's quality of life and social environment... medication is just the beginning. (Disclosure 3)

Many times, after treatment is finished, patients have reconstruction or plastic surgery. That also requires (psychological) support, for example, in head and neck surgeries, breast reconstruction ... Things are also moving, [requires] adaptation to the new situation. (Disclosure 10)

20. Lack of support and coverage of travel and accommodation costs for specific treatments

Out-of-pocket expenses associated with treatment schemes, especially when conducted at some distance from home, can conspire with adherence and divert funds that could be used for food or other purposes.

Treatments cover medication, but not out-of-pocket expenses, such as transportation. There are people who live in Lobos (in the suburbs, far away from the city) and have to travel to receive the radiotherapy, which can be 40 sessions of 3 minutes every day, from Monday to Friday for 5 weeks. There are people who

stay in the hospital just for that. Or have to rent a pension or hotel. Others need caregivers, to take care of the children... when you think about health or illness you don't think about all that person had to stop doing or what they had to hire. (Disclosure 2)

The biggest problem is the misallocation of resources: there is money left over and it is poorly distributed. It’s wrong that the Ministry of Health pays for medicines that cost $50,000 a month to prolong the life of patients by a month and that patients with a tumor in their neck living in Berazategui cannot stay at a hotel so that they can be irradiated, and so they need to take the bus [and don't get the therapy session] because it's raining and they can't get out. (Disclosure 3)

A person living far away from the city comes to the Capital... that person has to stay in the city, has to go to the radiotherapy center, has to have chemotherapy... and not all the health insurances cover the possibility to get a taxi or staying at a hotel. (Disclosure 13)

I also had 21-day radiotherapy and needed to travel from Gonzalez Catán to the Hospital Español for the treatment... a 2 and a half-hour trip to get there, and the same to go back. ***(...)*** *No matter the rain, the cold, you had to go out anyway. And if you were offered the seat you would sit down. Sometimes I'd travel with a surgical mask on, then they'd notice. The oncologist told me to wear a mask because of the air, better to take care of yourself. (Disclosure 14)*

21. Lack of support and coverage of outpatient support medication for specific treatments

The focus on oncology medication coverage loses sight of the demand for access to analgesics, antibiotics and even granulocyte-colony stimulating factor (filgrastim) to prevent or reduce the severity of chemotherapy-associated febrile neutropenia.

It is a "marginal" benefit, but for the patient it is more than important as if they have an infection and have to change a meal or something that gives then comfort in order to buy the antibiotic, steroid or medication he needs for an already aggressive treatment. (Disclosure 3)

My wife sometimes went with almost zero white blood cells to get the chemo. And then, I remember the first time, it was at night and they told her that she had to receive the colony activator and they didn't have it there, they sent us out to buy it. (...) I remember the scene: at 8 or 9 o'clock at night, both of us leaving the XXXX, where there is nothing around at night, we didn't know where the pharmacy was, to find something to get her white blood cells up. On top of that, it was winter and it was freezing. (Disclosure 9)

22. Unnecessary transfers and late or non-existent referrals

Identifying the most appropriate centers to treat oncological pathologies according to their type or severity rationalizes costs and would make it possible both to avoid transfers to remote hospitals when such effective care could be provided closer to the house of the patient, and to make timely referrals when the medical and technical capabilities of the nearest center are insufficient.

Some patients require access to highly complex centers and others need to stay in their place of origin for treatment because, given the complexity of their medical situation, it is not wise to transfer them. There are many patients from other cities with very serious illnesses that could perfectly be treated there, but want to come to the Capital looking for miraculous help... and then, other patients who should have come to Buenos Aires, for example, with a complex tumor, such as an osteosarcoma, and they stayed in their city and were not offered the best treatments. (Disclosure 13)

23. Flagging family members or caregivers

Caring for or accompanying the patient also means a psychological and physical burden for the patient's family members, which increases the risk of cancer in the intimate circle and may leave the patient unprotected.

"Try to dose your sadness and your effort, because there will come a time when you will feel run out," I always told this the relatives. Family members get exhausted too. (Disclosure 3)

Not everyone has someone from the immediate circle who visits you, calls you, asks you... there is a job to be done and usually the patient is not in a position to do it because they are facing treatment. (Disclosure 10)

Where do you think they are going to hospitalize a patient because the relative has quit, that is, when they feel overwhelmed and get sick? (Disclosure 6)

I used to have all the check-ups, the last one was in 2017. In 2017 my sister died and then I didn't go for a check-up. That year we were focused on my sister, on the issue of colon cancer, no one had check-ups that year, neither I nor my other sister, because we wanted to accompany her. (Disclosure 14)

24. Deficits in hospital infrastructure

There are establishments that do not have isolation rooms or hoods to prepare the cytotoxic medication.

Not all hospitals have isolation rooms and sometimes they have them for respiratory isolation... (Disclosure 6)

Manipulating drugs is highly toxic. [Staff] needs a protected area and biosecurity measures, not a bonus. There are many places that don't even have a hood. Not all hospitals have them. (Disclosure 11)

25. Unequal access to genetic studies for family counseling

If certain genetic tests on patients' relatives were covered, guidance or counselling could be provided for the primary prevention of new cases.

Free genetic studies are not available, they are not within the scope of the tests considered important in the PMO. There are some tests that can be done at (Hospital) Rivadavia, like BRCA [gene mutation] tests, but not much more. That can prevent a lot of complications in the family. A good primary prevention would be to prevent relatives from getting sick from something they knew they could get sick from. (Disclosure 6)

26. Burnout and overworked physicians

The demand on physicians to be specialized in patient-physician relationships and their actual working conditions affect their performance.

The patient becomes dependent on his doctor, he needs a word from him. And that exhausts the doctor too. They are very complex diseases because patients are facing the end of their lives. But it's inherent in the specialty. In the early years, I got very involved, and I would get a lump in my throat listening to [patient messages on] the answering machine. (Disclosure 3)

The entities that support and finance health care, whether private or public, are more concerned about the costs of medication than about the doctor's work, the professional fee. Then the professional is immersed in a model of sacrificial work that is very unprofitable, which discourages them. So, this reduces the time to get training, to be professionally prepared, and doctors are then not prepared to offer the best that they have for health, and that is a serious mistake. (Disclosure 13)

27. Medication errors

Failure to issue prescription and inexperience or negligence in the management of cytostatic extravasation are two examples of preventable adverse events associated with the cancer patient's medication.

I had a chemo that made me feel bad, they forgot to include a painkiller. I had the chemo and they gave me two pills that I had to take, Deltisone to treat allergy and I don't know what else, I have everything written down. But they didn't give me a painkiller. Then when I went home that day, I took a bath, I remember, and the pains started, the joints, the muscles... I couldn't stand it. I got in the shower, it was like a gout attack, an intense pain... I spent a terrible night and day. (Disclosure 14)

A nurse puts in the needle, hooks it in tightly, and the fluid comes out a little bit. Then the nurse took the gauze, I told him the fluid came out... then he put a gauze on me and dried it. That's wrong, I didn't know then. Later, the oncologist explained to me that he should have taken [the line] out and insert it in another vein, clean the area and discontinue [the administration] in that site. [...] "We're going to ask another doppler echo because we might have to open up your arm" [the doctor told me several days later] and I said: "Why?" I had a burning sensation. "Because the fluid," the doctor told me, "is very strong and possibly damaged a tendon or something else there." [...] I was hospitalized for 7 days and had antibiotics for 7 days. Never in my life I had so many antibiotics. (Disclosure 14)

28. Overdiagnosis

For certain tumors, early detection does not necessarily reduce mortality and, instead, labels the patient as "cancer patient" and exposes them to tests and treatments that are finally more harmful than the lesion itself.

There is a worship of early diagnosis to get better outcomes, and this worship of early diagnosis is driven by many things: the idea seems plausible and it's not necessarily better to get there first. (...) If you have screening tests many times, what you detect are turtles, painless tumors, which are not meant to kill or which progress very slowly. Incidence is greatly increased, but mortality remains unchanged. (...) Then appears the phenomenon of overdiagnosis: many people were diagnosed with cancer early, but not timely, because it is a cancer that would never have killed them. (...) Women who are over-diagnosed, who were operated on, irradiated and received tamoxifen unnecessarily, we do not know they really are victims. We don't even have a name for them. (Disclosure 4)

29. Delay in diagnostic suspicion

Certain warning signs of cancer can be missed by the primary care physician, which delay diagnosis.

We must deepen teaching of warning signs, work with primary care physicians so that they learn how to detect earlier diagnosis without symptoms... ask about cancer cases in the family, 6% of cancer cases have a hereditary component, we must not ignore that... oncologists ask this question, although I have to recognize that family doctors do not ask it so much. (Disclosure 13)

30. Incomplete information on samples received by the pathologist

The quality of information from tissue samples submitted to the pathologist is often poor, which can interfere with interpretation and diagnosis.

The information on the samples is incomplete. Data is missing, age, medical history of the patient, why the biopsy was requested... in general, data is missing and you have to make a call, and find out the site the biopsy was taken from... sometimes you don't know where the sample was taken from. For example, if I am sent a biopsy of vagina and I am not informed, that biopsy might be from vagina, cervix or vulva. They look the same. The same epithelium. (Disclosure 7)

31. Communication difficulties for doctors

Half words, silences, attitudes, gestures and time spent on communication have an influence from the moment of diagnosis notification to the pre-surgical dialogue with the surgeon or the frank and transparent exposition of the expectations of the treatment.

Doctors of the 21st century are either human or a nuisance. Patients have become adults. There's a problem of training, of self-worth and of time. Doctors need to feel their word is a medicine, and must have time to say it. (Disclosure 1)

When doctors communicate with hope, the way to cope is totally different. It's not the same when the doctor says: "I have some very bad news for you", as saying: "there are many possibilities here." (Disclosure 10)

In medical school, there is no training in communication skills. They communicate diagnoses according to training models... empathy, this must be learned. There's a lot of work to do on that. Thinking about how the patient understands what the doctor is saying. Check if the patient understood and realize that the information has to be progressive... in a consultation you can't evacuate all the concepts, (the patient) can metabolize very little of what was said... the information has to be gradual and progressive. (Disclosure 10)

I always say that the patient should be explained in words they can understand, not in technical words. Doctor can talk for an hour and patients will not understand a word. (…) The patient signs the informed consent without knowing... "it's too many things at once.” A lot of medical technical words that the patient doesn't understand. The patient who receives an explanation will accept the treatment more willingly. Sometimes the remedy is the word. (Disclosure 11)

For me the doctor was like an enigma to decipher, because he says one thing and you go and when you leave, you start thinking everything he said and you begin thinking many things. (…) I advise my friends to write down the questions, to go with a little notebook and to record the answers... And to ask everything, because the doctor is not going to say anything that is not asked. (Disclosure 12)

Usually, patients are unaware of the symptoms that chemo can cause. (…) When I see a new patient, I ask them what they know about their diagnosis and what they know about the drugs they will be given. You don't have to be afraid: you have to be careful. (Disclosure 11)

No, [we didn’t talk about how many nodes I was going to have removed], the doctor just told me that "I'm going to operate you on, take out the tumor and some nodes," but the doctor didn't say how many. (Disclosure 14)

Doctors are not trained to talk to patients and provide appropriate end-of-life care: There's an enormous fear of talking to patients and telling them that therapeutic weapons will harm them more than benefit them. There’s an enormous resistance to telling the patient that the disease is not curable. (Disclosure 1)

A fluid communication between the family oncologist and the family, the participation of the palliative care group, and the harmonic communication without coarseness end up flowing and placing the family in a situation of needing to end with aggression or futile procedures. (Disclosure 13)

32. Refusal or postponement of palliative care

Timely and early access to palliative care throughout treatment relieves pain and other symptoms, improves quality of life, and prevents therapeutic rampage at the end of life.

There is a great deal of neglect for palliative care and a huge waste in treatments that not only do not benefit, but do harm. And all that spending should be directed towards palliative care. (Disclosure 1)

Sometimes we observe that, until it’s time for inter-consultation for palliatives, the patient has gone through a period of much pain... what I have observed is that it is not accepted that the patient cannot continue with the chemo. (…) There is a kind of resistance on the part of doctors, although not always palliative (care) is a synonym for death: it means the patient will have a better quality of life during the course of the disease. (Disclosure 11)

I recently had an argument with a doctor: "Did you know you're committing iatrogenesis? You're hurting the patient more than he already is and you're not going to achieve anything." I think the doctor experiences it as a failure. It's like assuming the patient as a property. Somehow, doctors lose or share the patient... there's no other coherent explanation. (Disclosure 11)

Some doctors are very jealous and careful of their patients, retain them until the last moment and prefer not to send them to palliative care until they can bear the situation. It's a very personal issue. There are unconscionable doctors as there are unconscionable engineers or lawyers. (Disclosure 3)

Clinical Trials show that those patients who do not receive adequate palliative care have higher rates of pain, anxiety and depression, and also other symptoms undertreated. And there are other trials that show that early palliative care leads to improved well-being and quality of life for the diseased. It also implies better decision making by the patient and the family, because when they are heard and relieved of these demands, they remain longer in their homes and try to avoid excessively interventionist measures that are useless and have no good results. And this has been proven. (Disclosure 15)

[Oncologists] may have a sense of failure, but it is reduced as long as dialogue occurs. You start to realize that this vision of reducing medical aspects to problems is a reductionist approach, and the end of life is not a problem in itself, it's a fact in itself... The problem is that the patient has pain, a severe depression, desperation... We have to try to solve the problems that can be solved, and embrace the rest from compassion. We cannot avoid situations, but we can accompany them. And this is slowly being achieved. (Disclosure 15)

Palliative care comes late. The oncologist does, does, does... and when there is nothing else to do, between quotes, there is really a lot to do. And palliative care comes in. There's a lot of literature stating that palliative care should come first... Referring the patient to palliative care only at that time of the disease is an awful procedure. It must be done earlier, even during treatment with curative intent. (Disclosure 4)

That day, they wanted to take her for a uterus surgery and I told them "you're not going to touch her anymore" because she wasn't up for it. They were coming to massage her feet, all that stuff, but it wasn't for her... it made her suffer more. (Disclosure 14)

Palliative care must be seen from two points of view: from the need to provide the best to the patient and from the need to optimize costs, that is, not to administer unnecessary treatments, not to hurt patients with high cost treatments that are not going to benefit them. The therapeutic lead has a problem because it depends on the patient’s need, the family’s need, the doctor’s permeability and it depends on the pressures of the system. (Disclosure 13)

33. Rejection, contempt or disregard for the right of patients to decide on their treatment

Physicians' resistance to respecting, accepting and accompanying patients' decisions regarding their treatment violates rights and transgresses ethical boundaries.

The medical-hegemonic model, where the physician is the master of health and truth, is still in place. I explain to patients what their rights are: "You have the right to choose, you can refuse treatment." (Disclosure 11)

One of the bases of palliative care is ethical aspects and decision making, shared decision making is not washing your hands off... Where palliative care teams exist, that approach is fulfilled. For most patients, such types of professionals are absent, thus that is far from being the case. (Disclosure 15)

The important thing in medicine is not that a person engages in any common medical practice, but that they do what is in line with their values. If despite understanding the benefits and harms, people decide not to do it, what is the problem? (Disclosure 4)

I think the patient ultimately decides what to do with his life. You have to tell them the truth and accept the patient's decision. I tell the patient who does not want to be operated on "I do not agree, but I accept your decision and I will accompany you in your decision". You have to accompany them. That's my position, but I don't know what happens elsewhere. (Disclosure 8)

34. "Self-censorship" of indications

Some oncologists choose not to indicate innovative, high-cost therapies in groups of patients who, although they could benefit medically, would not be able to access them because of their health insurance coverage or socioeconomic status.

Are there times when oncologists don't indicate something because they know their patient won't be able to access the treatment? It's a terrible complex phenomenon. It shouldn't happen. (Disclosure 13)

I talked to some oncologists: "Our hands are tied, we know we should tell them this [innovative, high-cost medication] but they're not going to be able to get it." There are ethical dilemmas. (Disclosure 2)

35. Rejection of screening due to ignorance, apprehension or fear

Psychological factors ("not wanting to know") and the invasiveness of certain screening tests may have an effect on people with low coverage insurance.

Middle class people have all the means. Why don't they do screen tests? Because they don't want to know. Or, in the case of colon cancer, because they don't want to have the colonoscopy... there's still an apprehension about the method, it's annoying, a rejection. For breasts, cervical, male PSA, it's not wanting to know: "I'll go later, next month". (Disclosure 3)

She never got checked-up... she had the police health insurance plan, but she said "it's okay". Though she was a terrible heavy smoker. (Disclosure 14)

36. Late consultation for symptoms

The delay of patients in consulting a doctor when symptoms appear is a factor contributing to the late diagnosis and limits the prospects of treatment in some cases.

*People sometimes consult physicians late for different reasons, either because they do not know their body, or there is no record of regular monitoring, they do not follow such practice of accessing health and consulting for any symptoms.
Other times, patients are aware, but are afraid of the diagnosis... sometimes they have gone through situations with their family and consult late. (Disclosure 6)*

The time between the onset of symptoms and the first consultation is a major issue and is always a concern. (...) People with the lowest socio-cultural level access consultation later. More than 30 years ago, the World Health Organization defined the warning signs of cancer that any well-trained oncologists I believe know, and patients do not consult early. (Disclosure 13)

I have results (in a private institution) different from those of the public hospital... patients arrive at another stage, consult later, there is no awareness... for example, they have a cough or repeated infections and do not consult. (Disclosure 8)

My dad was recently diagnosed with lung cancer, he smoked his whole life, he's 73 years old, he rested on a bit with the diagnosis... Perhaps this is a question of behavior or the patient's way of being, it's something more personal (...) In fact, as I told you before, cancer is associated with a taboo. (Disclosure 5)

37. Patient's reluctance to "confess" second opinion consultations

Patients may be reluctant to share a second opinion consultation with other specialists, which can bring up misunderstandings or unaddressed questions and doubts.

I don't know why I didn't discuss it [with the surgeon], I always say the same thing: Why? I didn't ask him anything, I didn't ask him how many nodes he was going to take out. He didn't know about the second consultation I had with the doctor in Laferrere. (Disclosure 14)

38. High price of oncology medication

The rising costs of innovative treatments challenge the sustainability of the system.

Nowadays prices are irrational, as they do not reflect cost, efficiency or safety. The most important predictor of drug price is which drug it will replace. There's no way a new drug can be cheaper than the previous one. The vast majority have only been shown to be better than the placebo. Prices limit access, and put the health care system in a position of bankruptcy. (Disclosure 1)

There are very expensive drugs these days. (…) There is uncertainty regarding the benefit, on one hand, and a great uncertainty regarding the cost, the impact it will have…, if the health ministry can afford a therapy like this. (…) It is logical if one puts oneself in the point of view of a decision-maker, [because covering these treatments] means less vaccines, or less therapies for other patients with other pathologies that are equally serious. So, these are dilemmas that society has to face. (Disclosure 5)

39. Stigma of the disease

The taboo and stigma associated with cancer affect both early detection (fear can delay consultation when faced with early symptoms) and the quality of life of patients.

People stigmatize the patient. I knew a colleague who forbade her family and residents to say she had cancer. "Poor thing, he's going to die." They cross you out. (Disclosure 3)

40. Patient's guilt

The "prevention ideology" assumes that every cancer, at some point, is "the fault" of the patient who did not adopt the healthy behaviors necessary to prevent it, which adds an additional burden to the suffering of the disease.

Not every cancer detected at an advanced stage is a failure of medicine. The biology of some cancers is such that early diagnosis is very difficult, such as pancreatic cancer. Or interval breast cancers. That brings pride down. "Bodies find ways to die": that's the number one rule of epidemiology. Everything can't be prevented; you have to get out of porn-prevention. Even mammography is not a "vaccine": it reduces breast cancer mortality by 20%. (...) Blaming the patient who suffers is a horrible thing to do. (Disclosure 4)

41. Short medical leaves and difficulties in reintegration

Medical leaves are too short for some patients, and the survivors often face more barriers to get a job.

Many young women have to go back to work right away and medical leave is not enough... for some patients, going back to work is healthy and for others, not so healthy. And losing a job for a patient who had cancer is a catastrophe, because getting a new job with that diagnosis... I'm cured. But if two years after the diagnosis I had to get a job, it is very likely that between two or three candidates, I would not be chosen. Cancer diagnosis is still a barrier to getting a job. The disease has a period between 6 and 9 months in which you cannot work. It depends on the cases and the type of work. (Disclosure 2)

42. Alternative Therapy Offerings

The unscrupulous offer of alternative therapies of unproven efficacy involves spending money, unnecessary effort, and in some cases, it distracts from the focus of conventional treatments, and can affect adherence.

I find alternative therapies very dangerous. (...) I saw people die because they used therapies such as the Hansi method... they were dying just the same, one with Crescenti, one with someone who did macrobiotics, called José Luis, someone who I went to consult and I cursed. I went to see this José Luis in Córdoba, a very peaceful and loving atmosphere, he offered me a very strict macrobiotic diet and I got angry, I treated him badly, went out, and said: "I'm not going to medicalize my life, I'm not Japanese, I'm going to live like this, bye."

But then he treated a friend of mine who ended up almost starving to death. She did everything strictly and suddenly tests were bad. These people take advantage of the extreme vulnerability of the patients. (Disclosure 12)

Discussion and conclusions:

In general terms, inequities and fragmentation of the health system permeate almost all identified barriers. There is broad consensus that there are differences in screening practices, early diagnosis, initiation of treatment and access to drugs, molecular tests and specialists, among others, according to the socio-economic stratum and the healthcare sub-system.

In her book "Biography of my cancer", Patricia Kolesnicov, one of the interviewees for this paper, wrote about this question: "'I have cancer' doesn't conjugate in the past tense and lurks the future. In a lurking future. I live in Argentina: I can't be unemployed because I can't live without social security service. If you compare the situation with that of those who depend on the State to get oncological drugs, all my problems with the prepaid health insurance were a walk on the Grand Canal with a tuned gondolier humming"[xviii]. One interviewee summed it up with these words: "The reality of the public hospital is different from that of patients with social security service."

The barriers, in turn, may be separated according to the primary responsibility of those who promote or generate them. Barriers from 1 to 26 might be attributed to generic deficiencies in the system, the State and health organizations (health system being understood as the sum of all organizations, institutions and resources whose main objective is to improve health). Barriers from 27 to 34, to the performance of physicians themselves. Barriers from 35 to 37, to patients' behavior. Barrier 38 (high price of oncological medication), to the pharmaceutical industry. Barriers from 39 to 41, to the social and occupational environment.

However, this classification of responsibilities is clearly arbitrary, reductionist and even unfair. And there are often combinations and exchange between the different barriers. For example, the lack of review of tests by another pathologist (a system failure) can lead to false positive and overdiagnosis. Or patient's reluctance to trust their doctor and ask for a second opinion is also a problem for the treating physician who does not know how to enable or build trust for them to share it.

On the other hand, personal "faults", such as medication errors or miscommunication between different professionals treating the patient, are best interpreted as system failures. The same happens when patients consult their symptoms late or do not undergo screening due to ignorance or apprehension about the method... is it a problem of individuals or the system that does not implement awareness campaigns or offer mobile mammography, home testing for HPV or fecal occult blood at home or the workplace? When doctors do not indicate certain drugs to patients because they know they will not be able to access them, is it a failure of the doctors, the system or the industry that imposes exorbitant prices on their most innovative treatments?

Some of the barriers identified are more relevant or better recognized by specific agents, such as the quality of the information on samples submitted to the pathologist or the shortage of oncology nurses. Others appear to be more cross-sectional and visible for most interviewees, such as the refusal or postponement of palliative care or unequal access to medication and other treatments. Some are cancer-specific and others barriers appear across all specialties, such as medication errors. In any case, we insist on the point: the sum of citations of the barrier may guide priorities, but it does not necessarily correlate with the relative importance of the different barriers to be addressed.

Disaggregating the barriers also produces results that are not visible in the listing and that, in fact, respond to many possible causes. For example, late diagnosis can result from lack of campaigns, barriers to access screening, delayed consultation due to ignorance or fear, the stigma of the disease, the inability of primary care physicians to recognize early symptoms of the disease, or the fact that patients threw themselves into alternative therapies to find relief. Poor communication is tacitly explained by the lack of time for consultation imposed by the health system, although this is not the only reason.

In some cases, barriers do not impact directly on current patients, but they may do so on future cases, such as the under-reporting derived from non-compulsory reporting, which (among other effects) prevents a better understanding of the epidemiological reality and the implementation of specific actions from the State. Others, such as the stigma of the disease, may cross the entire continuum of care and even precede it. Cancer “still has an obscene sense, in the original sense of the word: of bad omen, abominable, repugnant to the senses", wrote Susan Sontag in 1977,[xix] and some echoes of that prejudice, though attenuated, are reluctant to disappear. There are still patients who believe that it is grudges that make them sick, or complain that the word cancer carries the status of a "bad word" in the world around them.

Several barriers described here have already been the subject of complaints and specific trials, and there are commendable actions underway from the National Cancer Institute to address them. The 2018 National Mammography Census of the National Cancer Institute and the National Ministry of Health, for example, found that only 8% of the 381 public hospitals in the country providing mammography services have digital equipment, which is the one that offers the best quality images.[xx] The operational conditions of tomographers in public centers is also a concern: in a major inter-regional referral hospital in La Plata, for example, it was reported that, between July 2017 and May 2019, the equipment worked only 337 of 669 days, and that an average of six tests per day could be made, "far from the minimum necessary, which should be 25."[xxi] Experts estimate that palliative care in Argentina is provided to only 1 in 10 patients who need it.[xxii]

Inequalities in access to screening, consultation, diagnosis and treatment have also been documented. Breast cancer, for example, was diagnosed in more advanced stages in public hospitals (58% in stages II and III) than in a private centers (66% in stages I and II), according to data from Argentina's Institutional Tumor Registry in the period 2012-2017.[xxiii] Waiting time to see a doctor is socially stratified, according to socio-economic characteristics, type of coverage and place of residence.[xiv] In public hospitals in Buenos Aires, the time from diagnosis to treatment in a subgroup of lung cancer patients with indication for adjuvant and neoadjuvant therapy is up to four times longer than in private centers: 83 (64-99) vs 22 (14-37) days ($p < 0,0091$).[xxv]

The increasing high cost of cancer medication, the true extent of its benefits (in terms of price) and its impact on the sustainability of health systems has also been and continues to be the subject of great debate.[xxxvi] Nine of the 13 drugs that in 2018 represented the highest billing costs for PAMI, the country's largest social security service, are used to treat cancer. And the share of that segment in total spending on drugs in that organization rose from 12% in 2016 to 19% in 2018, which meant twice the annual spending in millions of pesos in that period: from 3,660 to 7,650.[xxvii] How will States and systems cope with this trend that seems unstoppable? "These are dilemmas that society has to face," emphasized one of the interviewees.

In any case, and as shown in this report, access to medicines is very important, but it is not the only obstacle or challenge faced by patients in their journey. Nor should it necessarily be the priority objective at all stages of the disease. Ernesto Gil Deza, another of the interviewees, warns in his book *El cáncer y sus demonios* [Cancer and its demons][xxviii] about the displacement of faith and the change of paradigm that make the patient and his family focus on betting everything on the "last treatment": getting the medicine, administering the drug, tolerate the drug and everything that has to do with the person's care, leaving aside the reasons for living, the living circumstances and the limits to medical aggression.

Even the term "personalized treatments" for therapies targeting certain molecular targets seems to assume that the tumor and the person are the same thing. That course cannot be lost.

From the way news is given to the preparation to talk about death or to listen to the patient, their needs, their anxieties or their fears, good communication is a key component of the doctor-patient relationship in cancer. "The doctor has to feel that his word is a medicine," summarized one of the interviewees. A recent study assessing the emotional impact of communication on the experience of cancer from the patients' perspective identified some disturbing phrases or comments by the doctor, such as "it can't hurt.”[xxix] “You have to add humanity and empathy to medical knowledge," was the conclusion.

Honest information about the real expectations of treatment is a special chapter in that plan. The Spanish philosopher Fernando Savater, in his book *La peor parte. Memorias de amor* [The worst part. Love memories][xxx] forgives the doctor who deceived him about the chances of survival of his partner for 35 years, Sara, a victim of an aggressive brain tumor that killed her in nine months: "He told me what I wanted to hear, the only thing I could *bear* to hear." But Spanish oncologist Marcos Gomez Sancho's list of terminal patient rights, cited in Gil Deza's book, includes the following: "I have the right not to get an honest answer, whatever my question is" and "I have the right not to be misled". How many times is that respected? Are there ethical justifications for not doing so?

Recent rigorous qualitative trials on cancer have adopted a different classification of the barriers patients face in their healthcare journeys.

For example, Ramos et al. in 2018 divided them into personal barriers (financial issues, patients' beliefs), interpersonal barriers (occupational issues, family responsibility, patient-physician communication), and health system barriers (organization of services, quality of care).[xxxi] For the purposes of this qualitative exploratory approach, which includes the visions and perspectives of other people involved, we preferred a clear and disaggregated list of the obstacles identified. And, in any case, it enables the possibility of subsequent analyses grouping the intervening factors into more comprehensive categories.

In any circumstance, we insist that this paper is not intended to replace or be assumed as qualitative research in the strict sense, following a precise methodology for obtaining information and interpreting meanings.

Finally, we remained with the feeling that, had the sample of interviewees been larger, other barriers or aspects for improvement might have appeared in this list. Or even that there has not been sufficient representation of some profiles, such as image specialists, carers of patients who have died or professionals from other cities of the country. Just as it is said that there is not one cancer but hundreds of them, there is not "one" oncologist, "one" psychologist, "one" surgeon or "one" patient, but thousands or millions of them. Any exploration of this nature must recognize its preliminary character: it is a flashlight aimed to illuminate areas in the environment, yet unable to prevent dark areas to be there. We need more flashlights, as well as more decisive actions to smooth out the path of care, to work on all the aspects that can be improved and not to add more discouragement and anguish to the misfortune, the vicissitude or the destiny of the sick and their loved ones, who are, were or could be all of us.

Both the in-depth interviews and the preparation of this report were carried out by the science journalist Matias Loewy.

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