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Qualitative Study on Barriers to Access from the Perspective of Patients and Oncologists

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Abstract:- Cancer is the second cause of death in Argentina. Countries with fewer resources have poorer cancer control outcomes, with high relative cancer mortality rates. If no comprehensive and efficient cancer control policies are implemented, a growing burden of chronic non-communicable diseases, most notably cancer, is expected in the coming years. OBJECTIVE: To understand and describe cancer patients' experience with a focus on process improvement opportunities relevant to patients. METHODS: After a quantitative phase, a qualitative cross-sectional study was conducted. The quantitative phase included 400 men and women from the Metropolitan Area of Buenos Aires (AMBA) with a diagnosis of cancer, recruited using semi-structured interviews. This phase was followed by a qualitative study using in-depth interviews with 15 patients and 5 physicians from the same geographic area. RESULTS: delays from symptom onset to diagnosis and from diagnosis to treatment were identified. Delays were greater in patients with public health insurance only. Low access to early cancer diagnosis was identified. Interviewees described personal, interpersonal, and health system barriers. In addition to the existing difficulties, the complexity of the COVID-19 pandemic added the digital barrier and prolonged such delays. CONCLUSIONS: This research, not restricted to the public health sector, provided evidence to understand the barriers faced by cancer patients in the studied region, and helped identify opportunities for improvement to reduce delays in continuous cancer care, especially for the most vulnerable patients.

Keywords:- Barriers, Control Cancer, Patient Journey, Public Health, Continuum Care.

I. INTRODUCTION

As population age and infectious disease control increase life expectancy, cancer and other non-communicable diseases are becoming increasingly important burdens of mortality in low- and middle-income countries (LMICs). (1). More than 70% of cancer cases will be diagnosed in LMIC by 2030. However, most developing countries do not have the required resources or infrastructure to prevent, diagnose, or treat such a growing cancer burden. (2). In most developing countries, the problem is the lack of cancer registries and cancer treatment capacity; only a few countries have developed comprehensive cancer control plans, amongst which is Argentina (3). Leading medical and public health organizations have led international initiatives to raise awareness of this issue, but there are still great needs (4).

Cancer is the second cause of death in Argentina (5). One of the contributing factors to the high mortality rate is the diagnosis in advanced stages of the disease (6), especially for patients attending the public sector (7). In addition, delays in diagnosis and/or treatment represent the loss of opportunity for cure, which impacts survival (8). All this increases the burden of the disease (9) and involves more costly and aggressive treatments (10).

The objective of this study was to understand and describe the experience of cancer patients, with a focus on opportunities for process improvement relevant to patients.

II. METHODS

A cross-sectional qualitative study was designed. The study was complemented by a preliminary approach to collect research needs and develop collection instruments and was preceded by a quantitative study for exploring and measuring patients' experiences under a hierarchical ranking of inefficiencies. The qualitative stage was conducted to deepen the concepts detected in the quantitative phase from the perspective of patients and professionals.

The population for the quantitative study included men and women over 18 years of age, residents of the Metropolitan Area of Buenos Aires (AMBA) with a diagnosis of cancer, with public or private health services. The sample of 400 patients was weighted to represent the percentages of the different cancer types according to the Globocan 2018 estimates. All patients provided their consent before participation.

The quantitative phase period was from December 26, 2019, to May 9, 2020. Data were mostly collected through face-to-face or telephone semi-structured 40 minutes interviews since the emergence of the pandemic by COVID-19.

The specific objectives of the qualitative study were to describe the journey through the health system and its impact on daily life from the patients' perspective, from diagnosis to the present time, addressing economic, emotional, social aspects; to describe in detail those critical points of the patients' experience in their cancer treatment; to explore in-depth the patients' interactions with different stakeholders in the health system (human or technological/bureaucratic); to detect situations in which they have faced different problems throughout their journey in aspects such as diagnosis and clarity, psychological support or other resources, access to information, quality of information, coverage; quality of care throughout the patients' journey with a focus on problems of access, cancellation or deferral in diagnoses/results, coverage, and management, etc. And COVID-19 impact: pre-COVID versus during COVID-19. From the perspective of health professionals, the objectives were to cross-reference patient experiences with in-depth interviews with those from oncologists and hematologists to complement and strengthen the analytical framework. The qualitative study was carried out using in-depth telephone interviews lasting approximately 1 hour with specialists and patients. Sampling was purposive with conventional recruitment. Recruitment control included total verification of the recruitment filters. The population for the interviews included oncologists and onco-hematologists treating patients with breast, lung, colon, prostate, and multiple myeloma cancers, and patients with these same pathologies. Both professionals and patients were residents of the AMBA (Metropolitan Area of Buenos Aires). In total there were 20 interviewees, of which 15 were patients and 5 were health professionals. All participants signed the informed consent before entering the study.

The sampling was primarily purposive according to compliance with the required profile criteria (conventional recruitment) and using a database. Recruitment control was carried out by random verification of the recruitment filters and participants eligible for the research met the following criteria: no participation in trials of the same category to which they were about to enter for the prior 6-month period; no participation in trials of a different category for the prior 3-month period; no participation in trials from other companies for the prior 3-month period, regardless of the category; no participation in more than 3 trials in the last year. The quantitative interview guides are included as appendices.

III. RESULTS

Quantitative phase: of the total of 400 patients interviewed, 360 cases were patients without a prepaid health insurance plan (including PAMI and state health insurance services, not private companies) and 40 cases had a private health insurance plan. Within this population, the greater proportion included the most prevalent cancers in our country, such as breast, colorectal, lung, and prostate cancer (Figure 1), gender ratios were balanced, with 45% men and 55% women, and the mean age of the total sample was 55 years.

Sixty-four percent of patients were in active treatment at the time of the interview. When asked "What was the stage at first diagnosis?", 68% answered at an initial stage, with the following distribution: 41% at stages 0-1 and 27% at stage 2; while 29% appeared at an advanced stage of disease, with 10% at stage 3 and 19% at stage 4 or metastatic cancer (3% was unaware of the stage at diagnosis). According to tumor type, earlier diagnosed cancers in this sample were lung, breast, and cervix types (see Figure 2).

When asked "¿How was cancer diagnosed?", only 12% reported having attended a screening program according to age, gender, or a specific risk pattern; 69% were diagnosed after symptoms onset, and 19% as incidental findings. Among asymptomatic patients at diagnosis, this is the case for 90% of patients with colorectal cancer. There were differences also according to health insurance: patients with public health insurance only were less likely to have access to screening programs (10%), as compared to those with some type of private or social health insurance (23%).

The mean delay from the onset of symptoms to diagnosis was 6.2 months for the total sample. Significant differences were observed in patients without prepaid health insurance, where 29% showed delays over 6 months versus 14% for patients with prepaid health insurance; mean delays were 4.3 versus 6.4, respectively. In addition, according to the type of tumor, delays observed in this sample were significant for colorectal cancer, with 35% of cases showing delays over 6 months; in contrast, breast, cervical, and hematological cancers had the shortest delays (Figure 3).

Mean time from diagnosis to treatment initiation was 2.5 months, maintaining the previously described patterns.

Seven out of 10 patients consider that they had a great deal or a fair amount of participation in treatment decisions. The perception of the quantity and quality of the information received was rated as adequate. However, 6 out of 10 patients would have liked to receive more information regarding treatment (24%), disease (22%), management of adverse events and symptoms (15%).

The main challenges reported by patients were regarding symptoms associated with treatments and disease, as well as financial toxicity. The financial impact of the disease represents an opportunity to improve patients' experience, since personal and family loss of work is significant, as well as the financial burden associated with secondary expenses.

People who have a higher disbursement in their health insurance coverage have a higher demand of expectation from the health system (Figure 4).

However, the financial assistance received is not in line with patients' needs (Figure 5). The qualitative phase included 15 patients diagnosed with breast, colorectal, lung, prostate cancer, and multiple myeloma. Of the 5 physicians interviewed, 3 were oncologists and 2 were onco-hematologists. The interviews addressed experiences and needs from the personal, interpersonal, and health system perspectives. The personal perspective included how they faced their new reality and their fears, which redefined the course of their lives. Verbatim of a breast cancer patient: "***'I don't know if it is clear to you that you have cancer, it is very likely that you will go to surgery and have your breast removed,' and I was just... I can't believe what I am hearing. 'Get an appointment as soon as you can,' and as I was a little confused, I told her 'Well, tomorrow I'll get one,' and she said 'No, no, you'll get it now.'"*** From the interpersonal perspective, a new relationship is established with the patients' environment: family, physicians, and other patients. And they relate to the health system from a different need. In most cases, the patient's journey is long and complex. The interviews with professionals confirmed the findings of the quantitative phase regarding the low detection rate of cancer diseases in early detection programs. Some possible strategies based on physicians' opinions to help improve this indicator may include: 1. Considering the disease as a public health policy by facilitating awareness of early symptoms in patients. 2. Development of early detection or population screening programs that are well known and easily accessible. 3. Promoting regular check-ups to allow detection at early stages. The findings of the quantitative phase were confirmed, there was a 6-months mean time from symptoms onset until the patient received the diagnosis. Early diagnosis depends on a multiplicity of factors, with accessibility to complementary tests being the most important one. The time differences remained lower for patients with some kind of health insurance versus those without, who experienced prolonged waiting times for diagnosis. The time from diagnosis to treatment initiation reflects the values observed in the quantitative phase. Some of the main variables identified were the difficulty in obtaining authorization from their health insurance for treatment; verbatim of a patient with colon cancer: "***The health insurance does not cover Tramadol, it does cover 40% of cost for other drugs but Tramadol, because it is not an oncological drug, it is for pain, it costs $1,700***", changes in treatment due to a change in health insurance status from employee to retiree, permanent disability, or patient's decision not to start treatment due to personal issues.

Once treatment is decided, patients rely on the physician's choice of treatment and do not expect to play an active role. Although physicians provide them with information on the type of treatment and adverse effects, patients do not always understand it. This raises the need to use a simple and common language to facilitate the understanding of the procedures and the treatment effects, avoiding a source of stress and surprise for the patients due to lack of knowledge. During the treatment stage, other problems experienced by patients were identified, such as access difficulties (non-authorization/rejection of prescribed drugs, non-delivery of requested drugs or incomplete deliveries, change of health insurance plan, which delays administrative procedures); frustration due to the progression of the disease, and the difficulties in transportation to therapies that must be borne by their own means, verbatim of a lung cancer patient: "***In the first few months I had a breathing compromise. So, I didn't drive myself, I asked for a car, that was the most I spent;***" Verbatim of a colon cancer patient: ***"I have always been a working person. What worries me the most is not being able to work and to support my family and having to depend on my children"***. Regarding the interdisciplinary management of patients, there are no standardized management parameters in all institutions, and only institutions where protocols require meetings of various specialties, patients receive comprehensive management.

Regarding the scenario posed during the COVID-19 pandemic, for physicians, care during this period has been complex and their concern has been the decrease in adherence to treatment. They notice a decrease in treatment attendance due to fear of infection. They prefer not to schedule visits due to exposure in clinics managing COVID patients, they use telephone or text message (WhatsApp or similar) for management. They face the challenge of developing telemedicine (virtual and telephonic), however, they do not always have the tools at hand. They foresee a drop in new patient visits, with the subsequent post-COVID consequence of under-diagnosis of cancer patients or patients in later stages. This new scenario brings new challenges for specialists that are not easy to handle, especially in a profession that exposes them to infection. It is a time of stress and complicated scenarios for physicians on a professional and personal level.

For patients, virtual care and access are a difficult barrier especially in a non-digital group of people who have had face-to-face care all their lives. It entails feelings of abandonment and frustration.

IV. DISCUSSION AND CONCLUSION

Through this approach, we found inefficiencies in the quality of the service provided at different times of the cancer patient's life, which make it a difficult journey for all stakeholders: patients and physicians.

Shortcomings in the health system and its response capacity, as well as administrative bureaucracy, are the main weaknesses in the management of the disease. They lead to cross-sectional consequences at different times in the journey of oncology patients. Focusing the disease care process from the time of diagnosis and centering on the patient's needs allows patients to have certainty on what their disease means and what lies ahead for them in the course of management.

The delay in the detection and diagnosis of the disease continues to be a goal in order to detect patients at early stages and change the current cancer scenario in Argentina. Therefore, it is necessary to recognize the need to typify cancer according to first symptoms occurrence, identifying the differences between cancer types.

Recognizing specialists' humanity and the difficulties they face in a weak health system and unstable labor policies becomes an opportunity to accompany them in order to generate value for patient care.

Taking into account the "negative" perception of patients towards patient support programs (with socialization objectives), these groups need a new meaning that makes them relevant as a mechanism to help patients and their families on different approaches.

The recent pandemic has changed how the disease is managed in terms of access to consultations, therapies, and treatments, making the cancer control scenario in our country even more complex. It is a huge challenge for patients, especially the elderly and the vulnerable population, to whom a new barrier is added: the digital world required to carry out procedures, requests, authorizations, and other health care issues.

All stakeholders have to work on the barriers identified at multiple levels, in order not to neglect any aspect of the cancer continuum of care, including primary and secondary prevention, timely and quality diagnosis, and treatment and palliative care, especially in the challenging times of this new scenario of the COVID-19 pandemic.

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FIGURES

Figure 1

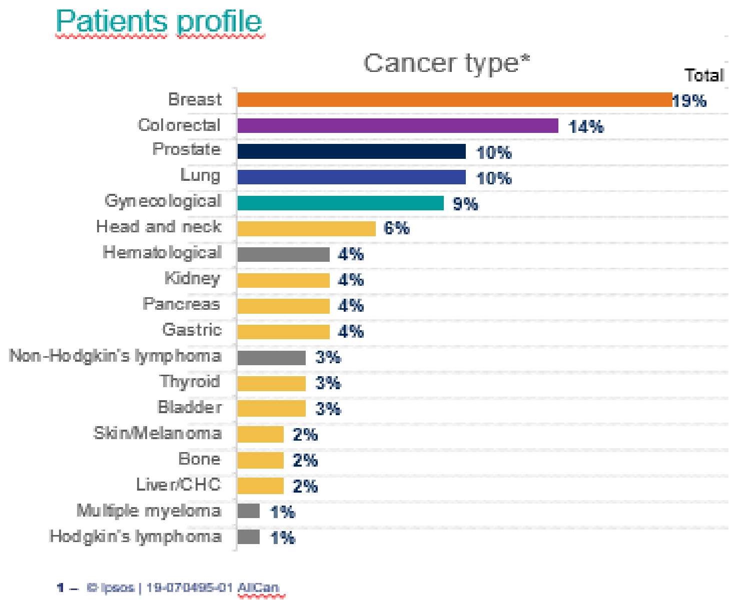


Figure 2

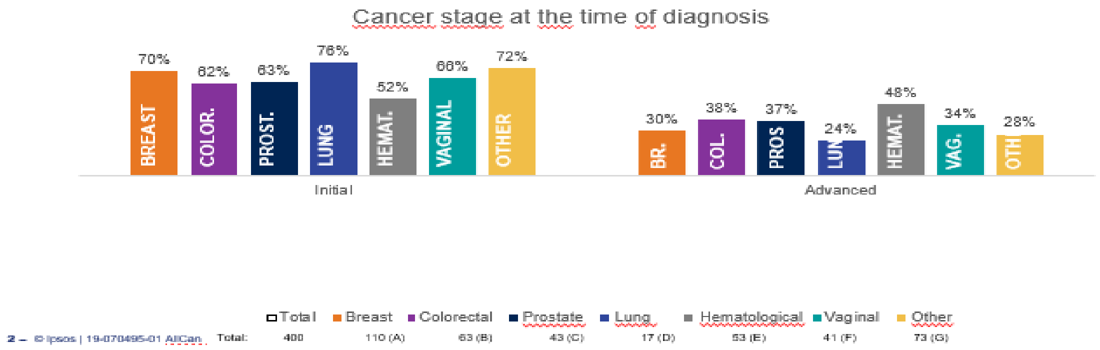


Figure 3

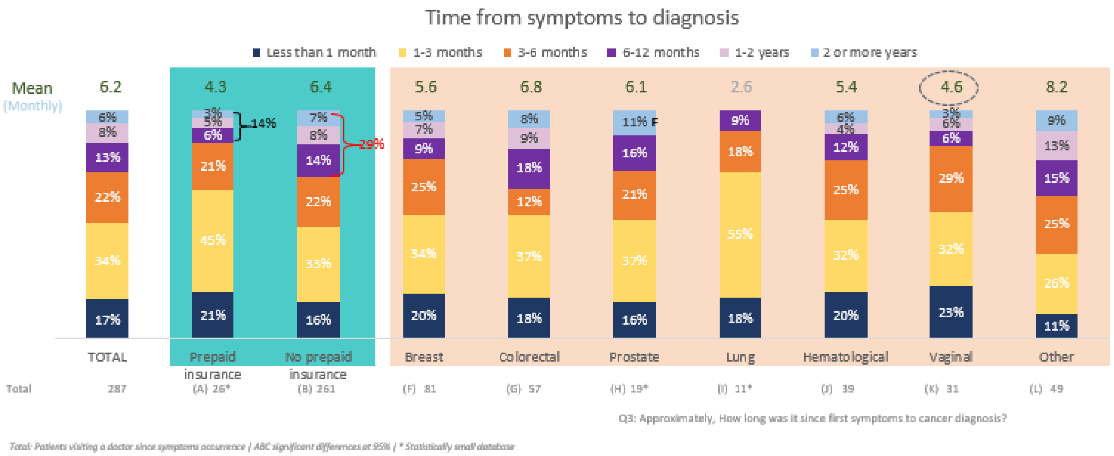
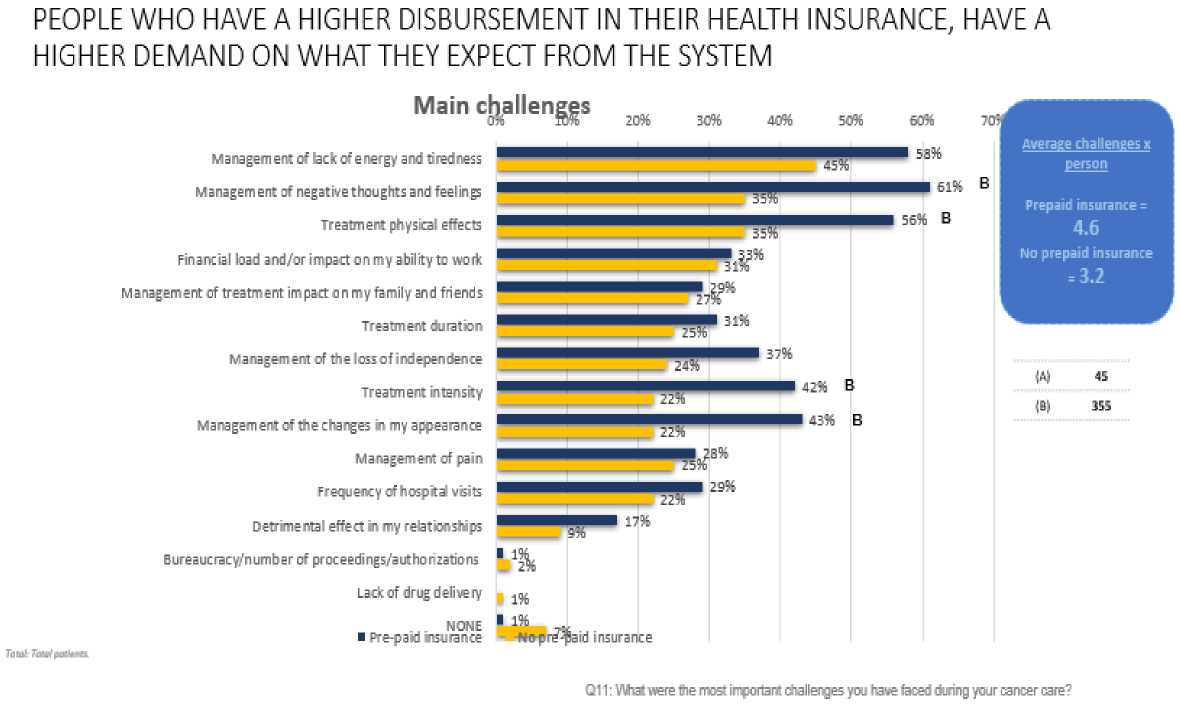


Figure 4



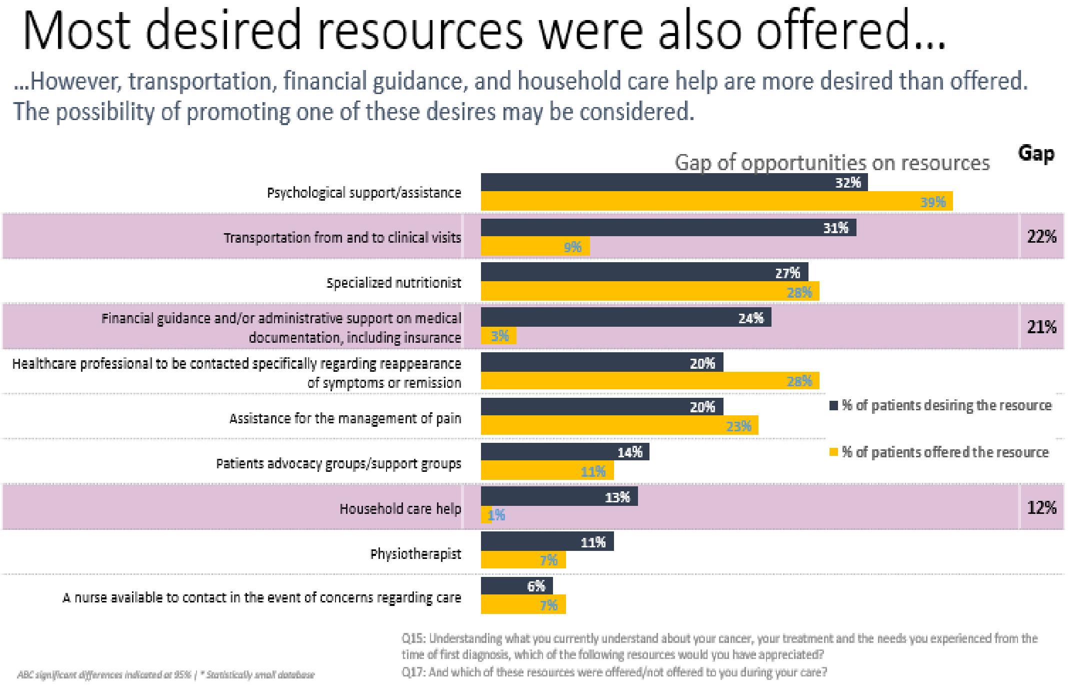
PEOPLE WHO HAVE A HIGHER DISBURSEMENT IN THEIR HEALTH INSURANCE, HAVE A HIGHER DEMAND ON WHAT THEY EXPECT FROM THE SYSTEM

Main challenges

Total: Total patients.

Q11: What were the most important challenges you have faced during your cancer care?

Figure 5



Most desired resources were also offered…

…However, transportation, financial guidance, and household care help are more desired than offered. The possibility of promoting one of these desires may be considered.

Gap of opportunities on resources

ABC significant differences indicated at 95% | * Statistically small database

Q15: Understanding what you currently understand about your cancer, your treatment and the needs you experienced from the time of first diagnosis, which of the following resources would you have appreciated?
Q17: And which of these resources were offered/not offered to you during your care?