# Breast Cancer Patients' Perspective On Healthcare Access

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### **Dissertation Chapter**

### Demographic Information

Cancer is a disease whose prognosis depends largely on timely diagnosis and treatment. Patients' fear of becoming infected in health centers may have caused them not to be screened, delaying the diagnosis and timely treatment of the disease. In some cancers, a three-month delay in diagnosis can have an impact on survival. Regarding demographic information, the entire population surveyed resides in New Orleans, Louisiana. Of these patients, 38.3% have stage II breast cancer, with the lowest percentage (10.6%) being stage 4. 11.9% have stage I (Appendix 1A).

For health care, the highest percentage of the population studied has insurance from the government (80.9%) and the lowest percentage does not have insurance (4.3%). This means that the population is highly assisted by state resources, which indicates that the laws have favored the health care of citizens. Concerning the benefits of ACA, the majority 66%, choose the three options: Before ACA (before 2010), during ACA (2010-2014), and after ACA expansion (Appendix 1B). This type of study, for the selected target population, is of great importance,

because the lack of economic resources of people together with the excessive and uncontrolled charging in the private sector for services provided in clinics is a fundamental limitation in the effective exercise of the right to health (Decker *et al.*, 2022). This is exacerbated by the current situation worldwide, as restrictive measures have led to job losses and the material impossibility of paying for care provided by the private health sector, to which all those who have not been able to receive services in the overcrowded public health system turn. In terms of resources, the annual income of the population is concentrated in a range of no more than \$30,000 (46.8%), and 31.9% with an annual income range between \$30,000 and \$50,000 (Appendix 2C).

At the same time, an important aspect to be taken into account is that family history is relevant in the population. Of the patients interviewed, 51.1% had no family antecedents, and 48.9%, the contrary, 48.9% had family antecedents. These data are necessary to evaluate and generate care and prevention for healthy families for the detection and control of cancer.

About the ethnic group, 68.1% were African-American. 19.1% are white, 8.5% are Hispanic and a lower percentage are Asian (4.3%). Concerning the age group, the highest percentage of the surveyed population is over 60 years of age (36.2%), followed by the 50-60 age group and, to a lesser extent, younger age groups in the 18-25 range. 51.1 % of the respondents have a High School level, and only 19.1 % have a Master's degree (Appendix 1A). At the same time, the highest percentage of patients (48.9 %) are employed, 17 % are self-employed and 23 % are unemployed. The highest percentage of patients (48.9%) are single and 34% are married, the lowest percentage is widowed with 6.41%.

## Dimensions of Accessibility

Accessibility implies that all available infrastructure (facilities, goods, health services) should be accessible to the entire population. This element has four dimensions to be observed for its fulfillment: non-discrimination (access must be, in fact, and law, real for all, including minorities, vulnerable groups, and those excluded from society), physical accessibility (within geographical reach of the entire population, within reasonable distances, and facilities must have appropriate access for people with disabilities or vulnerable groups in general), economic accessibility (payment for health services provided, whether public or private, must be based on the principle of equity so that a disproportionate burden does not fall on poor and disadvantaged households, with economic considerations becoming a limit to the realization of this right) and access to information, the right to receive, request and disseminate health-related information (Al-Quteimat & Amer, 2020).

In the surveyed population, only 40.4% consider it acceptable that medical care is accessible. At the same time, 61.7% agree that they have received the necessary information for treatment and care from the provider (Appendix 2C).

On the other hand, 36.2 % do not agree or do not see it necessary, for the health care provider to improve the quality of communication. In the case of information, the inadequacy and lack of effective channels of dissemination have been elements linked to late diagnosis. This lack of information can promote vague and abstract perceptions, either on the part of women or their families (Chai *et al.*, 2021). To some extent, the lack of information is explained by the fact that it is neither accurate nor conclusive. For example, there is no consensus regarding the causes and risk factors related to the onset of the disease. The only thing that is known with certainty is that early detection is a key factor in the possibility of successfully combating the disease and increasing the survival of diagnosed women (Vuagnat *et al.*, 2020).

# Acceptability

One aspect to consider, 40.4% consider that the health care provider treats the patient with respect and dignity and with individuality. Despite the values and perceptions noted above, in the population surveyed, 21.3% (strongly agree) and 36.2% (agree) in having suffered discrimination in care (Appendix 3).

The discrimination pointed out in the results of the survey, once again demonstrates the problem in health care and the barriers that are present.

Regarding the relationship with service providers, several studies describe the lack of awareness, interest, preparation, updating, and skills of health personnel (particularly physicians) to determine the timely diagnosis of breast disorders (Patt *et al.*, 2020). Likewise, women express mistrust of health services and fear of doctors, especially when it comes to accepting certain diagnostic procedures (breast examination and mammography).

Studies in the United States have found that cervical cancer incidence rates are 45% higher among women of African descent and 65% higher among Hispanic women, compared to white/mestizo women; about breast cancer, some studies show that rates are higher in young women of African descent compared to women of other ethnicities. On the other hand, survival, timeliness of diagnosis, and access to cancer prevention programs among Afro-descendant women are low, as problems of access to health services, lack of health insurance and other social and cultural factors that delay seeking care have been identified. Overall, 55.3% agree that the health professional is sensitive to values, culture, and gender (Appendix 4).

Because of this aspect, it should be remembered that breast cancer is a public health concern and it is necessary to provide care for this neoplasm under precepts of efficiency, quality, and opportunity, coupled with the rational use of the limited resources available in the country for this purpose (Alpert *et al.*, 2021; Johnson *et al.*, 2021). In addition, the growing complexity in the selection of diagnostic and therapeutic procedures, the wide range of drugs, and the need to restructure the supply of services, among others, are examples of the need to evaluate alternatives and analyze health costs.

Studies conducted with women of African descent reveal multiple meanings given individually and socially to cancer; thus, with cancer, it has been found that there are cultural factors related to beliefs about the disease, fear of cancer and death, lack of knowledge about the adverse effects of treatments, family relationships, family support, and spirituality, as well as multiple barriers of the health system to undergo treatment and follow-up.

As other elements, acceptability and quality are highlighted. Acceptability consists of respect for medical ethics and cultural diversity (Paige *et al.*, 2022).

### Availability and Accommodations

Access is conceived as the process of interaction between users and services, to enable the sick individual to receive the service, without discrimination. In other words, the population can seek health services and obtain care. In this study, it was found that 46.8% of patients with breast cancer pathology in the community (Appendix 3). Access depends on factors related to the population, the organization, the delivery of services, and the relationships between them.

From a redistributive perspective of social justice, the basic capabilities of each person must also be taken into account about the resources provided. Therefore, in addition to the

provision of technological means for scheduling and delivery of results, it will be necessary to devise training programs for women and their families on the use of such means. The population receives information about breast cancer care through email (48.9%) and telephone calls. In addition, 53.2% agree that visits and appointments are available in the community (Appendix 3).

In this sense, to the results described above, it is necessary to start from an approach in which the planning of safe programs with remote mediation is added, with educational interventions that allow the inclusion of all women, particularly those who have family environments with little stimulation in the technological and health care areas. The population of 36.2% considers medical care during and after emergencies acceptable (Appendix 4).

It has been established the need to find a balance between coronavirus prevention and the consequences that can be obtained and generated by the absence and infrequency of preventive consultations in women who have not had cancer detected or the resulting discontinuity of treatment. This represents a serious shortcoming in women's health, so it is important to determine a balance in favor of the quality of life of this population. In the study, it was found that although more than 60% were able to continue medical care during the pandemic, a large percentage of the population (21.3 strongly agreed and 27.7 agreed) considered that COVID-19 had a negative impact (Appendix 5).

In times of covid pandemic, when it is difficult to care for patients due to the saturation of hospital centers, fear of contagion and exposure of patients, and comorbidities, remote care has been necessary. With telemedicine, certain advantages can be highlighted, such as It allows for continuity in patient care. It generates joy and containment in the patient. It allows us to educate and reinforce the continuity of treatments, mainly hormone therapy (Miyashita *et al.*, 2020). It allows for clearing doubts and concerns that arise over time, concerning hormone therapy,

examinations, and control hours. It allows the management of future care (medical or psychological appointments, exams, and prescription renewals, among others). Facilitates administrative patient care, such as discarding pathologies and discharge to primary care. Allows continuing with most of the activities of the Breast Pathology Unit that do not correspond to patient care. It allows the management of quick and effective treatments that must be received by the patient (radiotherapy, chemotherapy, hormone therapy).

It facilitates the care of bedridden patients, those who need to be accompanied, and those with reduced mobility or who live in remote areas. Some disadvantages can also be established with the use of telemedicine: such as problems with physical examinations, restrictions in the taking of examinations, technological problems, and the impossibility of communication or emotions, in a doctor-patient relationship. Technological problems, the impossibility of communication, or emotional, a doctor-patient relationship.

### Affordability

In addition to the consequences of physical health, psychological, education, culture, economy and so many other aspects of life, like any crisis, it can also be seen as an opportunity to analyze and improve our behaviors, such as the way we manage chronic patients. 44.7% and 36.2% of the population agree that breast cancer has caused financial difficulties and problems in their quality of life. The highest percentage of the population (29.8%) cannot afford the disease. At the same time, 34% do not consider that they have not received medical care for their cancer treatment. This means that health care has been significant. In these patients, health insurance covers breast cancer care of the surveyed population, 44.7% (Appendix 5).

The current management of breast cancer requires the coordinated interaction of different health professionals from the moment of diagnostic confrontation. This interdisciplinary concept becomes critical during treatment planning and execution. In a public center such as ours, with limited resources and in which not all these specialists are available on-site, it is necessary to communicate quickly with providers of the public and private systems to articulate the care of our patients, which presents us with a daily challenge.

It is considered that the difficulties during the COVID-19 pandemic have increased considerably and we have had to adapt our management to provide timely, safe care that does not generate more risk of contagion and taking into account the limitations inherent to the lack of hospital infrastructure that has occurred worldwide.

A great challenge is also related to the imperative level of making a diagnosis of the impact that this period of pandemic generates on the health condition of patients, especially to collect the results of those who had to wait for surgeries, either in hormone therapy or neoadjuvant chemotherapy, calculating the eventual increase in morbidity and mortality due to postponed or suspended treatments (Chino *et al.*, 2017). Again, it is important to describe high-priority populations and to broaden the management alternatives in certain groups of patients at surgical risk or who for some other reason must defer their surgery.

The pandemic had an enormous impact on hospital activity, generating an organizational restructuring in hospitals. This has resulted in restrictions on the availability of operating rooms, consultations, imaging tests, and other routine activities. At the same time, there is a reduction in the number of physicians available, both staff and residents, in cancer services. There are also reasonable suspicions of the possibility of transmission of the disease by asymptomatic carriers or

carriers with few symptoms, which could lead to inadvertent transmission between patients and physicians.

### Appropriateness

One effect of COVID-19 is that it has changed treatment plans in some cancer patients. Some expert panels have published recommendations on this issue, such as the expert consensus of the European Society of Medical Oncology, on, for example, which patients to defer surgery or chemotherapy treatments. It has been determined that, in oncology patients with systemic therapy, in 27% of the cases there was a modification in the treatment, reaching 41% in lung and head and neck cancers (Resio *et al.*, 2018). In the study, 38.3% of the population, which represents the highest percentage (Appendix 5).

The population indicates that the opinions and thoughts to make decisions on treatment and care are not taken into account by the healthcare provider. At the same time, the highest percentage of the population did not experience follow-up by the care provider to ensure that they received community care, resources, and updates (Appendix 6).

Some 27.7% and 38.3% experienced a decrease in quality due to the health crisis (Appendix 6). The discomfort is not only reflected in poor care, which may represent a barrier, but also in the level of danger of being infected with the virus (Schrag *et al.*, 2020; Pigozzi *et al.*, 2021).

About the population studied, there was continuity in cancer treatment, but, COVID-19, as pointed out by the respondents, had a considerable impact on treatment and health care in general. A phenomenon that was determined worldwide is that the number of patients who consulted health centers decreased, delaying their check-ups and not consulting for new symptoms, for fear of

contracting SARS-CoV-2. This may provoke another health crisis, with late diagnosis and treatment, which may increase the morbidity and mortality rate for these pathologies (Brugel *et al.*, 2021). Some studies have shown that the time it takes for a breast tumor to double in size varies from 45 to 260 days. This is a wide range that does not help us determine the real effect of delayed diagnosis on survival. There are also estimates that, within 6 months, up to 50% of breast tumors could increase in size by more than one centimeter. To this can be added that many health centers in the world deferred screening, surgery, and adjuvant therapies to give priority to the care of hospitalized COVID-19 patients. This was not the case in our institution where oncologic surgeries were given priority.

### **Public Health Policies**

The current management of breast cancer requires the coordinated interaction of different health professionals from the moment of diagnosis. This interdisciplinary concept becomes critical during treatment planning and implementation (Butler, 2020; Ueda 2020). The research population agrees that current health policies are centered on considering the needs and requirements of the patient, which is significant in health care. A high percentage consider that the health policies related to the Affordable Care Act changed concerning access to health care, and breast cancer care has improved since the enactment of the Affordable Care Act, 2010 (Appendix 6).

Despite all the difficulties faced, the fears of patients, health and administrative staff, and logistical complications, we have generated a powerful learning process that has allowed us to design alternative and complementary methodologies to our usual medical practice, to maintain throughout this period continuous and adequate care of all our patients and in the best possible way in these circumstances. It has managed to diagnose, control, and indicate treatments and thus

generate a continuum that is not affected by this unusual period, so we consider it essential to emphasize that if we had not implemented this modality of care, we would see an impact on the prognosis of the disease, which can be evaluated shortly. The great challenges faced after the pandemic are related to the implementation of remote work in a more formal, organized, and coordinated manner, in addition to recovering lost time, especially in terms of surgical activity, since the wards were temporarily closed and reconverted to care for COVID-19 patients, which has left a huge surgical waiting list (Marron 2020; Riera 2021). A great challenge will be the imperative duty to make a diagnosis of the impact that this period will have on the health condition of our patients, especially to gather the results of those who had to wait for surgery, whether neoadjuvant chemotherapy, calculating the eventual increase in morbimortality due to postponed or suspended treatments, for academic purposes but also to describe high priority populations and expand management alternatives in a certain group of patients at surgical risk or who for some other reason must defer their surgery.

It is well known that screening mammography is a type of medical imaging that makes it possible to discover changes in the breasts of women who are not yet showing symptoms of cancer. A screening program with mastography consists of regularly studying healthy women and its objective is to detect the disease early and thus increase the chances of cure with less aggressive and cheaper treatments (Yao *et al.*, 2021). The main advantage of organized and quality screening programs with mastography is that they save lives, as long as they are accompanied by referral mechanisms for timely treatment.

Finally, it should be clear that, despite Covid-19, for example, breast cancer screening is as important as ever. It is possible to prevent and transform forms of exclusion with safe screening

programs, but the processes of collaboration and linkage of centers and hospitals that dedicate part of their activity to the timely detection of breast cancer must also be promoted.

It has been determined that the difficulties during the COVID-19 pandemic may increase considerably and we have had to adapt the management to provide timely, safe care that does not generate more risk of contagion and taking into account the limitations inherent to the lack of hospital infrastructure that has occurred worldwide (Krok-Schoen *et al.*, 2021). A high percentage of the population (80%) considered that mandatory closures, quarantines, and face-to-face visits negatively affected breast cancer care (Appendix 6).

After confinement, there is a better understanding of the effectiveness of protective measures, and supplies of protective materials are considered to be more stable than at the beginning of the pandemic (Casella *et al.*, 2020). In addition, social distancing and hygiene measures have had a positive effect in slowing the spread of the virus.

For example, the cost of patient care includes the value of screening plus radiotherapy, chemotherapy, the diversity of surgical procedures, and the cost of follow-up. In the specific case of screening, it includes the cost of case detection in the general population plus diagnostic procedures for patients who test positive for breast cancer.

The analysis presented in this paper corroborates the importance of consistent diagnosis in the treatment and diagnosis of the disease and the quality of care while eliminating racial issues that may affect patient care. The low use of services in case of need by the population may represent evidence of barriers, which may be geographic, cultural, economic, functional, informational, legal, and gender. Due to the importance of the right to health in the development

of individuals, international instruments have been issued that recognize in a particular and fundamental way this right to certain vulnerable groups such as women and children.

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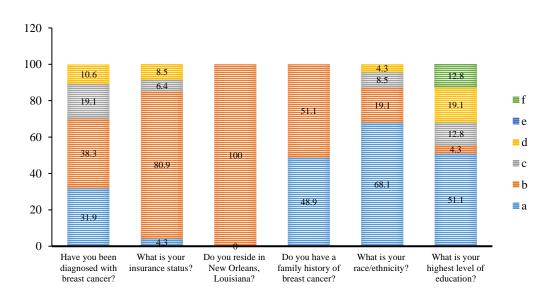
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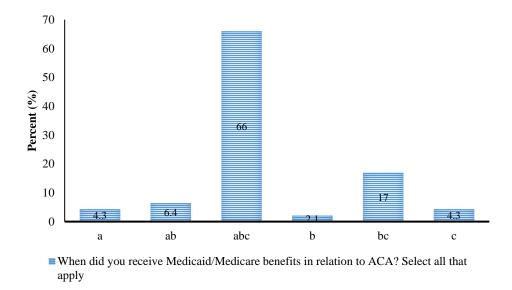
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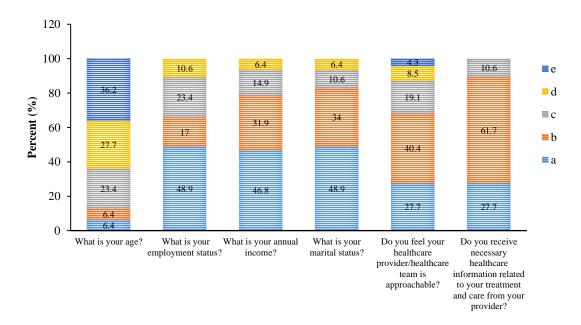
# Appendices



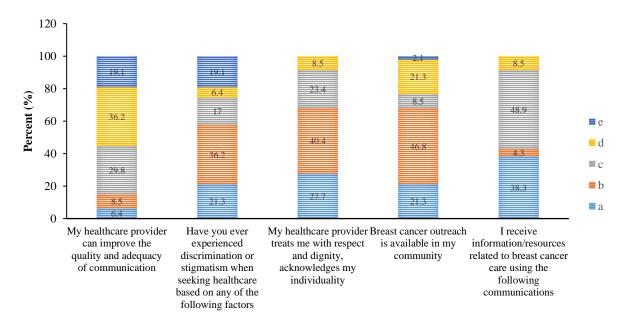
Appendix 1A. Demographic information of patients with breast cancer, residing in Louisiana, 2022



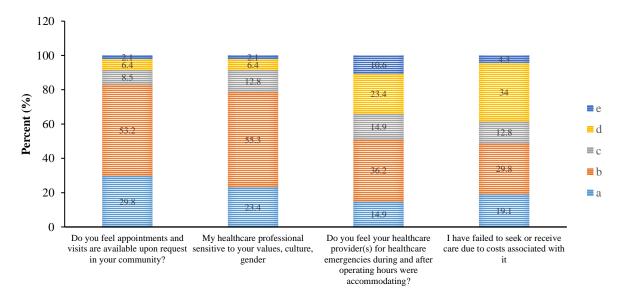
Appendix 2B. Demographic information of patients with breast cancer, residing in Louisiana, 2022



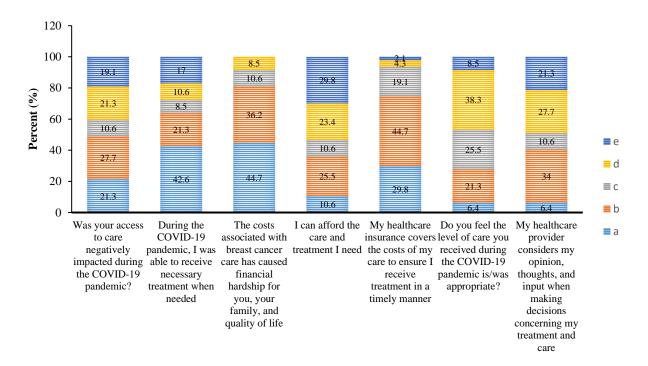
Appendix 2C. Demographic information of patients with breast cancer, residing in Louisiana, 2022, and Dimensions of Accessibility



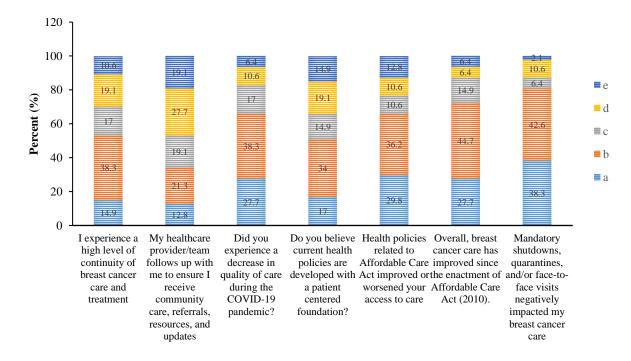
Appendix 3. Questions related to the dimensions of Approachability, Acceptability, Availability, and Accommodations, 2022



Appendix 4. Questions related to the dimensions of Availability and Accommodations, 2022



Appendix 5. Questions related to the dimensions of Availability and Accommodations, Affordability, 2022



Appendix 6. Questions Related to Appropriateness and Public Health Policies Dimensions, 2022