Breast cancer patient attitudes and experiences of health care in the post-COVID era: Landscape of recovery and trust at an urban US cancer center

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Abstract

Background: The fall-out of COVID-19 on breast cancer care delivery is yet to be fully understood and measured from the vantage point of all stakeholders, particularly the most vulnerable. At a U.S. comprehensive cancer center serving a very diverse, urban, and low-income community that was at the epicenter of the pandemic, identifying the impact on health care trust among these breast cancer patients is an important step in developing a roadmap for full recovery and responsiveness in the backdrop of a changing health care model. **Methods:** This descriptive analysis of an IRB-approved psychosocial needs assessment study examines attitudes and experiences around COVID-19, cancer care delivery, and medical mistrust from March 2024 to June 2025 among an ethnically diverse and underserved breast cancer patient cohort. Patients (n=135) were referred to a psycho-oncology program by their providers based on interest in counseling or support services. Patients identified as Hispanic (56%) or Black (38%) and were a mean age of 57.15 (25-86 yrs), with a median time since diagnosis of one year. **Results:** A COVID-19 history assessment found that 52% of patients had a past diagnosis and 28% lost a loved one to the virus. Almost all (94%) received the COVID-19 vaccine for reasons of: protecting self (63%), family (56%), or community (45%), chronic health condition (31%), MD recommendation (41%), reducing worry (38%), and job requirement (39%). While 65% felt getting vaccinated was the right decision and 42% report they are likely to get boosters, 27% regret getting the vaccine and 19% felt it harmed them. Next, patients were queried about their impressions of their most recent health care visit (80% oncology-related) using the Health Service Utilization Scale. Positive to negative ratings were as follows: wait time (85% to 5%), treated respectfully (93% to 3%), clear provider explanations (90% to 4.5%), shared treatment decisions (89% to 4%), private discussion time with providers (95% to 2%), happy with provider (88% to 5%), and facility cleanliness (96% to 1%). Lastly, based on items from the Group-based Medical Mistrust Scale in which "people of my ethnic group" is the reference perspective, 26% of patients reported disagreement with the statement that they receive the same medical care as other groups with 20% endorsing that doctors don't take their medical complaints seriously and 14% felt they should be suspicious of information from health care workers and modern medicine. **Conclusions:** This psychosocial assessment of underserved breast cancer patients in the immediate post-COVID period sheds light on a wide range of health care perceptions from high satisfaction with care to substantial levels of medical mistrust and decisional regret. The contrast in these held beliefs may hold an important guidepost in how both the patient and the cancer care system can mutually heal and rebuild its relationship, with dialogue around values, goals, and shared decision making at the center.

Methods and Materials

This survey study took place at the Montefiore Einstein Comprehensive Cancer Center (MECCC) which is the major cancer care provider of the Bronx, NYC. Patients referred for psychosocial oncology services through MECCC's Bronx Oncology Living Daily (BOLD) Cancer Wellness Program were administered a needs assessment in English or Spanish by trained clinical interviewers or student interns. Participation in the survey is optional for IRB-research purposes but over 95% of patients opt-in.

Measures include the Distress Thermometer[1], Health Care Utilization Scale[2], and the Group-based Medical Mistrust Scale[3].

Sample characteristics are displayed in Table 1 below.

Table 1. Sample Characteristics (n=135)

	%
Race	
Hispanic	56
non-Hispanic Black	38
Other	6
US Born	49
Language	
English	70
Spanish	30
Education	
<HS	22
HS	35
College	36
Graduate School	7
Live alone	24
Live w/partner	25
Live w/children	55
	M* (sd), range** ***Median/Cut-off
Age	57.15 (11.14), 25-86 yrs *Median=57.97 yrs*
Time Since Diagnosis	3.87 (6.4), .01-41 yrs *Median=1.03 yrs*
Distress Level (low to hi: 0-10)	5.7 (3.1), 0-10 *% with clinical distress=73%*

Results

Figure 2. Covid Experiences and Attitudes.

	%
Past hx of Covid-19	52
Lost loved one to Covid-19	28
>1 loved one	40
Lost more than 2 loved ones to COV	24
Received Vaccine	94
Reasons:	
• Protect Self, Family, Community	63, 56, 45
• Chronic health condition	31
• MD recommendation	41
• Reduce worry	38
• Job requirement	39
Attitudes about Vaccine:	
• Right decision	65
• Will get boosters	42
• Regret getting vaccine	27
• Felt it harmed them	19

Chart 2. Health Care Utilization Scale – Perceptions of Health Care Delivery

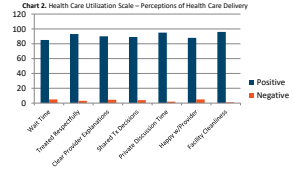
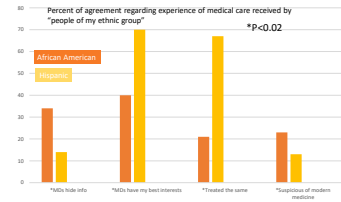


Chart 1. Group-based Medical Mistrust



Conclusions

This descriptive assessment of health care attitudes in an underserved and diverse population of breast cancer patients suggests that the pandemic may have left proverbial scars. In particular, the high rate of decisional regret around taking the vaccine and concerns that they were harmed by it may have reinforced, if not exacerbated, mistrust of the medical system. As can be seen above, African American patients reported significantly more medical mistrust than Hispanics. In contrast, perceptions of health care delivery were uniformly positive. Perhaps patients may feel they have received overall good care themselves, but believe that their ethnic group may receive less than optimal care as a whole. These findings point to an opportunity to open a dialogue with our patients on their concerns, questions, and goals about their medical care. It should be noted that this sample of patients were referred for psychosocial support with nearly three quarters experiencing clinically significant distress. As such, this study is generalizable to patients experiencing clinical distress. Future research will examine association of medical mistrust to treatment adherence and if a perceived positive relationship with one's provider mitigates mistrust and nonadherence.

Contact

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