



Identification of barriers at the primary care provider level to improve inflammatory breast cancer diagnosis and management

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ARTICLE INFO

Keywords:

Breast cancer
Primary care
Health disparity
Medical education
COVID
Telemedicine
Rare disease
Race

ABSTRACT

The purpose of this study, based in the United States, was to evaluate knowledge gaps and barriers related to diagnosis and care of inflammatory breast cancer (IBC), a rare but lethal breast cancer subtype, amongst Primary Care Providers (PCP) as they are often the first point of contact when patients notice initial symptoms. PCP participants in the Duke University Health System, federally qualified health center, corporate employee health and community practices, nearby academic medical center, Duke physician assistant and advanced practice nurse leadership program alumni were first selected in a convenience sample and for semi-structured interviews (n = 11). Based on these data, an online survey tool was developed and disseminated (n = 78) to assess salient measures of IBC diagnosis, health disparity factors, referral and care coordination practices, COVID-19 impact, and continuing medical education (CME). PCP reported access to care and knowledge gaps in symptom recognition (mean = 3.3, range 1–7) as major barriers. Only 31 % reported ever suspecting IBC in a patient. PCP (n = 49) responded being challenged with referral delays in diagnostic imaging. Additionally, since the COVID-19 pandemic started, 63 % reported breast cancer referral delays, and 33 % reported diagnosing less breast cancer. PCP stated interest in CME in their practice for improved diagnosis and patient care, which included online (53 %), lunch time or other in-service training (33 %), patient and provider-facing websites (32 %). Challenges communicating rare cancer information, gaps in confidence in diagnosing IBC, and timely follow-up with patients and specialists underscores the need for developing PCP educational modules to improve guideline-concordant care.

1. Introduction

In the United States, the NCI defines rare cancers as those which occur in fewer than 15/100,000 people each year, representing about 27 % (400,000 Americans) of all US cancer diagnoses (About Rare Cancers, 2019). In Europe, rare cancers are defined as occurring in < 6/100,000 people per year, representing 24 % of all cancer diagnoses (Casali and Trama, 2020, Gatta et al., 2017). The five-year survival rates for rare cancers are also lower than those for common cancers, accounting for a disproportionately higher rate (25 %) of all cancer deaths.

There are around 200 forms of rare cancers, and they are generally understudied compared to common cancers, resulting in diagnostic criteria and standards of care similar to those for common cancers in that

organ/type (Pillai and Jayasree, 2017). Breast cancer, the most common cancer in women worldwide, is one example where recent improvements in treatment options have considerably increased survival outcomes (Heer et al., 2020). However, subtypes like inflammatory breast cancer (IBC), although designated as a rare cancer (1–6 % incidence) is responsible for a disproportionately high mortality of almost 10 % of all breast cancer deaths globally (Abraham et al., 2021). Furthermore, IBC symptoms are unique and attributed to the diffuse nature of the tumor growth (clusters of tumor cells termed as tumor emboli) in the breast parenchyma and dermal lymphatics (Arora et al., 2017). Instead of a palpable tumor mass like in most breast cancers that can be radiographically identified, IBC patients present with painful, swollen breast with skin changes (dimpling, reddish color) that look like a chest wall

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<https://doi.org/10.1016/j.pmedr.2023.102519>

Received 5 June 2023; Received in revised form 19 November 2023; Accepted 20 November 2023

Available online 21 November 2023

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inflammation or infection (Schairer et al., 2019, Hester et al., 2021). This often leads to mis- or late-diagnosis dealing to treatment delays and poor clinical outcomes (Balema et al., 2021, Chippa and Barazi, 2021, Arora et al., 2017). In addition, like most rare cancers there are fewer clinical trials offered due to low patient numbers. Currently, IBC patients receive a trimodal regimen of chemotherapy, surgery, and radiation similar to that for locally advanced breast cancers, but with reduced overall survival outcomes (Adesoye et al., 2021, Chaitikun et al., 2021, Fayanju et al., 2020). In addition, 30 % of IBC patients present with metastatic disease, further underscoring the importance of a prompt diagnosis (Postlewait et al., 2021). Most importantly, IBC is a NIH-designated cancer health disparity (Institute, 2016) with increased global incidence and mortality in minoritized and marginalized populations (Relation et al., 2021, Schinkel et al., 2014, Gudina et al., 2019). This is consistent with reports of distinct reproductive risk factors like younger age at first pregnancy, multiparity, and breastfeeding in IBC (Fouad TM, 2018) (Linhares et al., 2020, Mejri et al., 2020). These studies highlight the significance of primary care providers (PCP), including physicians, physician assistants, and nurse practitioners, who are often the first point of contact when patients begin to notice symptoms (Nekhlyudov et al., 2017). Although PCP play a key role in prevention and early detection of IBC, few studies have examined PCP knowledge and practices related to IBC. To fill this gap, we conducted qualitative interviews and developed a survey instrument to assess PCP experience related to awareness, barriers, and facilitators of identification and treatment of IBC. In this article, we report the providers' IBC knowledge, attitudes, structural practice barriers, and the need for educational strategies to improve diagnosis and care.

2. Methods

We conducted formative research using a mixed methods approach to develop and pilot test the questionnaire. The two phases (key informant qualitative interviews and an online quantitative survey) are described below.

2.1. Study participants and data collection

Participant eligibility for both phases of data collection included the following two inclusion criteria: 1) Primary care provider who is licensed/credentialed as a Medical Doctor, Doctor of Osteopathic Medicine, Nurse Practitioner or Physician Assistant; and 2) resident of North Carolina.

Qualitative interviews: Sample size in the qualitative research phase ($n = 11$) was guided by the principle of information power, which indicates that the amount of information the sample holds relevant to the research purposes, the fewer number of participants are needed. Based on this conceptual model, the adequacy of information power should dictate whether a smaller or larger number of participants is required. Information power depends on factors like the research objective, the specificity of the sample, the theoretical foundation, the quality of communication, and the analysis approach (Malterud et al., 2016). Our study was conducive of needing fewer participants because our research objective was focused (we wanted to know PCP knowledge, attitudes and practices related IBC), our sample was closely tailored to our research questions (recruited only PCP); we had clear interview communication between trained qualitative researchers and PCPs to elicit the information we desired, and the analysis involves a thorough examination of narratives shared.

Between August 2020 and April 2021, experienced graduate degree trained qualitative interviewers and data analysts (LJF, MF) from the Duke Cancer Institute Behavioral Health and Survey Research core (BHSRC) conducted semi-structured interviews with 11 PCPs via Zoom. (Zoom Video Communications, Inc.; San Jose, CA). Using purposive sampling, these participants were recruited via email invitations and were employed at Duke University Health System (DUHS) along with a

local federally qualified health center and corporate employee health practice.

Online survey: Using purposive sampling, three hundred and nine (309) eligible individuals received the initial study email invitation. In an attempt to expand the sample, an additional 10 PCPs in local medical practices were later contacted via email with a request to share the email invitation with 2 of their eligible colleagues (snowball sample total of 30 individuals). Thus, total number of study invitations were shared with 339 individuals (309 + 30). The participants who received email invitations to participate included PCP based at DUHS along with a local federally qualified health center and a corporate employee health practice ($n = 137$). In addition, emails were sent to North Carolina-based PCP alumni from the Duke Physician Assistant program, Duke Primary Care Transformation fellowship and the Duke-Johnson & Johnson Nurse Leadership program ($n = 192$).

To create the online survey, we first developed a key informant interview guide informed by a literature search, prior research, and grounded theory approach (Devi et al., 2019, Woodward, 2017, Devi et al., 2019b, Shah et al., 2006). The interview questions focused on differentiating IBC from common breast cancers; IBC symptom recognition and diagnosis; health disparity issues at the patient, provider, and community level; explaining IBC to patients; referral practices; and connecting with specialized clinical centers (Appendix 1). Interviews lasted approximately 30 min and were audio recorded prior to transcription by a research assistant. There was no one else present during the interview except for the researcher and participant. Table 1 describes interview participant characteristics.

A subset of the participants ($n = 5$) who completed the qualitative interviews reviewed the survey draft via a telephone cognitive interview (Appendix 2) prior to dissemination to refine the survey instrument and reduce response errors (Willis, 2017). The second author reviewed the survey with the participant. For each question, participants were asked to identify anything that was unclear about the questions and for suggestions to make the question clearer.

Based on the key informant and cognitive interview data, we developed and administered an online survey via the secure web application, REDCap (Harris et al., 2019, Harris et al., 2009), to assess PCP knowledge, attitudes, and practices for identifying and treating IBC. This quantitative survey (Appendix 3) aimed to assess: 1. information needs 2. referral and care coordination patterns and 3. potential knowledge gaps and care coordination issues among PCP. The surveys were conducted August 2021-March 2022 and 78 participants completed the online survey. Table 2 describes respondent characteristics. This study was approved by the Duke University Institutional Review Board. Informed consent was obtained from survey participants.

Table 1
North Carolina PCP qualitative interview cohort characteristics ($n = 11$), 2021.

Characteristic	Categories	% (n)
Gender	Male	36.4(4)
	Female	63.6 (7)
Role	Nurse Practitioner/Certified Nurse	27.3 (3)
	Midwife	
	Physician Assistant	27.3 (3)
Specialty	Physician	45.5 (5)
	Internal Medicine	9.0 (1)
	Family Medicine	91.0 (10)
Number of Years Practicing Medicine	5 to 9	27.3 (3)
	10 to 14	9.0 (1)
	15 to 19	9.0 (1)
	20 or more	54.5 (6)

Table 2
North Carolina PCP Online Survey Cohort Characteristics (n = 78), 2021–2022.

Characteristic	Categories	% (n)
Gender	Male	17.9 (14)
	Female	79.5 (62)
	Prefer not to answer	2.6 (2)
Hispanic or Latino/ Latinx	No	91.0 (71)
	Yes	7.7 (6)
Race	Asian	6.4 (5)
	Native Hawaiian/Pacific Islander	1.3 (1)
	Black or African American	12.8 (10)
	White	67.9 (53)
	More than one race	2.6 (2)
	Other	1.3 (1)
	Prefer not to answer	7.7 (6)
Role	Nurse Practitioner/Certified Nurse	9.0 (7)
	Midwife	
	Physician Assistant	26.9 (21)
	Physician	62.8 (49)
Specialty	Other	1.3 (1)
	Internal Medicine	47.4 (37)
	Family Medicine	46.2 (36)
	Obstetrics/Gynecology	2.6 (2)
	Other	3.8 (3)
Number of Years Practicing Medicine	<5	17.2 (5)
	5 to 9	17.2 (5)
	10 to 14	20.7 (6)
	15 to 19	17.2 (5)
	20 or more	27.6 (8)
Main Practice Setting	Individual practice	5.1 (4)
	Group practice	23.1 (18)
	Hospital	17.9 (14)
	Academic medical center	65.4 (51)
	FQHC or FQHC like setting	5.1 (4)
	Employer-based clinic	7.7 (6)
	Other	2.6 (2)
Number of Patients Seen Per Week	0 to 10	9.0 (7)
	11 to 20	9.0 (7)
	21 to 30	21.8 (17)
	31 to 40	19.2 (15)
	More than 40	39.7 (31)
	Prefer not to answer	1.3 (1)

2.2. Data analysis

2.2.1. Qualitative

We used a rapid analytic approach to analyze the PCP interview data (Koenig et al., 2016, Hamilton and Finley, 2019, Skillman et al., 2019). We developed a deductive coding template based on the interview guide to structure the analysis. The coding template included 7 primary areas for data summarization based on the aims of the research. Two members of the research team (LJF, MF) used the template to code one transcript and resolved discrepancies. After initial coding, the template was revised and the remaining 10 transcripts were coded by two members of the research team (LF, MF). The team met to discuss and reconcile discrepancies between coders to yield a single coded template for each PCP. Next, we created a matrix with data from coded templates for each PCP to analyze the information in each domain (Averill, 2002). Prior to disseminating the survey, cognitive interviews were summarized using the same process described above to explore feedback regarding completion of the survey (Hamilton and Finley, 2019, Koenig et al., 2016, Skillman et al., 2019).

2.2.2. Quantitative

Using REDCap (Harris et al., 2019, Harris et al., 2009) and GraphPad Prism version 9.3.1 for macOS (GraphPad Software, La Jolla, California, USA, www.graphpad.com), descriptive statistics and figures were generated from the data to describe the quantitative survey results. Categorical variables were summarized in frequencies and percentages.

3. Results

3.1. Qualitative data analysis

Participant characteristics are shown in Table 1. Sixty-four percent (64 %) were female; 46 % were physicians, 91 % specialized in Family Medicine and 55 % had been practicing for 20 years or more. We identified specific barriers and facilitators for PCPs in IBC recognition and care; Table 3 includes representative quotes related to the sub-themes below.

3.1.1. Barriers in differentiating a rare subtype amongst other breast cancers

Overall, providers acknowledged that IBC is a rare cancer, and most had not seen patients with IBC in their practice. They reported a general awareness of unique symptoms of IBC but recognized that IBC is not likely to be part of typical differential diagnosis when patients present with mastitis or skin changes. In particular, respondents mentioned the importance of monitoring skin changes in the breast when patient complaints include pain and itching. In such cases, providers reported prescribing antibiotics and recommending a return visit in 7–10 days. Some providers reported that they would also refer the patient for a mammogram.

3.1.2. Barriers related to cancer health disparity

Race-related: Providers were aware of racial/ethnic disparities in cancer diagnosis and treatment. Although none of the participants indicated direct experience with racial/ethnic disparities with IBC, most believed that factors related to other health disparities are likely similar with IBC. These include systemic racism, medical mistrust, access to care, socio-cultural constructs of health, stress, and comorbidities.

Rural-urban divide: PCP responses included distance and transportation to clinics as major barriers to cancer diagnosis and treatment, and that distance to treatment locations likely contributes to observed disparities in rural areas. Sociocultural factors of health and provider shortages in rural areas can exponentially worsen the barrier of distance, contributing to mis- or late diagnosis and treatment delays.

Socioeconomic status (SES): Participants described a link between SES and education, which may impact health literacy. Patients may delay care because they may not recognize signs and symptoms. Further, inability to pay for care can lead to patients ignoring signs and symptoms.

Knowledge gaps regarding Standard of Care: Providers stated they were not familiar with the epidemiology of IBC; they lacked understanding of the impact of age and that IBC incidence is higher in younger premenopausal women. General sentiments included: mammograms are probably the appropriate diagnostic test for IBC; acknowledgement that older women are less likely to have screening mammograms; and older patients likely have fewer health insurance barriers to accessing care due to Medicare coverage.

Gender: One provider mentioned potential barriers to breast health promotion for transgender individuals, commenting, “Sexuality, especially for transgender patients, screening, how comfortable the provider is bringing up breast issues, breast exams, mammograms” (Table 3). These barriers may result in differential care, with fewer breast exams and screenings for transgender patients.

IBC care - Barriers and facilitators: Providers discussed access to care as the single most important barrier to treating IBC and breast cancer in general. Issues like timely referrals, cost of care/lack of insurance, competing roles (caregiver or childcare) and transportation were mentioned. Providers identified the need for better access to specialists for rare condition consultations. One provider suggested that partnership with cancer centers with expertise in rare cancers like IBC would be beneficial to improve relationship with PCP. All providers mentioned that they would submit a referral to a larger breast center in the local area and request a specialist consultation. However, participants noted

Table 3
Sample of North Carolina PCP Interview Quotes, 2021–2022.

Theme	Quote	PCP
Barriers to Diagnosis	(1) "I have only seen one IBC patient in 30 years. Her case was pretty advanced, and it all happened pretty fast."	Medical Doctor
	(2) "From a patient point of view, patients might think suspected IBC is a rash or sunburn and might not seek care. A provider also may not recognize it and treat it like mastitis. Early diagnosis could be a problem"	Physician Assistant
	(3) "I have very limited experience and have not read much on IBC. So, it would be helpful for providers to know it presents differently, because often we think if there is pain it is not breast cancer."	Nurse Practitioner
	(4) "Over the past couple of years, have not had enough patients with IBC. I would not have had enough knowledge to explain that I could either reassure them or give them info to make decision. I would be afraid of causing them more angst."	Medical Doctor
	(5) "Often we are dealing with many acute and chronic issues in one 25 min visit. With so many competing demands there is always a risk that less dramatic breast changes would be missed. Or that there wouldn't be follow up for something like a presumed fungal rash. We could use so much more help in primary care with systems to track unresolved issues. I do so much of it manually and on my own."	Medical Doctor
	(6) "Not familiar with IBC."	Medical Doctor
	(7) "I'm actually not sure what imaging would be appropriate to order for IBC (if that's next step, if suspected?)"	Medical Doctor
	(8) "Primary care docs already struggle to provide optimal care for common, high impact conditions. Hard to get the bandwidth for things we almost never see".	Medical Doctor
	(9) "Tyranny of the urgent and the expectation that I'm supposed to see 10—12 people in a half day, how deep can I get".	Medical Doctor
	(10) "The biggest patient determined factor barrier to care is follow up. I may treat a patient with mastitis with very clear instructions that if it does not respond to antibiotics please come back, and they never come back. So you assume it got better, but patients needing follow up can never make it back due to barriers to access. If I saw a woman with hot tender painful breast, I would treat it as a mastitis first with caution but that barrier to o follow up is huge."	Nurse Practitioner
	(11) "Insurance is a big barrier to care."	Nurse Practitioner
	(12) "With patients who have no insurance, it is difficult to figure out where to send them for mammograms."	Physician Assistant
	(13) "In my experience, the patients who do not want to do a mammogram are typically minority patients do not want to do a mammogram due to bad experience or mistrust with it. We need improved health literacy for mammograms."	Physician Assistant
	(14) "Primary reason for delay in routine breast imaging has been COVID vaccinations – Patients have had to choose between delaying mammograms or delaying vaccinations."	Primary Care Provider
	Subtheme: Health Disparities	(15) "Sexuality, even like screening and coming in for symptoms and then going into treatment, all those aspects can be

Table 3 (continued)

Theme	Quote	PCP
Subtheme: Health Disparities (cont'd)	potentially affected by gender identity like if a patient identifies as trans or some people are treated differently in healthcare even though it's not right."	
	(16) "Our patient population is what many would classify as underserved. We have a lot of challenges with staffing, and resources, and access with our patients."	Nurse Practitioner
	(17) "If they do not trust the system, they are not going to enter it early to help their outcome, delay their treatment. If someone is trying to hold down a job and they do not have time off and knowing that they may get treatment they may have a huge bill or if they have a high deductible, they do not want to be a burden on their family."	Nurse Practitioner
	(18) "There are many rural communities that do not have PCPs, people may not even know where to go. There are many gaps in the rural areas."	Nurse Practitioner
	(19) "My understanding is women in rural areas have a harder time getting in for treatment."	Physician Assistant
	(20) "Ability to pay, transportation to get to a mammogram, knowledge about mammography and recommendations,"	Physician Assistant
	(21) "In primary care you see things that could be an infection. If someone comes in with mastitis, you will do a breast exams and it won't fit with mastitis presents differently. There are cases where I will treat with antibiotics and then also schedule a with a mammogram appointment at the same time. I usually see them back within 7–10 days to make sure it cleared up."	Nurse Practitioner
	(22) "We want to make sure it is not something serious like breast cancer, usually think of breast cancer as lump in the breast that gets bigger over time, but sometime can present in different ways like changes in the skin, want to do an additional evaluation just to make sure"	Medical Doctor
	(23) "Sometimes you see something where you treat it and think it will be okay, it is probably fine but maybe not. Something we it is really hard to call someone else in the department for a second opinion. We do not have any mechanism for consult to speak with a provider on call about complex cases. We do not share an EMR with anyone. We are a small team, but we do not have any avenues to get another pair of eyes or a brain on it."	Nurse Practitioner
	(24) "I do not tend to find out what something is until well after the workup is done. We do not hear about the diagnosis for quite a while. If there was information available for what puts a patient at a higher risk of IBC as a primary care provider that would be helpful to know. And the how to help best support my patients when they go into treatment for it. Knowing risk factors would help us screen for IBC and understanding if there is a genetic component."	Medical Doctor
Explaining IBC to Patients	(25) "In an ideal world, we would create a care plan with a core list of principles at the top, where the patient is in their treatment, main side effects of their medication, and changes in their treatment over time. For example, what are the side effects and needs of their treatment as an algorithm. Some sort of continuing relationship with your primary."	Primary Care Provider
	(26) "Making IBC a part of CME curriculum. I did CME two years ago that	Physician Assistant
Referrals and Connecting to Cancer Centers		
Educational Strategies		

(continued on next page)

Table 3 (continued)

Theme	Quote	PCP
	went over breast cancer but did not discuss inflammatory breast cancer specifically.”	
	(27) “In increasing IBC awareness with storytelling - whether online or in print - having stories of patients is what sticks with PCPs.”	Nurse Practitioner
	(28) “Including IBC in any breast cancer talks. Have oncologists talk to our practice. It would be nice to have more of a relationship between cancer doctors and PCPs for what it looks like and what to look out for because it is rare. Knowing it exists is half the battle.”	Nurse Practitioner
	(29) The best way for me to learn about a topic like this is to have had a patient who has had this type of cancer. Fortunately, I have never had someone diagnosed with this. But that means my knowledge is limited. If I had someone come in with the clinical scenario above, I would read and refer.	Medical Doctor
	(30) “Info needs to be simple, we have so many medical issues to be aware of, info needs to be focused and practical”	Medical Doctor

some confusion regarding where to refer patients and what might be covered by patient insurance. Most reported that they would refer patients to radiology for a mammogram, with referral location dependent on insurance type.

Low health literacy and lack of trust in the health care system were also identified as potential barriers to IBC patient care. Providers reported that it is difficult to present all the information about a rare

disease upfront during a patient visit, given the many aspects of care they must cover in the limited 20-minute appointment per patient, in addition to the high patient volume seen daily.

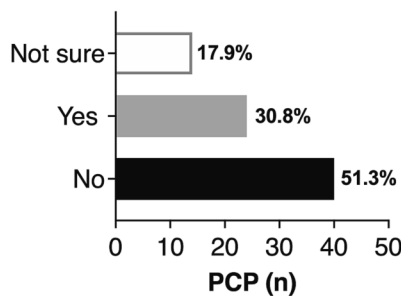
3.2. Quantitative analysis

3.2.1. PCP survey dissemination (Quantitative)

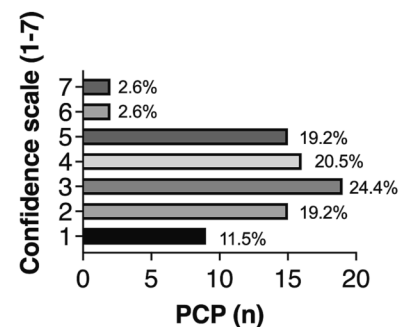
Of the 339 individuals contacted via email with the online survey link provided, seventy-eight (78) respondents completed the survey; this is the denominator for findings unless otherwise noted. The response rate was 23 %. The majority of respondents were primary care physicians (62.8 %, 49), and the remainder included physician assistants (26.9 %, 21) and nurse practitioners/ certified nurse midwives (9.0 %, 7). Although a majority of survey participants (39.7 %, 31) reported a high patient load [seeing > 40 patients/week], 65.4 % (51) estimated diagnosing < 5 common types of breast cancers among their patients per year. 30.8 % (24) had ever suspected IBC in a patient, 51.3 % (40) had not, and 17.9 % (14) were unsure (Fig. 1A). Overall, PCP were only moderately confident in their ability to recognize IBC (mean = 3.3, range 1–7) (Fig. 1B). Answers options and responses were: 1 Not at all confident (9, 11.5 %), 2 (15, 19.2 %), 3 (19, 24.4 %), 4 (16, 20.5 %), 5 (15, 19.2 %), 6 (2, 2.6 %), 7 Completely confident (2, 2.6 %), Prefer not to answer (0, 0.0 %).

To identify provider knowledge of the hallmarks of IBC, providers were presented with common clinical presentations of IBC (question 17; Appendix 3). Responses revealed a gap in ability to correctly differentiate IBC from other breast cancers - a result of high clinical relevance, with 44.2 % (34/77) of PCP respondents selected palpable breast mass as an IBC symptom. Other specific IBC symptoms of inverted nipple and nipple discharge (other than breast milk) were correctly identified by 69.2 % (54/78) and 57.1 % (44/77) of PCP respectively.

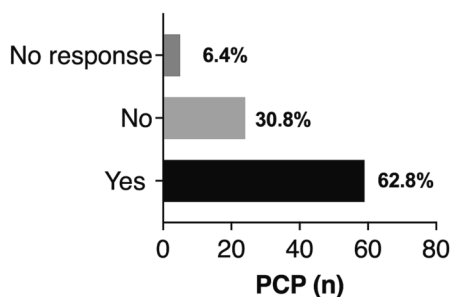
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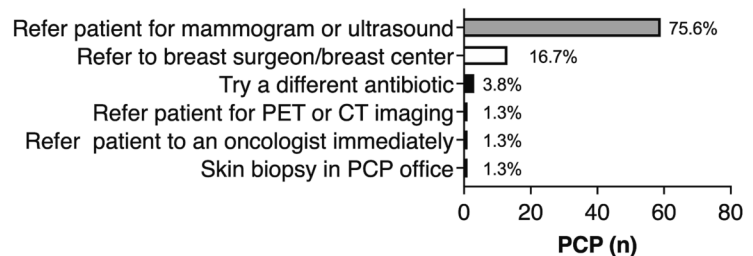


Fig. 1. North Carolina PCP responses, 2021–2022 (n = 78): (A) Frequency of PCP familiarity with diagnosing IBC; (B) PCP confidence level in ability to detect IBC (Scale of 1–7; 1 low, 7 high); (C) Frequency of PCP experiencing delays in referring patients to specialists; (D) PCP preferred follow up care in response to breast changes.

To assess steps taken when IBC is suspected, providers were presented with a hypothetical case describing a woman with left breast pain and inflammation, whose PCP prescribed antibiotics for a potential skin infection or mastitis (question 18; Appendix 3). When asked what the appropriate follow-up care for this woman would be, should the condition not resolve with antibiotics, 75.6 % (59) responded that they would refer the patient for breast imaging (e.g., ultrasound, mammogram), 16.7 % (13) would refer the patient to a breast surgeon/breast center, 3.8 % (3) would try a different antibiotic, 1.3 % (1) would refer the patient for a PET scan/PT scan, 1.3 % (1) would refer the patient to an oncologist, and 1.3 % (1) would do a skin biopsy in the PCP office (Fig. 1D). Collectively, these data suggest gaps in clinical knowledge regarding the diagnostic hallmarks of IBC and the appropriate treatment for suspected IBC.

3.2.2. COVID-19 impacts and telemedicine

When providers were asked how the COVID-19 pandemic impacted screening and diagnosis of breast cancer among their patients, 33.3 % (26) reported lower breast cancer diagnoses than pre-COVID-19, 46.2 % (36) reported having made the same number of diagnoses, and 11.5 % (9) indicated a higher number of diagnoses (Table 4). PCP also reported delays in breast cancer referrals since March 2020, with 62.8 % (49) reporting referral delays (Fig. 1C). Regarding telemedicine, 28.2 % (22) of PCP responded conducting 11–20 % of their visits via telemedicine (Table 4).

3.2.3. Educational strategies for PCP

Providers suggested educational programs are needed to raise awareness of and better understand IBC signs and symptoms. When asked what methods providers would find most helpful to learn more about diagnosing and caring for patients with IBC, the top three modes of preferred education were via online Continuing Medical Education (CME) options (56.4 %, 44); lunch-time or other in-service training (39.7 %, 31) and websites for patients and providers (33.3 %, 26). In the qualitative interview phase, it was identified that partnering with the Duke IBC Consortium could be beneficial to learning about IBC. However, at the time of the survey, only 7.7 % (6) of providers were familiar with this entity. Some providers also suggested patient education in parallel is critical to helping women understand that skin changes in

Table 4
North Carolina PCP Response to COVID-19 Related Impact on Breast Cancer Care (n = 78), 2021–2022.

Characteristic	Categories	% (n)
Change in the number of breast cancer diagnoses made by PCPs since COVID-19	Same number of diagnoses	46.2 (36)
	Lower number of diagnoses	33.3 (26)
	Higher number of diagnoses	11.5 (9)
	Prefer not to answer	9.0 (7)
Percentage of patient visits conducted remotely or via telemedicine since March 2020	<5%	26.9 (21)
	5–10 %	24.4 (19)
	11–20 %	28.2 (22)
	21–30 %	6.4 (5)
	>30 %	7.7 (6)
Delays in referrals to diagnostic imaging for breast cancer since March 2020	Prefer not to answer	6.4 (5)
	No, never	30.8 (24)
	postponed	9.0 (7)
	<5% delayed	21.8 (17)
	5–10 % delayed	5.1 (4)
	11–20 % delayed	2.6 (2)
	21–30 % delayed	3.8 (3)
	>30 % delayed	20.5 (16)
Unsure	6.4 (5)	
Prefer not to answer	5.0 (4)	

their breasts may indicate this rare cancer, along with peer coaching from women who have been treated for IBC. Other responses included the need for a care plan that includes a core set of principles for diagnosing IBC, such as treatment algorithm, side effects, changes in surveillance, and plan over time, as well as provider training on how to deliver bad news to patients in a clear, concise manner.

4. Discussion

We succeeded in developing a survey instrument to assess PCP knowledge gaps and barriers to timely diagnosis and care of IBC patients. The responses collected post-survey dissemination revealed that although PCP are an essential part of the interprofessional approach to diagnosing and managing cancer patients, they lack knowledge of IBC symptoms, are uncertain regarding standardized IBC screening and treatment plans, and desire improved collaboration with cancer specialists. These three significant factors impact timely IBC diagnosis and treatment. Furthermore, participants indicated a desire to develop PCP-targeted IBC educational tools. To our knowledge, this is the first mixed methods study developed to identify the needs of primary care providers to effectively diagnose and treat IBC in the United States.

As we examine the study's findings, it is crucial to acknowledge certain limitations. Firstly, this research employed a non-probability purposive sampling method, which means that the results can, in theory, only be applied to PCPs in North Carolina, from where the sample was drawn. Despite the survey method not being randomized and being limited to PCPs in North Carolina, the findings still hold significance. They validate a central theme that arose from an interactive community engagement session at an IBC national meeting with diverse stakeholder attendees to address critical needs in IBC clinical care and outreach (Devi et al., 2019a). During this national conversation, it became evident that a primary factor contributing to disparities in diagnosis, care, and referral practices was the lack of education at the primary care provider level. Secondly, the survey had a low response rate, standing at only 23 %, which raises the possibility of nonresponse bias. Nonresponse bias occurs when individuals who choose not to participate in a study, or who drop out before completion, differ systematically from those who fully engage (Bose, 2001). This raises the question whether the PCPs who completed the survey were different from those who did not. Unfortunately, a thorough analysis of non-response bias was not feasible in this study because the usual strategies employed for such analysis were neither applicable nor feasible. For instance, because the online survey was the sole instrument used, there were no additional screening or follow-up tools to gather more common variables for comparison between respondents and non-respondents. The only variable we were able to clearly ascertain that had noticeable distinction between respondent and non-respondents was the PCP role (physician, physician assistant, or nurse practitioner). Physician Assistants (PA) made up approximately 50 % of the invited sample, mainly due to a sizable listserv of PA program alumni at our disposal; yet, only 27 % of respondents were PA, with the majority being physicians (62 %). However, it's worth noting that PA were oversampled in our study. When compared to the national distribution of PCP roles, our survey respondents' distribution actually mirrors the national landscape, where physicians hold a significant majority presence (70 %) in primary care practice (Content last reviewed July, 2018). Another important consideration in non-response bias is the assumption that later respondents are more similar to non-respondents than earlier respondents. However, our analysis revealed that there were no significant differences between PCPs who responded later to the survey and those who responded earlier. To reduce potentials of possible nonresponse bias in future studies, we can aim to increase participation rates by employing strategies such as offering advance notice of study, incentives, multiple modalities for participant response, more follow up attempts, and personalized correspondences (Phillips et al., 2016).

Despite the study limitations outlined, it is still worthwhile to

consider intervention implications based on this study's findings. To address the difficulties of IBC symptom recognition among PCP, a clinical intervention of interest is the development of a clinical decision support system (CDSS) embedded within the electronic health record (EHR). CDSS can improve healthcare delivery by enhancing medical decisions with targeted clinical knowledge, patient information, and other health information (Osheroff et al., 2012). CDSS could be strategically used to aid in IBC symptom recognition and diagnosis, imaging recommendation, and specialist referral support (Georgiou et al., 2011). Current data suggest that CDSS can have a positive impact on the quality of cancer care delivery (Pawloski et al., 2019) with the goal of being embedded directly into the EHR to avoid workflow disruption (Sutton et al., 2020).

Additionally, knowledge gaps among PCP regarding symptom recognition and management of suspected IBC highlight the need for the development of enhanced educational opportunities. PCP reported a preference for online CME modules to improve differential diagnosis and their ability to educate their patient population. Recent literature has shown that CME is effective in contributing to knowledge gain among primary care providers in the United States (Gupta et al., 2019). Specific to IBC, two studies report the benefits of CME programs employed in Egypt and Tunisia (Shah et al., 2006) and in Pakistan (Soliman, 2006) toward improving IBC knowledge, early detection, and referral of IBC cases.

Breast cancer-screening guidelines in the US and Europe are increasingly recommending risk assessment for breast cancer be performed at the PCP level (McClintock et al., 2020, Bellhouse et al., 2021). Our survey instrument could be valuable in assessing deficiencies before developing specific educational modules, a crucial step for effective learning among PCP (Armson et al., 2020) regarding cancer diagnosis, treatment, and survivorship care (Bober et al., 2009, Potosky et al., 2011). In the future, it would be valuable to evaluate a pilot IBC CME program among PCP based on pre- and post- CME surveys of knowledge. It is also important to note that classic textbook images that do not capture the range of presenting signs and symptoms across diverse skin tones may contribute to missed diagnoses in patients with atypical presentations. Thus, it is imperative to include varying IBC clinical presentations. We should also identify opportunities to integrate IBC education modules into existing clinical curriculums for PCP trainees to enrich understanding of IBC and how to better navigate care coordination.

5. Conclusions

In conclusion, IBC is understudied and associated with a lack of care concordant guidelines, and the involvement of PCP from diagnosis to quality monitoring has the potential to improve patient survival, quality of life, and health equity. The survey instrument tested here may serve as a blueprint to design, implement, and evaluate interventions to support PCP in diagnosing and managing IBC and could be expanded to include other rare cancers.

6. Institutional Review Board Statement

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of Duke University (Pro00105843, approved July 16, 2020).

7. Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

Funding

This study was funded in part by the Duke School of Medicine Behavioral Health and Survey Research Core Facility Award (GRD, ANT); Duke MERITS Education Grant (GRD); Department of Surgery research funds (GRD); Duke Cancer Institute Community Outreach, Engagement, Equity Seed Grant (GRD, ANT) as part of the P30 Cancer Center Support Grant (Grant ID: P30 CA014236). Trainee engagement supported by Duke Undergraduate Research Fellowship (DSURF) and the Nakayama Public Service Scholar Award (AB). We also acknowledge NIH 1R01CA264529-02 (GRD), American Cancer Society Mission Boost Grant Award MBG-20-141-01-MBG (GRD).

CRedit authorship contribution statement

Gayathri R. Devi: Conceptualization, Funding acquisition, Investigation, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing. **Laura J. Fish:** Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. **Alexandra Bennion:** Formal analysis, Visualization, Writing – review & editing. **Gregory E. Sawin:** Formal analysis, Validation, Writing – review & editing. **Sarah M. Weaver:** Formal analysis, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing. **Katherine Reddy:** Visualization, Writing – review & editing. **Rashmi Saincher:** Visualization, Writing – review & editing. **Anh N. Tran:** .

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data will be made available on request.

Acknowledgement

The authors would like to thank BHSRC interviewer, Margaret Falkovic, LCSW; Courtney Simpson and Charlotte Patterson for editorial assistance; and members of the Duke Consortium for IBC for facilitating valuable discussions.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pmedr.2023.102519>.

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