Engaging the Community to Improve Patient-Centered Care for Inflammatory Breast Cancer

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Breast cancer remains the most common cancer diagnosis among women in the United States, affecting one in eight women today. Inflammatory breast cancer is a little-studied but highly lethal breast cancer subtype, accounting for more than 10 percent of all breast cancer deaths.[1] The aggressive characteristics of inflammatory breast cancer and the late stage at which it is typically diagnosed lead to poor survival outcomes.[2,3] Inflammatory breast cancer is unique from other breast cancers in that it is diagnosed based on a clinical presentation that is described as the rapid onset of breast erythema and edema occupying at least one-third of the breast with or without a breast mass.[1] Given this non-classic presentation of breast cancer, patients are often misdiagnosed or treated inappropriately.

According to National Comprehensive Cancer Network guidelines, all inflammatory breast cancer patients without metastases at the time of diagnosis should be treated with trimodal therapy, including chemotherapy, surgery, and adjuvant radiation.[4] But even this aggressive therapy is not a definitive cure, because many patients go on to develop local or distant recurrences. However, evidence has shown that treatment with timely guideline-concordant care can dramatically improve survival among patients with inflammatory breast cancer.[5,6]

The individuals involved in the diagnosis, treatment, and long-term care of patients with inflammatory breast cancer include a diverse set of people, including patients, patient advocates, clinicians, researchers, and community and national organizations. To improve awareness about inflammatory breast cancer, promote education about the disease, and advocate for patient-centered care, these individuals must collaborate in order to identify gaps that prevent appropriate diagnosis and treatment and identify ways to engage the inflammatory breast cancer community to enhance awareness and patient support.

Through a community engagement session and focused interviews, researchers from Duke University School of Medicine held a consortium to help stakeholders identify barriers to inflammatory breast cancer awareness, diagnosis, and appropriate treatment.

The Duke Consortium for Inflammatory Breast Cancer formed in the winter of 2014 when a group of basic, translational, and clinical investigators; research administrators; and patient advocates with diverse research and clinical interests from Duke University, the University of North Carolina at Chapel Hill, NC State University, and North Carolina Central University came together as part of an interdisciplinary initiative at the Duke University School of Medicine. Based on an analysis of the strengths, weaknesses, challenges, and opportunities available at Duke University and the local community to address the unique features and challenges of inflammatory breast cancer research and patient care, the group ratified the critical need for a multidisciplinary and cohesive effort in North Carolina, an ethnically and economically diverse state with 100 counties and home to the Research Triangle Park and multiple institutions of higher education, comprising a major hub for research, medicine, and education. The consortium is committed to the goal of translating research into action and held its first meeting on Feb. 28, 2018 at Duke University.[7] The meeting included researchers,

Based on participant responses from the community engagement session and post-meeting interviews, researchers identified three concepts related to the unique needs and challenges facing stakeholders in inflammatory breast cancer treatment and research: (1) barriers to timely diagnosis and treatment, (2) strategies for community engagement, and (3) the need for provider education.

practicing physicians, patients, advocates, and community stakeholders. The consortium consisted of three sessions occurring on the same day that addressed:

1. Global partnership in the clinical management of inflammatory breast cancer
2. Research challenges and opportunities in inflammatory breast cancer
3. Engaging advocates and community partners to improve inflammatory breast cancer research and education

Participants pre-registered for the meeting, attendance was recorded, and attendees were not compensated. Facilitators obtained approval from the institutional review board for the study of human subjects.

Community Engagement Session

During this session, facilitators led conversations to identify and address critical needs in inflammatory breast cancer clinical care and outreach. Small groups of three to eight participants—along with group facilitators and/or notetakers—discussed the following open-ended questions:

- What gaps prevent the timely diagnosis and appropriate treatment of inflammatory breast cancer?

  How can you advocate for inflammatory breast cancer awareness and work with local community health providers to become part of patient care?
- Identify ongoing grassroot/programmatic efforts in your community. How are you advocating in your community? How are you supporting patients and survivors?
- How can we partner to promote philanthropy for research and awareness?

Post-Meeting Interviews

After the community engagement session, researchers contacted representative patients (from whom written consent was received), group facilitators, and community partners to give more in-depth responses to the following questions:

- From the interactive session, do you remember themes that stood out to you?
- Do you remember a story that stood out to you?
- What was your overall impression of the session?

Two additional questions were included for foundation leaders:

- What challenges are you facing right now?
- What are your greatest strengths as an inflammatory breast cancer or breast cancer foundation?

Thematic Analysis

Researchers recorded and transcribed conversations from the community engagement session for the purpose of qualitative analysis to identify key themes across core domains. The researchers aggregately analyzed participant responses using qualitative data analysis software. Three coders independently analyzed data and identified initial codes and emergent themes. An in-depth review of responses allowed the development of initial codes that were then refined by consistent cross-checking and team discussion. Coders met to examine and compare emergent themes across each core question. When one team member derived a different code than the other team members for a particular response, the team discussed the response and came to a group consensus.

Themes were highly aligned across coders. A thematic analysis using a systematic, multi-step, rigorous process as outlined by Braun and Clarke was conducted to ascertain, compare, and contrast key concepts and emerging themes across the responses.[8] Grounded theory shaped the design and analysis of the research.[9]

Conference Attendance and Follow-Up Interviews

In total, 174 people attended the Duke Consortium for Inflammatory Breast Cancer meeting. Of the attendees, 28 percent were local community members (patients, patient advocates, and North Carolina government representatives); 15 percent were healthcare providers (physicians and nurses); 15 percent were Duke Cancer Institute or Duke University School of Medicine staff; 13 percent were research and clinical faculty representing both local and national academic and medical institutions; 9 percent were trainees (undergraduate and graduate students as well as postdoctoral fellows); and 16 percent were other community stakeholders. Following the meeting, researchers contacted representative patients, advocates, and community stakeholders and conducted seven in-depth interviews.

Analysis of Concepts from the Community Engagement Session

The community engagement session findings for major themes and most commonly reported subthemes are summarized in Table 1, right.

A total of 506 unique responses were recorded. Responses to the four questions from the community engagement session were tabulated and translated into word clouds. The size of the words was weighted by the frequency of the words used (Figure 1, page 54). The top five word frequencies were as follows:

1. IBC (inflammatory breast cancer): 3 percent (*n* = 53)
2. Community: 1.5 percent (*n* = 27)
3. Patient: 1.5 percent (*n* = 27)
4. Cancer: 1.5 percent (*n* = 26)
5. Support: 1.5 percent (*n* = 26)

Emerging Themes

From the participant responses, six major themes were identified:

- Strategies for community outreach: 43.3 percent
- Barriers to timely diagnosis and treatment: 29.4 percent
- Need for education: 16.4 percent
- Fundraising: 6.3 percent
- Legislative processes: 1.4 percent
- Other: 3.0 percent

The major themes were then subdivided into patient/community level, provider level, and organizational level as appropriate (see Table 1).

(continued on page 54)

Table 1. Summary of the Parent Themes and Most Commonly Reported Subthemes from the Community Engagement Session

Theme	Frequency	Percentage of Theme[a]	Percentage of Level[b]
Strategies for community outreach	241		
Patient/community level	109	45.2	
Media-related outreach	30		27.5
Patient-specific programs	30		27.5
Provider level	51	21.2	
Create research agenda/grant writing	21		41.2
Need for education	236		
Patient level	28	11.9	
Provider level	107	45.3	
Lack of education among providers	85		79.4
Inaccurate profile (e.g., age, pregnancy)	14		13.1
Organizational level	2	0.85	
Barriers to timely diagnosis and care	175		
Patient level	75	42.9	
Rural location/distance to treatment center	16		21.3
Lack of social support (e.g., lack of child-care, family needs, work responsibilities, religion)	15		20.0
Organizational level	41	23.4	
Lack of access to appropriate treatment or inability to get a timely appointment	19		46.3
Lack of a central source of information	9		22.0
Fundraising	32		
Legislative process/priorities	7		
Other	15		

[a] Values represent the percentage of responses coded to the patient/community, provider, and organizational levels.
[b] Values are the percentage of responses coded for subthemes under each level.

Figure 1. Word Cloud from the Community Engagement Session, Inclusive of All Responses

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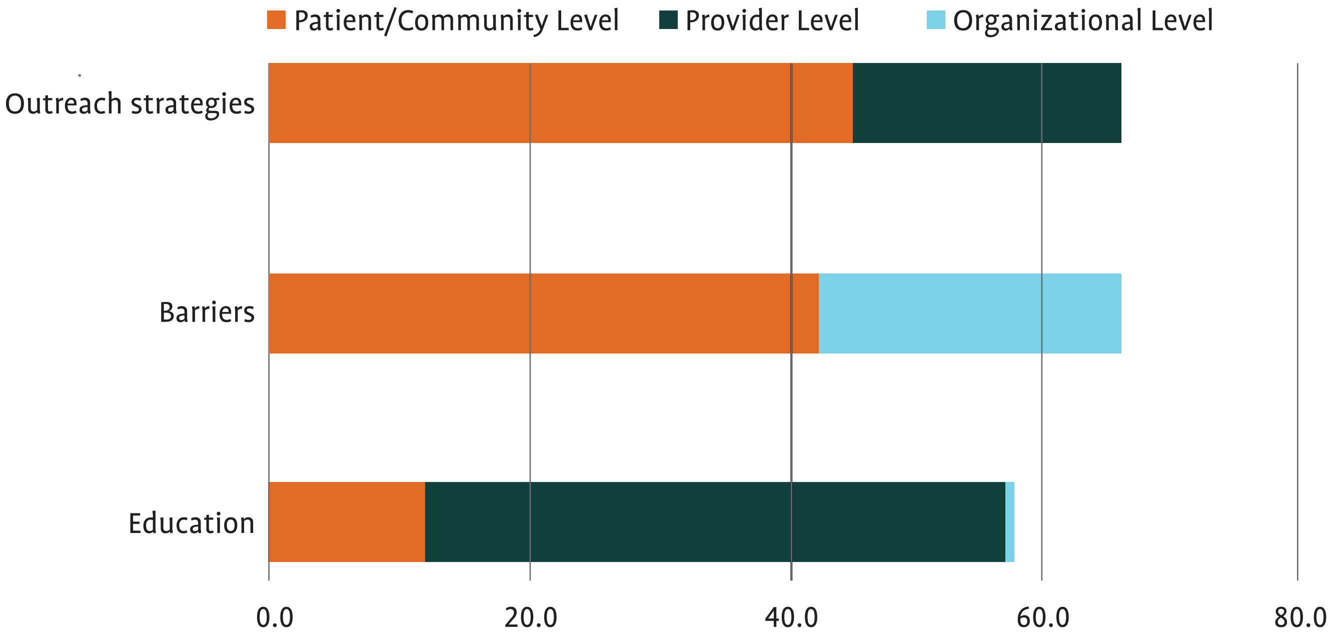
Figure 2, below, depicts the percentage of responses for community outreach strategies, barriers to timely diagnosis and appropriate treatment, and education when categorized according to patient/community, provider, and organizational levels. Participant responses demonstrate a need to initiate community outreach efforts, primarily at the patient/community and provider levels (45.2 percent and 21.2 percent, respectively). No responses in the community outreach theme were coded at the organizational level. Respondents indicated that barriers to treatment and care were greatest at the patient/community level (42.9 percent), followed by the organization level (23.4 percent). No responses in the barriers theme were coded at the provider level. For education, the highest percentage of responses indicated a need to educate providers (45.3 percent), followed by the patient/community (11.9 percent) and the organization (0.85 percent).

Barriers to Timely Diagnosis and Treatment

According to participants in the community engagement session (Figure 3, right), the primary barrier to timely diagnosis and appropriate care is residence in a rural community/distance from

Figure 2. Responses for Primary Themes of Barriers, Education, and Community Outreach at the Patient/Community, Provider, and Organizational Levels.



Note: The participants' responses were coded via the Braun and Clarke methodology. Numerous responses were assigned more than one thematic code.

a treatment center (21.3 percent). Almost one-fifth of respondents indicated that a lack of social support for responsibilities, such as juggling childcare and work duties, was a common barrier to care, followed by fear of diagnosis or treatment, financial concerns, and issues with insurance coverage (15.8 percent each). Barriers at the organizational level included limited or lack of access to an appropriate treatment center/an inability to schedule a physician appointment (46.3 percent), lack of standard of care for patients (20 percent), lack of a central source of information about inflammatory breast cancer (22.0 percent), and a lack of patient navigation (8.9 percent).

Strategies for Community Outreach

Participant suggestions for outreach strategies (Figure 4, page 56) identified multiple ways to engage community members, including media involvement (e.g., social media, TV, and brochures, totaling 27.5 percent), patient-specific programs (e.g., programs incorporating testimonials/stories and support programs, totaling 27.5 percent), churches or faith-based outreach (13.8 percent), and outreach to families and caregivers (10.1 percent). Suggestions for outreach at the provider level included strategies such as creating an inflammatory breast cancer research agenda/grant writing (41.2 percent), building/strengthening academic and community partnerships (13.7 percent), and attending conferences and meetings (11.8 percent).

Need for Education

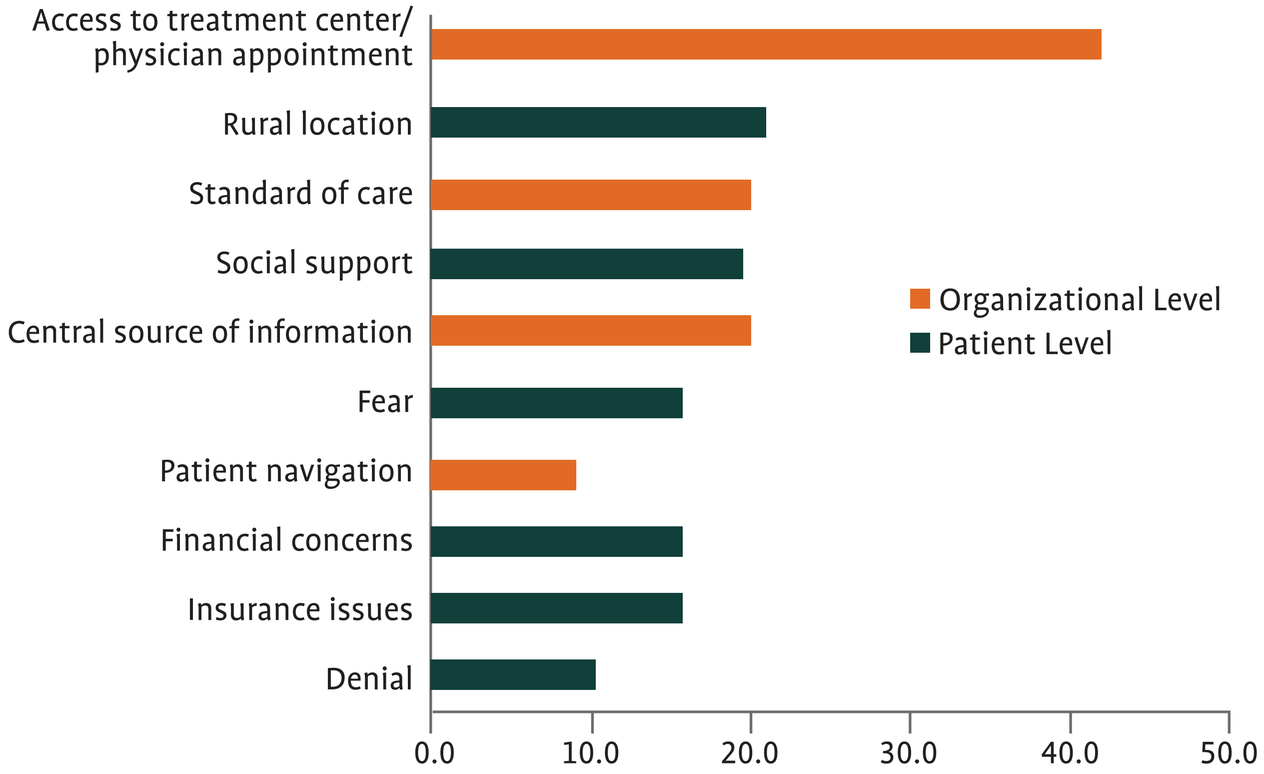
There were no subcategories at the patient/community and organizational levels. However, Figure 5, page 56, indicates that the primary issues among providers are a lack of education on inflammatory breast cancer (79.4 percent), misdiagnosis due to patients not fitting the typical profile for breast cancer (13.1 percent), and lack of communication between physicians and patients (7.5 percent).

Discussion

Based on participant responses from the community engagement session and post-meeting interviews, researchers identified three concepts related to the unique needs and challenges facing stakeholders in inflammatory breast cancer treatment and research: (1) barriers to timely diagnosis and treatment, (2) strategies for community engagement, and (3) the need for provider education.

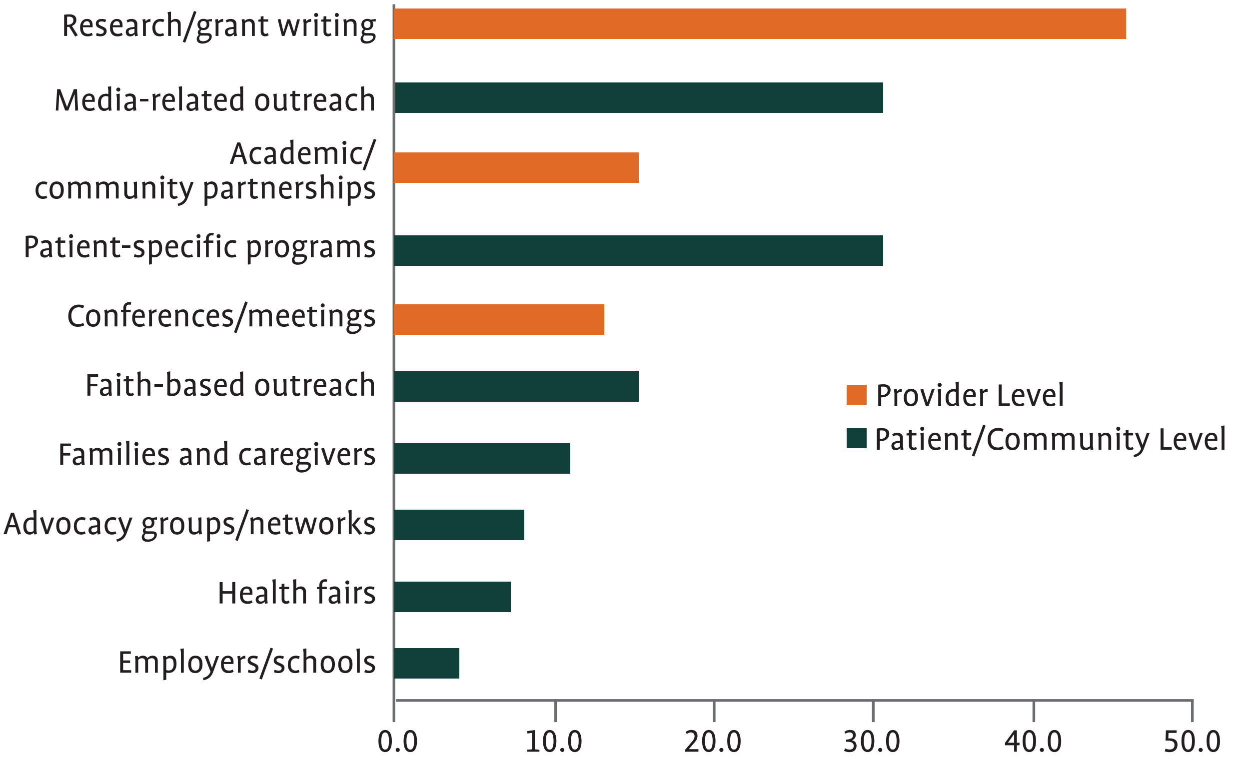
(continued on page 57)

Figure 3. Responses for Barriers That Prevent Timely Diagnosis and Appropriate Treatment at the Organizational and Patient Levels



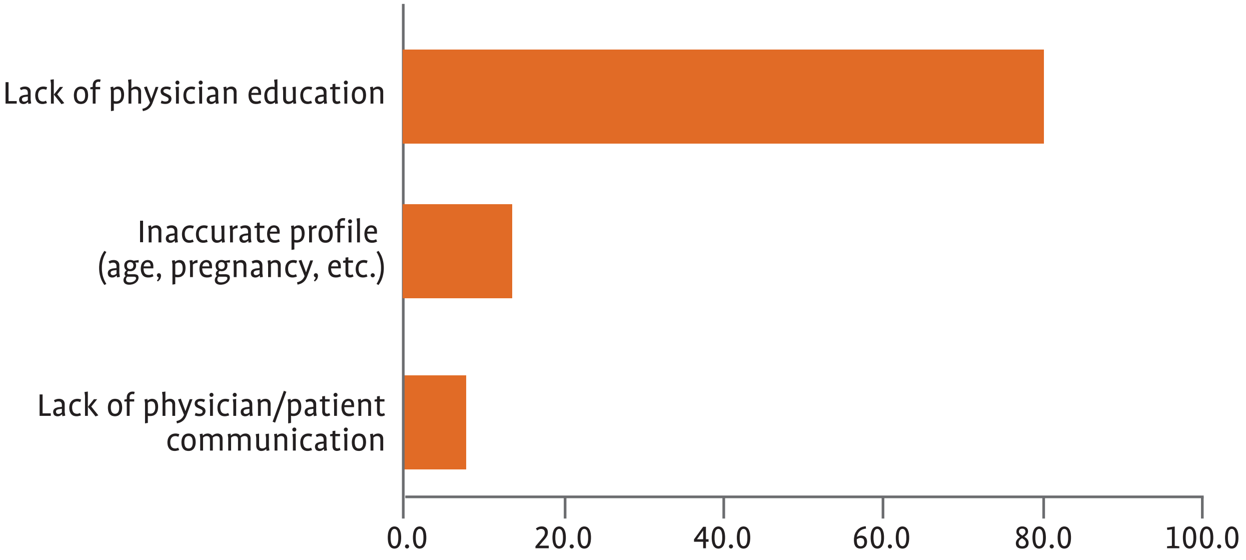
Note: No responses were coded at the provider level.

Figure 4. Responses for Community Outreach Strategies about Inflammatory Breast Cancer at the Provider and Patient/Community Levels



Note: No responses were coded at the organizational level.

Figure 5. Education Subthemes at the Provider Level



Note: No subcategories were coded for the patient/community and organizational levels.

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These concepts are further described below with illustrative quotes. Table 2, page 58, outlines a proposed strategic plan to address these primary themes.

Barriers to Timely Diagnosis and Care

Guideline-concordant care for breast cancer patients includes multimodal therapy, which translates into a significant number of diagnostic tests, increased risk for potential complications, and prolonged time away from work.[10] Two patients described the number of tests and need for support throughout therapy:

I had a PowerPort inserted in my left chest wall; had an ECHO [echocardiogram] of my heart; had lab work; had an ultrasound of my right axilla lymph nodes (which resulted in me having a lymph node biopsy—also cancerous); and attempted to have a PET [positron emission tomography] scan, which my insurance denied, so I had CT [computed tomography] scans of chest, abdomen, and pelvis plus a bone scan.

I can't deny that the effects of dose-dense chemotherapy were debilitating for me. I am thankful my mom came to stay with us because I could barely take care of myself, let alone my son.

Our analysis shows that problems with travel, social support, and insurance all contributed to delays in diagnosis and treatment. A 2003 report from the Institute of Medicine (now The Academies of Medicine) identified rural residence as a potential risk factor for health disparities, and studies have shown that patient survival and outcomes may vary based on area of residence.[11] For example, Hausauer et al. reported that invasive breast cancer incidence decreased by 13.8 percent among middle-aged women living in urban areas, but for similarly aged women living in rural areas, incidence decreased only 7.5 percent.[12] Compared to women who have breast cancer and live in urban areas, women who live in rural areas and are further away from treatment centers are more likely to undergo mastectomies. [13–15]

Although there is a lack of research surrounding social support and inflammatory breast cancer per se, social well-being in women with breast cancer has been linked to better quality of life and increased immune function, including improved CD8+ T-cell percentage and counts, natural killer cell activity, and lymphocyte proliferation.[16-21] Recent literature has shown that the amount and quality of social support varies throughout the cancer experience. For example, in women newly diagnosed with breast cancer, social support from both providers and family dropped significantly within the first year.[22] Patients with inflammatory breast cancer also tended to be younger and had a higher incidence in under-represented minorities, particularly black women.[23-25] There is potential for greater disease burden because treatment is often more aggressive, and with likely family and work demands, social support is even more critical.

Finances also emerged as a barrier to treatment and care, which is closely related to insurance issues, such as denials for coverage of tests or a lack of insurance coverage altogether. To our knowledge, no studies have focused on the economics of inflammatory breast cancer treatment and care; however, literature suggests that metastatic breast cancer can result in steep patient costs. Data on privately insured women diagnosed with metastatic breast cancer from 2003 to 2008 showed that the incremental annual total healthcare costs per patient were $5,100 for inpatient care, $37,231 for outpatient care, and $1,037 for prescription drugs.[26] Though the median income in the United States is $55,775, the median income in North Carolina is $47,884, allowing little money for living expenses.[27] Data from a study conducted at Duke University Medical Center indicated that among insured patients with cancer actively receiving chemotherapy or hormonal treatment (71 percent of study participants were diagnosed with breast cancer), 42 percent reported a significant or catastrophic financial burden. To save money, 24 percent of all participants avoided filling prescriptions, and 19 percent partially filled prescription drugs.[28]

Feedback from the community engagement session indicated that patients often receive multiple misdiagnoses before finding a physician who correctly recognizes inflammatory breast cancer. Many healthcare providers often mistake inflammatory breast cancer symptoms for mastitis and prescribe antibiotics for a period of time, delaying diagnosis and appropriate treatment

Strategies for Community Engagement

There was a strong consensus among participants during our interactive session about the inclusion of community members in the development, decision making, and/or implementation of programs that affect them. Recently, the National Cancer Institute mandated the inclusion of community outreach and education for National Cancer Institute-designated cancer centers, requiring actionable programs outlining how centers can make an impact on the populations they serve.[29] Since 2012, the Duke Cancer Institute, through the Office of Health Equity and Disparities, has engaged patients, providers, and caregivers in strategic planning and collaboration to enhance cancer services, identify research opportunities, provide critical services to improve cancer outcomes, and reduce disparities. Data from these strategic planning and collaboration efforts are expected to assist in developing inflammatory breast cancer-specific outreach and education programs for effective co-learning and partnership building among

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Table 2. Proposed Strategic Plan to Improve Patient-Centered Care for Patients with Inflammatory Breast Cancer

Identified Themes	Strategies and Recommendations
Barriers to timely diagnosis and treatment	Assess gaps of knowledge and issues during diagnosis and treatment among patients with inflammatory breast cancer.
	Develop a strategic plan to address time to diagnosis and appropriate care for rural patients who do not reside near a treatment center. The plan should also include access to an appropriate treatment center.
	Use community-facing patient navigation to address barriers to care, such as lack of social support in juggling childcare, work responsibilities, and difficulty scheduling physician appointments.
	Use treatment navigators to facilitate support resources for patients to address their fear of diagnosis and/or treatment.
	Use of financial navigators to address issues with insurance coverage and financial concerns.
	Create a central source to provide IBC standard of care information to community members and healthcare providers.
	Organizational level, a lack of standard of care, or lack of access to an appropriate treatment center.
Community engagement	Assess knowledge of IBC among local community members.
	Develop a culturally tailored IBC media campaign utilizing social media, television, radio, and print (e.g., newspapers, brochures/pamphlets).
	Create a centralized website for community members to receive IBC information.
	Conduct patient-specific support programs for families and caregivers incorporating testimonials and stories from patient advocates at churches/faith-based organizations, workplaces, schools, and health fairs.
	Incorporate celebrity involvement in community health education outreach initiatives.
Provider education	Assess knowledge and recognition of patient clinical symptoms among healthcare providers.
	Develop educational training opportunities for healthcare providers to address misdiagnoses due to patients not fitting the breast cancer profile. Methods include modules, sessions at academic conferences and meetings, and development of a research agenda with funding agencies and academic/medical institutions.
	Facilitate bidirectional communication between patients and healthcare providers.

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diverse stakeholders to develop interventions informed by the engagement process.[30]

Much work has been done to increase breast cancer screening and provide support for survivors, but, as one community partner stated, the focus has primarily been on patients with early-stage breast cancer rather than patients with late-stage or rarer forms of breast cancer.

I think now the next step is to talk about late-stage or more rare forms of breast cancer. One of the challenges I have is how to put out a unique message in a pink-weary world, and inflammatory breast cancer can be a scary message. I always try to wrap everything in hope because I'm here and others have survived much longer than me. I'm seeing women getting a quicker diagnosis because the disease is known, and that gives them a better chance of long-term wellness.

From our interactive session, one strategy that participants repeatedly mentioned for engaging community members was utilizing media—particularly social media, which has evolved into a knowledge exchange. Support groups for breast cancer patients are required for accreditation by the National Accreditation Program for Breast Centers and have proven to help patients by reducing anxiety and improving overall quality of life.[31-36] However, due to issues such as lack of transportation, patients often utilize the Internet and social media platforms—Facebook, Twitter, and blogs—instead of face-to-face meetings for information and support, because online mediums are convenient and affordable. Taken together, improving inflammatory breast cancer patient-centered care and outcomes requires linking local grassroots efforts to build awareness with national breast cancer charitable organizations and the inclusion of various subtypes of breast cancer as part of the conversation.

Need for Provider Education

Feedback from the community engagement session indicated that patients often receive multiple misdiagnoses before finding a physician who correctly recognizes inflammatory breast cancer. Many healthcare providers often mistake inflammatory breast cancer symptoms for mastitis and prescribe antibiotics for a period of time, delaying diagnosis and appropriate treatment, as two patients described:

I woke up, and overnight, my skin had gone from light pink to a quarter of my breast being streaked with purple and dark red circles. … That redness did look like an infection or a cut, that deep red underneath the surface of the skin. I saw the surgeon, who agreed with my self-diagnosis of an infection. He started me on an antibiotic.

A lot of times, the doctors do not know about inflammatory breast cancer; or they think they know about inflammatory breast cancer and if a patient's presentation is different from what they've read in a textbook, they say, "Oh, it couldn't be inflammatory breast cancer." … Doctors send people home with a second round of antibiotics or a third round of antibiotics, a cream, or a "Don't worry about it, dear."

Based on our community engagement session, three major themes emerged related to addressing challenges in inflammatory breast cancer care, including the need for increased support for inflammatory breast cancer patients, greater societal awareness of inflammatory breast cancer, and improved provider education.

Given this misinformation, both the group discussion facilitator and patients recognized that primary care provider and even surgeon/breast specialist education is crucial.

One of the needs that was identified was education of providers—especially primary care providers and dermatologists—about inflammatory breast cancer, its distinguishing characteristics, and the need to treat it quickly.

I think an important thing at our table is making sure that primary care physicians, gynecologists, and local doctors of all sorts are well educated about inflammatory breast cancer and that they know where to refer.

There is a lack of research on the impact of missed or mistaken diagnoses on the experience or outcomes for patients with inflammatory breast cancer.[5,6,37] Notably, women who seek care at local hospitals are the ones at highest risk of receiving care outside of national guidelines across multiple breast cancer subtypes. This highlights the critical need to address a lack of education about inflammatory breast cancer at the primary provider and local hospital levels.[6,38] Primary care providers are often the first point of contact when patients begin experiencing symptoms and can play a key role in early detection.[39] Because inflammatory breast cancer progresses rapidly, it is imperative that these physicians are familiar with the clinical presentation to avoid delaying treatment.

In some countries, physicians have made progress in recognizing the clinical signs of inflammatory breast cancer. In North Africa, primary care providers' knowledge of breast cancer and inflammatory breast cancer was evaluated following a presentation given by an oncologist.[40] Physicians showed a significant improvement in knowledge related to the management, symptoms, and methods of inflammatory breast cancer detection. A similar study was undertaken in Pakistan with primary care providers who were assessed on their knowledge about inflammatory breast cancer and locally advanced breast cancer.[41] Most participants (74 percent) had heard of inflammatory breast cancer, and knowledge regarding not prescribing antibiotics for symptoms lasting more than one week increased from 49 percent to 86 percent. However, knowledge about inflammatory breast cancer potentially manifesting without a palpable mass improved from 41 percent to only 60 percent. To our knowledge, no studies have been conducted to educate physicians about inflammatory breast cancer in the United States; interestingly, no further efforts have been made to educate physicians in the past 10 years, creating a critical need for further research.

Limitations

Our community engagement session and resulting themes are the first contribution of this type to the inflammatory breast cancer literature. Notably, our interactive session included a wide range of attendees from both the academic and inflammatory breast cancer stakeholder communities, and more detailed perspectives were captured from individual interviews. However, as with any qualitative approach, we recognize that the data may not be generalizable. Because the analyses included responses from all individuals who participated in the session discussions, we could not connect responses to specific individuals. We envision holding future town halls, focus groups, and strategic meetings that will allow us to collect demographics such as race, gender, and ethnicity.

Future Steps

Based on our community engagement session, three major themes emerged related to addressing challenges in inflammatory breast cancer care, including the need for increased support for inflammatory breast cancer patients, greater societal awareness of inflammatory breast cancer, and improved provider education. The inflammatory breast cancer community needs more information about where knowledge gaps exist among providers and how missed diagnoses impact patients in order to design useful interventions. We are currently taking steps to address these issues, which include:

- Assessing knowledge of inflammatory breast cancer among the lay public
- Assessing knowledge and recognition of inflammatory breast cancer clinical symptoms among primary care providers, including physicians, physician assistants, and nurse practitioners
- Surveying patients with inflammatory breast cancer regarding where specific issues arise during diagnosis and treatment

As part of our research plan, data sets from these populations will then allow us to develop appropriate interventions and educational opportunities that will address issues faced by patients with inflammatory breast cancer. As our current research demonstrates, addressing the needs of patients with inflammatory breast cancer requires a multifaceted approach.

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