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"How is it going to help?": Exploring Black breast cancer patients' questions about biomarker testing to predict chemotherapy-induced peripheral neuropathy

Katharine J. Head [a,*], Lisa R. Hayes [b], Nadia E. Miller [b], Safia Shakil [c], Casey L. Bales [d], Bryan P. Schneider [e]

[a] Department of Communication Studies, 425 University Blvd, Indiana University-Purdue University Indianapolis, IN, 46202, United States
[b] Pink-4-Ever Ending Disparities, 8770 Commerce Park Place F, Indianapolis, IN 46286, United States
[c] Department of Biomedical Engineering, 425 University Blvd, Indiana University-Purdue University Indianapolis, IN 46202, United States
[d] Department of Medicine-Division of Clinical Pharmacology, 950 West Walnut Street, Rm 402 Research Institute II (R2), Indianapolis, IN 46202, United States
[e] Department of Medicine-Division of Hematology/Oncology, Indiana Cancer Pavilion, 535 Barnhill Drive – 473, Indianapolis, IN 46202, United States

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ABSTRACT

Objective: Many Black breast cancer patients experience chemotherapy-induced peripheral neuropathy (CIPN). Our study assessed Black breast cancer patients' questions about a biomarker test that can predict likelihood of CIPN.
Methods: Nineteen Black women who were previous/current breast cancer patients participated in focus groups. Researchers briefly explained CIPN and the biomarker test, and then participants were asked what questions they would have about the test and its use in treatment decisions. These participant-voiced questions composed the data for this study and were analyzed using thematic analysis.
Results: Participants' questions centered on six themes: reasons for the test, effect on timeline of breast cancer treatment, testing procedure, limits of test (including accuracy), research done to develop this test (including research participants), and concerns about personal information connected to the test (including DNA).
Conclusion: This study provides an exploratory look at questions that Black breast cancer patients may have about toxicity biomarker testing use in breast cancer treatment decisions.
Innovation: These findings provide a starting point for developing patient-centered approaches for integrating this precision medicine tool into clinical care. The methodological choice to generate participants' questions (rather than answers to a question) led to robust, actionable data.

1. Introduction

Precision cancer medicine is evolving at a rapid pace and the integration of advances in this field should strive to be patient-centered, accessible, and equitable [1]. In addition to identifying differential cancer genomic variants among patients of different racial backgrounds [2], there is increasing focus to identify how racially diverse patients respond differentially to cancer treatments—especially in light of the fact that these groups have historically not been included in clinical trials at commensurate rates as their white counterparts [3]. Recent work done by Schneider and colleagues has identified a genetic biomarker which can indicate likelihood of chemotherapy-induced peripheral neuropathy (CIPN) in Black breast cancer patients [4,5]. Treatment side effects like neuropathy – defined as damaged nerves that can result in numbness, muscle weakness, pain, and other physical impairments [6] – are related to not only a patient's quality of life, but also increase risk of cancer recurrence due to related treatment reductions [7]. Therefore, the potential for this biomarker test to play a significant role in treatment decisions and outcomes is important to consider. However, given the plethora of complex medical information shared, tests performed, and data that is reviewed in breast cancer treatment discussions with patients, we must consider how to integrate this biomarker test into existing clinical processes in a way that addresses patients' information needs [8]. One first step is exploring what questions patients would have regarding this biomarker test.

2. Methods

As part of a larger study examining Black women's experiences with decision-making during breast cancer treatment, the current study explored the specific questions patients would have regarding the integration of

* Corresponding author.
E-mail addresses: headkj@iupui.edu (K.J. Head), lisa.hayes@pink-4-ever.org (L.R. Hayes), nadia.miller@pink-4-ever.org (N.E. Miller), sshakil@iu.edu (S. Shakil), bpschnei@iu.edu (B.P. Schneider).

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biomarker testing into their clinical care with the purpose of predicting risk of experiencing CIPN. Nineteen women who were previous or current breast cancer patients, lived in Indiana, and who self-identified as Black or African American were recruited into the study through direct recruitment by our community partners (authors 2 and 3) using personal emails and social media posts. The average age of participants was 59 years old. Participants had to indicate that they had undergone some type of treatment for their breast cancer (i.e., did not elect to forego treatment) and they voluntarily reported a range of breast cancer types (e.g., invasive ductal, triple negative, Her2+, etc.). Ten of the women voluntarily reported experiencing neuropathy as part of their treatment side effects. Focus groups, moderated by the first author but attended by the other team members, were conducted over Zoom between August and October 2020; focus groups ranged from 4-5 participants per group. Participants were compensated with a $40 gift card for their time. This study was approved exempt by the Indiana University Institutional Review Board. Focus groups were recorded and professionally transcribed.

During each of the four focus groups, a member of the study team briefly explained CIPN and biomarker testing; see Appendix 1 for this language. Women were then queried about what questions they would have about biomarker testing and its potential use in breast cancer treatment decisions. These participant-voiced questions composed the data for this current study. The lead author analyzed the questions using thematic analysis [9,10], a method particularly useful for applied health communication research. The data was reviewed iteratively. Initial codes were generated based on topic/purpose of the questions asked; these initial codes were then explored for similarity or relatedness, and then grouped into final themes and subthemes. To ensure reflexivity in the analysis and reporting of our findings [11], the entire team– including our two community member co-authors who are themselves Black breast cancer survivors - reviewed and discussed the results report to provide a quality check and to ensure that the analysis presented a clear, logical, and coherent account of our participants' questions.

3. Results

Participants' questions centered on six themes or categories. Below, each category is listed and briefly explained, and sample questions from participants are provided in Table 1.

3.1. Reasons for test

Participants voiced questions about the reasons for the test. These questions were often the first ones asked by participants during the focus group, and while less specific than later questions tended to be, these centered on the importance of starting with the overall purpose and benefit of the test.

3.2. Integration into care

Participants asked questions related to how clinicians would talk about and use the results from the biomarker test in their cancer care. These questions centered on two major topics, including how the test could affect the

Table 1
Categories of questions about biomarker test.

Question topic	Sample Questions
Reasons for Test	
Purpose	• Why do you need it? • What's it going to do? • What is this neuropathy and why should I even care?
Benefit	• How would it benefit me? • Why is it so important that you test me for this?
Integration into Care	
Timing	• So if I'm coming in there to hear my treatment plan, but I need to take this test to determine what my options are, what's the new timeline? • If I'm going to take this test, how much more time are we adding to the start of my treatment? • Once the oncologist looks at your case, would that be [biomarker test] discussed at the first meeting as far as this is what we suggest for your treatment plan?
Evidence to Support Treatment Choices	• If you tell me you have this [positive biomarker result], so now you're going to get this [other] drug, I would want some reassurance that have you also done a study on this drug and it is also as equally potent and as effective? • [If] neuropathy would be the side effects for one, what would the other [drug's] side effects be? In other words, would they give them the other side effects to make a choice, so they'll know whether or not they want the one with the neuropathy? • Would I still get the medicine that I need to kill this, or would my medicine be compromised or changed; I get a weaker dose or a different kind of concoction in my chemo or I wouldn't get as much radiation or a different type of something because I give you this side effect?
Test Procedure	
	• But exactly how would you test for it? • How often would the doctor perform the test, like the blood draw? • So how often is this biomarker used, like if you're only taking it one time, drawing the blood and then you're running a series of tests to see?
Limits of Test	
	• What is the accuracy? • So is it a chance that the body types, like they would have these type of side effects, is it 100% true? What is the percentage of that being accurate? • The blood draw would only be able to determine whether or not I would be able to handle the chemo, is that what you're saying?
Concerns about Use of Test on Others/Self	
Individual Concern	• And are you asking all of the cancer patients for their DNA? Or are you only asking me? • Are you specifically targeting me and only me? • So how are you choosing the women who get the test? Why me?
Statistics from Research/Other Patients	• So you're going to suggest this type of medication; well, where's the people that went before me? • Where's the data, the statistics to show that this really works? • I wouldn't mind having a blood test, but I would want to be in on the discussion of how many people have had it?
Personal Information	
Privacy	• What are you going to do with my DNA? • What are you going to do with that information after, that you get from me?
zPersonal Ownership of Health Information	• Will I have access to that information after you get the information? • Will this information be able to be shared with my family, and how relevant is it going to be to my offspring?

timing of their treatment and treatment discussions, and how the test results would be used to make decisions and weigh the pros/cons of treatment choices.

3.3. Test procedure

The third category of questions asked by participants focused on the procedural aspects of the test. While the biomarker test was briefly described to them during the focus group, participants still expressed the need to clearly address the specific details of the procedures used to do the test.

3.4. Limits of the test

Participants asked questions about the limitations of what information the biomarker test can provide. These questions focused on the accuracy of the test and what, specifically, it is predicting.

3.5. Concerns about use of test on others/self

Participants were interested in knowing how decisions about the use of this test were made. Specifically, these questions centered on why certain patients, like themselves, would be chosen to take this test, and also how data collected from past patients was informing their care.

3.6. Personal Information

The final type of questions asked by participants centered on how the information would be used in the future. These questions focused on concerns about the use of personal health information and the DNA collected, as well as whether the information gathered from the test could be accessed and shared with the patient and their family going forward.

4. Discussion and conclusion

4.1. Discussion

This study provides an exploratory look at what questions and information needs Black breast cancer patients may have when considering the integration of biomarker testing into breast cancer treatment decisions specific to CIPN. The findings suggest that Black women have a variety of information needs relevant to the use of this precision cancer medicine innovation. In line with other work examining the development and use of biomarkers in the precision oncology setting, the imperative to successfully move from bench to bedside will necessitate work like this study that can inform clinical communication and improve shared decision-making about these cancer treatment innovations [12-15]. Beyond purely informational needs, such as how the test works, participants in this study were also interested in knowing about larger issues of clinical research and statistics supporting the use of the test, as well as privacy concerns related to their own biomarker test results. These findings are supported by other work showing that Black women in particular have diverse information needs during breast cancer treatment [16]. Our findings also concur with other research showing the importance of evaluating Black patients' information needs within the precision medicine context [18] and acknowledging long-standing concerns among this population about the use of genetic information for medical and research purposes [17] which is not surprising given the historical and systemic research abuse and social injustices committed by the medical establishment on Black patients in the United States [19].

While individual patients may have additional questions, those categorized here can be used to help anticipate the types of information needed by Black breast cancer patients when presenting this biomarker test during treatment conversations. Future work should specifically explore concerns about integrating this test into initial treatment meetings (e.g., how it might affect timing), as well as anticipating how to handle concerns about privacy and personal use of the test results (e.g., patients' desires to ensure they "own" the information and can share it with their family). Importantly, the role of the provider remains one of the most influential elements in a Black woman's breast cancer treatment decision-making [20,21]. Therefore, conducting interviews with breast oncologists about these issues and concerns could help shed light on suggestions and ideas that these stakeholders have for communicating about this biomarker test with their Black patients. Additionally, the use of participatory methods, such as the "guided tour procedure" for quality improvement projects, may be particularly applicable in determining the best method for integrating this biomarker test into clinical practice [22]. The ensuing outcome of this kind of work will ensure that this precision medicine innovation is delivered in a way that addresses the six essential domains of care quality: efficiency, effectiveness, safety, equity, patient-centeredness, and timeliness [23].

While this exploratory study yielded important, actionable findings, it is not without its limitations. Women in our study described a range of breast cancer experiences, including type of breast cancer, type of treatment, and time since diagnosis. These differences may have influenced the types of questions they asked. Researchers/practitioners doing future research in this area may benefit from recruiting participants who are closer to the target population of patients who would be receiving this biomarker test into today's clinical setting.

4.2. Innovation

We contend that introducing the biomarker test during the focus group, and then eliciting and analyzing *questions* that participants had about the test, led to robust and insightful findings. Rather than focusing on participants' answers to researchers' questions, as is typical in focus group and interviewing procedures, the elicitation of questions allowed women to put themselves back in the position of being breast cancer patients and imagine what questions they would want to ask their oncologist about this biomarker test [24]. Other clinicians and multi-disciplinary teams who seek to integrate new tools into clinical care with specific patient groups may want to consider the question elicitation approach as a way to more fully understand their patients' needs. In sum, the findings provide a rich starting point for our future work in developing patient-centered communication, which is essential for ensuring patients understand the complex information associated with this biomarker test, increasing the likelihood of them engaging in their care and leading to higher care satisfaction overall [25,26].

5. Conclusion

This study sought to identify the types of questions that Black breast cancer patients may have regarding biomarker testing to predict risk of CIPN. The results revealed six categories of questions, or information needs, and can serve as a starting point for developing patient-centered approaches for integrating this test into clinical care.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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Appendix 1. Description of biomarker test provided to patients during focus group

"We know that a the one-size-fits-all approach to cancer treatment is probably not the best one, which is why we are focused on personalized

medicine. Personalized medicine looks at the differences in our own personalized blueprint (the DNA) to choose a treatment specifically for a person. The same differences that can make us tall or short, also impact how we accept drugs and the side effects that we have from them.

We are currently studying whether looking at DNA biomarkers in your blood can help us predict and understand how well the body responds to a treatment for cancer. Our goal is to use these biomarkers tests to help patients and physicians choose chemotherapy that has the most benefit and least side effects for every patient.

For example, we want to use these biomarkers to know which patients might be at a higher risk for a common side effect of chemotherapy called *neuropathy*. This side effect causes damage to the nerves and can result in numbness, tingling, and loss of feeling. Neuropathy can be severe and painful, can cause patients to drop things, trip, or fall, and can be permanent. Research shows that Black women tend to suffer from the chemotherapy side effect of neuropathy more than patients from other racial backgrounds. We hope to use this DNA biomarker test, which is done through a blood test, to predict which of our Black breast cancer patients are at a higher risk for neuropathy. The results from this biomarker test will allow patients and doctors to discuss different breast cancer treatments with less side effects and less chance for neuropathy."

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