Health Commun. Author manuscript; available in PMC 2022 October 01.

Published in final edited form as:

Health Commun. 2021 October ; 36(11): 1331–1342. doi:10.1080/10410236.2020.1751383.

“Nobody will tell you. You’ve got to ask!”: An examination of patient-provider communication needs and preferences among Black and White women with early-stage breast cancer

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Abstract

Patient-provider communication is a critical component of healthcare and is associated with treatment quality and outcomes for women with breast cancer. This qualitative study examines similarities and differences in patient perspectives of communication needs between Black and White breast cancer survivors. We conducted four focus groups (*N*=28) involving women with early-stage breast cancer on adjuvant endocrine therapy (AET), stratified by race and length of time on AET (< 6 months and >6 months). Each group was moderated by a race-concordant moderator and analyzed by emergent themes. Participants expressed common patient-provider communication needs, namely increased sensitivity from oncologists during the initial cancer diagnosis, personalized information to facilitate treatment decisions, emotional support during the transition from active treatment to maintenance, and rapid provider responses to mobile app-based queries. Communication differences by race also emerged. Black women were less likely than White women to describe having their informational needs met. White women

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Declaration of Interest Statement
Authors have no conflicts of interest to disclose.

praised longstanding relationships with providers, while Black women shared personal stories of disempowered interactions and noted the importance of patient advocates. White women more often reported privacy concerns about technology use. Unlike White women, Black women reported willingness to discuss sensitive topics, both online and offline, but believed those discussions made their providers feel uncomfortable. Early-stage breast cancer patients on AET, regardless of race, have similar needs for patient-centered communication with their oncologists. However, Black women were more likely to report experiencing poorer communication with providers than White women, which may be improved by technology and advocates.

Keywords

patient-provider communication; early-stage breast cancer; cancer communication; Black women; health information technology

Introduction

Patient-provider communication is a critical component of healthcare and is associated with treatment quality and health outcomes for women undergoing treatment for breast cancer (Bakker et al., 2001; Duggan, 2006; Kantsiper et al., 2009; Li et al., 2017). Past studies have highlighted the connection between patient-provider communication and a patient's self-management of health conditions (Heisler et al., 2002). Self-management behaviors can help mitigate negative side effects, which have been implicated as a leading cause of non-adherence and treatment discontinuation among women on adjuvant endocrine therapy (AET) (Aiello Bowles et al., 2012; Murphy et al., 2012). These findings are significant, considering women with breast cancer often report suboptimal communication with their oncology teams. Poor physician-patient relationships can also result in unmet informational and psychosocial needs (Burg et al., 2015; Harrison et al., 2009) that ultimately lead to worse clinical outcomes (Street et al., 2009) such as greater rates of cancer recurrence and higher mortality.

Racial/ethnic minorities report poorer care experiences and relationships with their non-minority providers compared to their White peers (Li et al., 2017; Medicine, 2003) and are less likely than Whites to have their clinical and psychosocial needs addressed (Johnson et al., 2004; Manfredi et al., 2010; Medicine, 2003; van Ryn, 2002). Racial discordance from their medical providers may result in communication barriers (Shen et al., 2018), and these barriers often lead to unequal access to health information and inadequate patient participation in healthcare decision-making that exacerbate racial disparities in health outcomes (Kreps, 2006; Shen et al., 2018). Specifically, Black patients, who are more likely to be in race-discordant relationships with their medical providers than White patients, are also more likely to have shorter clinic visits, less positive affect, and less perceived participatory decision-making (Medicine, 2003). Among women with breast cancer, one study found that patients who were younger and non-White were less likely to receive written treatment reports despite explicitly requesting them compared to older, White patients (Kent et al., 2012). Maly et al. (2015) identified profound patient-provider communication challenges among racial/ethnic minority individuals with breast cancer;

however, little is known about the unique patient-provider communication processes among female breast cancer survivors in the U.S. Mid-South and which perceptions of patient-provider communication vary by race. This type of examination is necessary to identify novel methods to ameliorate intergroup communication divides in order to optimize the health of racial/ethnic minority women with breast cancer.

Elucidating potential patient-provider communication differences among women with breast cancer is paramount in the context of wide gaps in healthcare outcomes between Black and White women. Nationally, Black women have 39% higher breast cancer death rates than White women (DeSantis et al., 2017), and these excess death rates are more likely to occur in Southern states (DeSantis et al., 2016). Observational studies have also found significant underuse (Bickell et al., 2006) and lower adherence to AET (Hershman et al., 2015; Murphy et al., 2012) among Black women compared to White women, which could play a role in the existing race-based breast cancer disparities in mortality. Memphis, Tennessee, the site of the study setting, has one of the highest mortality rates for breast cancer in the United States and one of the highest breast cancer mortality disparities between Blacks and Whites (Hunt & Hurlbert, 2016; Hunt et al., 2014; Ruddy et al., 2009; Vidal et al., 2017). Although there seems to be a decline in the Black-White breast cancer mortality disparity in some geographic regions (DeSantis et al., 2017), a recent study found that Black women in Memphis were 2.09 times more likely to die from breast cancer than White women (Whitman et al., 2012). Research has identified a link between patient-provider communication, treatment adherence, and breast cancer mortality (Liu et al., 2013; Sheppard et al., 2011), but there has been little focused research attention on unique communication practices among breast cancer survivors in the nation’s southern region despite evidence of patient-centered communication disparities among racial/ethnic minorities (White-Means & Osmani, 2017). Thus, a critical examination of racial differences in communication during the adjuvant phase of breast cancer treatment among women living in the U.S. Mid-South region is warranted, with the aim of implementing strategies to reduce health disparities influenced by communication within medical interactions (Penner et al., 2012).

In an effort to improve healthcare services and outcomes, some institutions have implemented health information technologies (HITs). HITs are web-based systems designed to facilitate health information access and exchange, improve provider and patient decision-making, facilitate social support, and encourage behavioral changes (Or & Karsh, 2009). These technologies might serve as a way of bridging the gaps in informational and psychosocial support that are apparent in the adjuvant phase of breast cancer treatment. For example, HITs can empower patients to engage in shared decision-making with their medical providers by facilitating communication between patients and providers via online interactions such as secure messaging and patient portals (Suggs, 2006). Moreover, patient portals that are integrated with an electronic health record (EHR) can be leveraged to make patient-reported data available to clinicians and may improve the coordination and quality of healthcare delivery (Basch et al., 2017; Fritz et al., 2012; Graetz et al., 2018; Jensen et al., 2015; Mandl et al., 2015). Despite numerous studies suggesting the value of web-based portals and apps in healthcare broadly (Buntin et al., 2011; Custodio et al., 2009), limited research has examined and juxtaposed the unique perspectives of Black and White women with breast cancer on the potential benefits of a web-based app to assist with patient-provider communication about adherence, side effects, and symptom management during adjuvant treatment.

Although patient-provider communication is a crucial determinant of clinical and psychosocial outcomes for women with breast cancer, patients' communication needs are less likely to be studied than other types of supportive care (Harrison et al., 2009). The intersection of race and geographic location creates a unique context in which to examine patient-provider interactions within oncological care. This qualitative research study examined patient perceptions of and possible race-based differences in patient-provider communication. In race-stratified focus group interviews, we explored the varying perspectives of Mid-Southern Black and White women with early-stage breast cancer during AET treatment, with a focus on distinguishing factors that might affect receptiveness to in-person and web-based communication needs and preferences. Findings from this study may prove useful for improving patient-centered communication and addressing racial disparities along the cancer care continuum.

Methods

Research Collaborator

The West Cancer Center Research Institute (WCCRI), our partner for this study, provides a network of fully integrated cancer care at 14 clinic locations. The WCCRI treats more than 1200 patients with a new breast cancer diagnosis annually. All study participants receive cancer care from the WCCRI; thus, certain aspects of treatment are constant across all participants.

WCCRI provider characteristics—The WCCRI has a network of 110 providers; 23 specialize in breast cancer. The majority of those WCCRI providers are male (61%, N=14) and White (91%, N=21). There are four Black medical oncologists within the WCCRI network (three males and one female).

Participants

Average age for the 28 study participants was 64 years (see Table 1). Most had Stage I or Stage II breast cancer at diagnosis (43% and 32%, respectively). Early AET users (e.g., ≤ 6 months) averaged 2.63 months on their prescribed medication; late AET users (e.g., > 6 months) averaged 16.55 months. Black participants comprised 46% of the sample (n=13) while White participants comprised 54% (n=15).

Sampling Method

Women who were 18 years and older, receiving care at the WCCRI, diagnosed with early-stage (I-III) hormone receptor-positive breast cancer, and prescribed an AET cancer medication (i.e., tamoxifen or aromatase inhibitor) were eligible for enrollment in this study. To recruit participants, the study nurse (TJ) reviewed EHRs to identify potential study participants. She contacted eligible women by telephone, and those who were interested in study participation were scheduled for a one-time focus group.

Procedures

This study was conducted to support the development and refinement of an intervention intended to improve patient-provider communication for women with early-stage breast cancer taking AET medications (Graetz et al., 2018). The intervention is designed to allow patients to share information about potential side effects of AET medication on a real-time basis with their oncology care team using an app on their own web-enabled devices (e.g., smartphone, computer) outside of clinic visits. We conducted four 90-minute focus groups, stratified by race (Black and White) and patient length of time on AET (< 6 months or ≥ 6 months). Racial homogeneity was desirable because race/ethnicity often dictates how focus group participants will interact (Carey, 1994). Some AET symptoms take several months to develop (Henry et al., 2012; Kahn et al., 2007), and medication adherence decreases over time (Henry et al., 2012); therefore, focus groups were also segmented by patient length of time on AET to reduce the likelihood of deference because of intragroup differences (e.g., women with more AET experience dominating conversations). Focus groups were moderated by a race-concordant moderator, using a semi-structured interview guide (see Appendix A). Participants were given a $40 merchant gift card to offset time and expenses associated with study participation.

Method of Analysis

Focus group sessions were audio recorded and transcribed verbatim. We used a modified version of Silverman (2016) transcription conventions. Transcripts were imported into NVivo 11Plus (QSR International Pty Ltd.). The first two authors (JA, CG) read each transcript and independently conducted line-by-line coding. JA and CG met to discuss codes for each focus group transcript, used differences to clarify code names and descriptions, and resolved differences of opinions. They engaged in an iterative process to ensure codes, categories, and themes represented data from each group. Final analysis yielded themes as well as categories and sub-categories for themes. Given the divergence in meaning across categories and themes by group, JA and CG created memos with definitions to represent the meaning of each category and sub-category. The third author (RK) assessed internal validity and reliability by independently examining the codes, sub-categories, categories, and themes for clarity, consistency, credibility, and meaning (Cho & Trent, 2014; Lincoln & Guba, 1985).

Ethical Approval

The University of Tennessee Health Science Center Institutional Review Board approved the study (IRB 17–05479-XP IAA).

Results

Participants expressed common patient-provider communication needs, namely sensitivity during the initial cancer diagnosis, personalized information to inform their treatment-related decision making, and social support from members of their oncology team. Participants also reported beliefs about the role of technology in increasing patient-provider interactions as well as generational differences in technology usability. Communication differences by race also emerged. Black women were less likely than White women to describe having their informational needs met. White women praised longstanding relationships with providers, while Black women shared personal stories of disempowered interactions and noted the importance of patient advocates. White women more often reported privacy concerns about technology use. Unlike White women, Black women reported willingness to discuss sensitive topics, both online and offline, but believed those discussions made their providers feel uncomfortable.

Common patient-centered communication needs

Emergent themes across all focus groups underscore the importance of patient-centered care at various treatment phases. The impact of HITs on communication practices also emerged.

Sensitivity during the cancer diagnosis call—Several participants in each focus group recounted the traumatic experience of receiving their cancer diagnosis via phone call. One participant was home alone when she received the diagnosis; another was in a painting class; others recalled driving while trying to process the news; and one participant said she only learned of her cancer diagnosis because a patient navigator called to make an appointment for surgery. One participant said, *"It was a very bad and terrible moment when I heard them say you have breast cancer."* Another participant agreed that it was difficult to absorb that kind of information in a phone call, saying, *"Yeah because it does play on your mental state to get a phone call, to get a diagnosis, and to hold a conversation over the phone."* Repeatedly, women in our study said they were not comfortable receiving their cancer diagnosis via phone call and would have preferred a pre-scheduled, in-person office visit so they could mentally prepare and bring a friend, family member, or member of the clergy for social support. One participant said, *"You have to have a moment just to yourself. But then after that…was like, 'Okay, alright. Now what am I gonna do?'"*

Need for personalized information—Women in our study said providers should be mindful that receiving a cancer diagnosis, having uncertainty about disease severity, and hearing about the extensive treatments needed to prevent recurrence can be fear-inducing, particularly for women who previously lost loved ones to cancer and must now face their own potential mortality. In one focus group, a participant shared that having to decide whether or not to undergo breast-removal surgery was "traumatic"—and all women in that group agreed with her. She added that having to then make decisions about reconstructive surgery options after a double mastectomy added to feelings of fear and being overwhelmed. Thus, participants said providers should be sensitive to their patients' ongoing request for information and resources, with one woman noting the following:

> [I needed] information…more than anything because, to me, it was very frightening. My mother and my sister had both died with breast cancer. So immediately your mind goes to 'that's it. I'm gone.' I don't know how you [medical providers] would make that adjustment, but it needs to be there because it's very frightening.

Support from oncology team—Overwhelmingly, participants said the most pressing need for a woman after a breast cancer diagnosis is information; thus, women in all four focus groups said they considered their medical care providers part of their social support team. Specifically, participants said they wanted their medical providers, including nursing staff, to thoroughly answer their questions, explain lab reports, and provide lifestyle guidance during survivorship (e.g., physical activity recommendations, resources for emotional support). Some participants also said they needed their providers to offer medication adherence motivation, especially when side effects or pain were difficult to manage. One participant said, *“I flat out told [my doctor] that I don’t want to take this anymore. I hurt everywhere all the time…And he just said, ‘Well if you stop taking it then your cancer will probably come back.’ Okay, enough said. I will take it.”*

Technology increases likelihood of provider rapid response to patient questions—Most participants in this study agreed that technology is helpful for increasing communication between a patient and members of her oncology team. For many participants, email and text-based communication with providers saved time and was “*better than waiting on the phone and going a million times around the world to get an answer*.” Similarly, participants said they preferred the ease of email, text, or other web-based applications for quick queries to assess whether or not a clinic visit was necessary. Participants also expressed favorable opinions about the opportunity for more frequent interactions with healthcare team members using new technologies, such as mobile apps. One woman explained that having access to a mobile app would be reassuring for patients who experience increased medication side effects or are unsure about changes in their body and question, *“Is this normal or not normal?”* In response to the proposed intervention, participants said that rapid provider response via a web-based platform would probably increase their feelings of connectedness, particularly when faced with several months between clinic visits. One participant said, *“Just that it gives you a feeling that you’re connected, I think. You’re not just, ‘Okay, here I am,’ one month and then again six months later.”* However, women reported concern that more web-based communication does not always equal better communication, especially for newly diagnosed patients. One participant explained: *“When you’re on a steady plane, it’s just a nice little communication. But if you are in an area where it is all new or you’re having difficulty and things are frightening, I think that [real-time communication] would be really comforting.”* Participants voiced concern and frustration about potential inadequacies in provider feedback, specifically guidance about how to interpret results from their lab work. One participant said, *“Technology is good, but if they are not going to communicate it to us on what they are finding or what the answers mean with you, then what is the point?”*

Generational differences in technology usability—Although most participants acknowledged the convenience of web-based communication such as secure messaging, opinions among older participants were mixed about whether they would use available technologies to engage with their medical care providers. Those who expressed reservations cited their limited technical knowledge, specifically an inability to use web-based platforms without assistance. Some older focus group participants acknowledged the existence of a generational divide in patients’ perceptions of technology usability. One participant said, *“And I’m speaking for the old folks. I’m not into all of this technology and this Internet and all of that kind of stuff…We feel kinda like we don’t fit in with what’s going on. So it can’t be too technical.”* Another participant echoed her sentiments, saying, *“I don’t think* *anything is ever going to replace speaking to a person about what's going on, but we all are in a technical world and the younger ladies coming up behind us are going to be more in tuned to this than maybe we are."*

Race-based differences in patient-centered communication

We also found evidence of race-based differences in women's perceptions of patient-centered communication, including technology-facilitated patient-provider communication.

Black women expressed frustration about their inability to obtain pertinent condition and treatment details—Black study participants made four statements about receiving insufficient informational support from their providers. Specifically, Black women reported not having their informational needs met by providers, in regard to information concerning treatment length, AET symptom management, and effects of AET on pre-existing chronic conditions. Overall, Black women reported the need to be proactive in asking questions and requesting specific information from their providers or outside resources (e.g., American Cancer Society, local support groups). For instance, one Black participant said she insists that a member of the medical staff explain her lab reports at each visit because, in her own words, *"Nobody will tell you about it. You've got to ask! If you don't, you won't get any answers."* Another Black woman said she had to ask her doctor to use patient-friendly terms, so that she could understand her treatment options: *"They were very thorough to me. They used a lot of big terms, but I would say, 'Can you break that down?'"* White women in our study made six statements related to being given the information they needed, often without asking for it first, but none about explicitly asking for information. For example, one White participant said, *"They gave me information on spiritual needs. If I was feeling anxious or anything, they gave all kinds of information on who to contact for any needs, so they have been wonderful."*

Black women noted the importance of having advocates during their interactions with providers—Black women also more frequently highlighted the importance of having a family member or friend accompany them during a clinic visit to help them interpret or remember information from providers. Black participants made five statements about the role of advocates in facilitating patients' support needs, compared to two statements made by White participants. One Black participant noted that having another trusted person in the room was necessary just in case a second opinion was needed: *"…a lot of people don't have an extra person in there with them, and they don't ask any questions. They just take face value what people say."* Similarly, Black participants indicated that some women may need trained patient advocates, such as a paraprofessional or an insurance-provided cancer nurse to help them navigate the healthcare system, in general, as well as their specific cancer treatments in particular. One participant said, *"I do think that there are people who need advocates and need that one-on-one to be able to have certain things explained to them."* Another Black participant suggested that the "live chat" function of some web-based platforms might facilitate real-time Q&A sessions between medical providers and patients, especially patients who may require additional explanation or advocacy.

White women expressed satisfaction with their relationships with healthcare providers—White women in our study more often expressed appreciation toward oncology providers and nursing staff who provided medical, mental health, and spiritual information and answered questions in a timely fashion without making them feel rushed. Specifically, White women made five comments referencing their positive, supportive patient-provider interactions while Black women made only two such statements. One White participant said, *"Sometimes you feel like when you go into a doctor's office that he is in a rush to see the next patient, and my doctors did not do that. They all have taken their time to take care of me and answer all my questions."* Several White women praised their longstanding relationships with primary care providers who offered additional informational and emotional support. For instance, one participant spoke glowingly of her relationship with her primary care provider, saying, *"I called and left her a message and let her know that I had gotten that diagnosis, and I really wanted to talk to her. I thought 'good luck,' you know, because they are so busy, but she was great! She called me back and spent quite some time that evening talking to me on the phone and helped ease some of my fears."*

Black women shared experiences of disempowering, paternalistic interactions with providers—Conversely, Black participants made four statements relating to disappointing interactions with oncology providers while White participants made zero statements. Black women in our study shared personal stories of disempowering, paternalistic interactions with providers and frequently mentioned the importance of changing providers to increase their comfort level. For example, one Black woman said, *"Well, I believe that if you are uncomfortable with a doctor you should let him know that you are uncomfortable with him because I am like this if I go see a doctor and I am uncomfortable with him then I let him know. Is there anybody else? Because you and me is not going to get along."* Another woman shared her story:

> Yes, there are good doctors, and there is not good doctors. And there are some that would sit with you, talk with you, and explain things to you. But the first doctor that I went to when they first diagnosed me with breast cancer, it was kind of harsh and a little mean, so I don't deal with people like that…because if you don't pull yourself together when a doctor come out and say, 'You got cancer, and if you don't take the operation you gone die,' that makes you angry. You don't tell me, 'Yeah, you gone die if you don't.' I said, 'Okay sir. Yeah. We all going to die, so what's the problem?'

This participant's interaction with an oncology provider exemplifies the patient disempowerment Black women in our study reported. One Black woman shared her frustration about her primary care provider's communication style: *"Just give me the answer. Don't go around the bush. Just tell me straightforward."* Black participants often discussed the importance of self-empowerment during the cancer diagnosis and treatment processes, namely not being afraid to ask numerous questions and repeatedly request information and being willing to change medical providers to increase personal comfort and patient-provider communication efficacy.

Black women more often expressed comfort discussing sensitive topics with their providers—White and Black women in our study also differed in their willingness to discuss sensitive topics, like menopause, sexual dysfunction, and mental health challenges (e.g., anxiety and depression). White participants made two statements explicitly stating their desire to be prompted by their providers to have sensitive discussions. Black women not only reported no hesitations (i.e., zero statements indicating the need for prompting) but they also made six statements regarding their disinhibitions to engaging in sexual health-related conversations with providers. One Black participant said*, "I'm too old to be hiding stuff. I'm just gone let it all out. I ain't got time to be shy about nothing."* Another woman said, *"I would love to tell it*," referring to her desire to discuss changes in her sexual functioning because of AET; all other women in the focus group agreed with her statement. Another woman added, *"No, these are not uncomfortable topics. I don't feel bad that I don't have the desires. It doesn't bother me."* Still, Black participants made seven statements regarding their beliefs that sexual and mental health-related discussions made their providers feel uncomfortable. Specifically, one woman said this: *"Sometimes the providers are more uncomfortable than the patients themselves. Especially men doctors when women go in there and you talking about your feminine parts and, um, 'Hey, I got this going on' and they probably looking like 'Lord, mercy. Jesus.' Like I said they would be more embarrassed than me."*

Not only did White women in our study report less comfort discussing sensitive topics with their medical providers but they also more frequently expressed how they found it difficult to engage in discussions about menopause, sexual dysfunction, and depressive thoughts via a web-based platform, making two statements. White participants said it would be "*strange*" to discuss difficult topics in any context other than a face-to-face clinic visit. Although both White and Black participants said they prefer face-to-face communication about sexual and mental health concerns (three total statements), Black women more often said the communication environment (in-person versus online or text) did not change their willingness to engage in candid conversations with their medical providers about sensitive topics. For example, one Black participant said, *"Look, I will talk to them about anything. Anything, so [web-based platform] or not, any topic."*

White women more frequently discussed concerns about privacy—White participants in our study more frequently shared their concerns about data privacy. White participants made three statements about online privacy compared to zero statements from Black participants. One participant said she feels "leery about putting stuff online" and has concerns about using web-based technology to communicate with her provider about her cancer care. She said, *"I've been very reluctant to sign up for these portals and apps and things because of, you know, I just feel like I have so much information online now. I have just been like, 'Oh my God! Another password for somebody to hack from me.'"* Although this participant admitted that web-based platforms could be convenient for getting one's lab results, scheduling appointments, receiving appointment reminders, and asking general questions, she said she still prefers to talk with a physician's assistant or nurse in person or via the phone. Although White participants more often discussed privacy implications of web-based communication than Black participants, most focus group participants said they had few, if any, privacy concerns. In fact, one participant asked, “*Is anything private anymore?”* while another said, *“People do banking and everything else on their mobile devices, so I can’t imagine this* [the intervention app] *being any less secure.”*

Participant recommendations for improved patient-provider communication

During each focus group, participants were prompted to provide recommendations to oncology care providers to improve communication practices with patients. Black and White women in our study offered actionable changes, borne from their personal experiences, that providers could implement during in-person clinic visits (see Table 2).

Discussion

Our study of women with early-stage breast cancer confirmed that oncology providers’ communication practices have a significant impact on patients’ psychosocial wellness. We found similar patient-provider communication needs across all focus groups, including increased sensitivity from providers during the initial cancer diagnosis, personalized information to facilitate treatment decisions, emotional support, expectations for rapid provider responses, and technical assistance for older, less tech savvy patients using HITs (e.g., patient portals and mobile apps). Race-based differences in patient-centered communication also emerged. Black women in our focus groups more often reported not fully understanding the details of their treatments despite requesting information and recounted personal experiences of disempowered interactions. White women often praised longstanding relationships with providers, yet they expressed reluctance to discuss sensitive topics (e.g., menopause, sexual dysfunction, depression). Black women reported discussing sensitive topics but believed those discussions made their providers feel uncomfortable. Our findings also suggest that the use of web-based technologies by patients and their providers can improve communication but may also create usability and privacy concerns.

All participants requested more sensitivity and empathy in their communication with healthcare providers, starting with the diagnosis. Cancer diagnosis is associated with significant psychosocial morbidity (Burgess et al., 2005; Ellis & Tattersall, 1999). Women who are unsatisfied with their cancer diagnosis communication are more likely to show long-term maladjustment (Mager & Andrykowski, 2002). A positive patient-provider relationship, which is key to treatment adherence and cancer survivorship, is established (or hindered) during the initial cancer diagnosis (McWilliam et al., 2000). Participants in this study were clear that they preferred a scheduled, in-person visit for receiving an initial cancer diagnosis to lessen the anxiety produced by unexpected or ill-timed phone calls. Participants also expressed desires for frequent conversations with their providers soon after the diagnosis to allow them time to process the “bad news,” weigh treatment options (e.g., breast-conserving surgery versus breast-removal surgery), and decide whether to undergo reconstruction. Guidelines for delivering serious information like the initial cancer diagnosis exist, namely that information should be delivered to patients in person while they are in street clothes (as opposed to partial undress), by a physician who is seated at equal eye level, and after advanced notice so patients can emotionally prepare for the serious information and bring an individual for social support (Girgis et al., 1999;

Hack et al., 2005). Still, our findings suggest these guidelines are inconsistently followed. It is possible that the personalized nature of cancer communication hinders development of “best practices” that can be universally employed (Thorne et al., 2014). Nevertheless, future research should evaluate cancer diagnosis communication practices to ensure existing guidelines for delivering serious information are sensitive to patients’ informational and emotional capacities. Dissemination interventions should also be developed to promote use of patient-centered guidelines that can be widely and uniformly implemented.

Our findings emphasize the critical role of patient-centered communication during the adjuvant phase. Anxiety and fears about cancer metastasis or recurrence are common among cancer patients (Campbell-Enns & Woodgate, 2017). Active surveillance (e.g., routine blood tests or scans, lab reports) can help alleviate these concerns (Kantsiper et al., 2009). The transition to adjuvant treatment has been labeled the “reentry phase,” for it requires women with breast cancer to address physical and emotional functioning as well as interpersonal relationships (Stanton et al., 2005). Thus, timely, patient-centered communication from medical providers can help patients contextualize a new state of “normal” (Thorne et al., 2014). Participants in this study, regardless of race, said they thought technology could improve communication with their oncology team members. Past research indicates that patients often prefer in-person clinic visits for more complex or sensitive issues and online communication for general questions or less sensitive issues (Katz et al., 2004). However, Houston et al. (2004) found that electronic communication emboldens patients to ask questions they might otherwise feel uncomfortable asking in person or on the telephone. Women with breast cancer want to stay connected to their oncology providers during the transition from active treatment to maintenance and throughout survivorship (Post & Flanagan, 2016); women in our study reported similar desires for medical interactions. Despite a few women’s articulations about privacy concerns, most study participants reported that the potential for increased online interactions with and rapid responses from providers would increase their feelings of connectedness.

Adverse sexual health symptoms (e.g., vaginal dryness or bleeding, orgasmic disruption, loss of libido, dyspareunia) are pervasive among breast cancer survivors (Bober & Varela, 2012; Derzko et al., 2007), and poor patient-provider sexual communication results in unmet sexual health needs during treatment and survivorship phases (Harrison et al., 2009). Many participants in our study reported sexual health problems during their treatment although few reported having discussions with their providers. While Black women in our study reported no hesitation discussing any topic, including sexual health challenges, in either in-person or online contexts, White women reported reluctance in discussing sensitive topics unless prompted and preferred face-to-face communication. Our findings reflect extant literature that has identified inadequacies in patient-provider sexual communication in oncological settings (Hordern & Street, 2007a, 2007b; Politi et al., 2009). However, little, if anything, is known about the unique sexual health communication practices of Black, Mid-Southern women with breast cancer or how those sexual communication practices influence patient-provider interactions in medical settings.

Although prior research indicates that Black breast cancer survivors often report the importance of being active knowledge seekers independent of their healthcare providers

(Royak-Schaler et al., 2008), these patients still expect their physicians to provide them with the necessary, personalized information to allay any cancer-related fears and inform their health decision-making (McMullan, 2006). However, past research has identified racial differences in information provision, such that physicians provide more information to their younger, White, and better-educated patients (Siminoff et al., 2006). In our study, personal accounts of patient-provider interactions among Black women often signal opportunities for increased patient-centered communication on the part of providers. Despite Black women in our study reporting using more direct language and initiating conversations with their oncology providers, especially when asking for treatment or symptom management-related information, they reported knowing details related to their treatment or alternative treatment options less often than White women. Similarly, a recent study of Black women with early-stage breast cancer in the mid-Atlantic region showed that while patients were satisfied with their interactions with providers, they lacked knowledge about their diagnosis and treatment (Sheppard et al., 2011). These findings seem discordant with findings from another study that examined oncologists' perspectives of Black breast cancer survivors in Memphis (White-Means et al., 2017). These authors found that oncologists believed that Black women were less likely to ask questions during clinic visits and more likely to defer to providers instead of engaging in shared decision-making. Given our study's findings, additional research is needed to further examine potential gaps in patient-centered communication for Black, Mid-Southern breast cancer survivors.

In addition to perceived inadequacies in informational support from their providers, some Black women in our study reported experiencing disempowering patient-provider interactions. Recent studies have found that Black women with breast cancer are more likely to experience discrimination in clinical encounters than White women (Check et al., 2018; Quach et al., 2012). Matthews et al. (2002) found that Black cancer patients expressed skepticism about their doctors' ability or willingness to communicate health information. Our paper adds to evidence of continued inadequacies in patient-centered care provision for Black women with breast cancer. Nearly two decades later, Black cancer patients consistently report beliefs that their medical provider will withhold information, which may lead to the kind of patient mistrust that negatively impacts patient-provider relationships. Poor patient-provider communication can hinder women's access to relevant information and limit opportunities for shared control; lack of patient-centered communication may be especially detrimental for Black women with breast cancer whose ability to engage in healthcare decision-making with confidence and self-efficacy often depends on information provision (Hack et al., 2005). Siminoff et al. (2006) found that physicians provide more psychosocial counseling and engage in more relationship building with White patients compared to non-White patients. Similarly, Black women in our study were less likely than White women to report longstanding relationships with primary care providers who could aid in the transition from active treatment to maintenance.

Race discordance between Black breast cancer patients and their oncology providers may explain some race-based differences in patient-provider communication found in current research. Patients who have racially discordant interactions with medical providers receive significantly less information and are significantly less active participants than patients who have racially concordant interactions (Gordon et al., 2006). This may be due to the fact that race concordance can strengthen patient-physician relationships because of a perceived shared identity, which has been found to positively impact patients' communication, trust, satisfaction, and treatment adherence intentions (Street et al., 2008).

Interactions between oncology providers and Black breast cancer survivors may be influenced by interpersonal power imbalances, stereotypes (provider) and stereotype threat (patient), and social norms that can perpetuate patient disempowerment. Communication accommodation theory (Farzadnia & Giles, 2015) may provide a useful framework for examining intergroup communication dynamics that can hinder patient-provider communication within the oncological setting. Specifically, this theory may provide a perspective for better understanding how sociohistorical contexts between Black Mid-Southern women and healthcare professionals can influence social norms about language convergence in the in-person clinic setting and online platforms.

Patient implications

Findings from our study have some direct implications for breast cancer survivors. Interventions that feature patient coaching sessions in which a trained researcher discusses specific information-seeking skills or strategies patients can use when interacting with their provider have been found to improve patient-provider communication (Lerman et al., 1993; Parker et al., 2005). Information provision inadequacies among Black breast cancer survivors in our study and others highlight the need for intergroup communication interventions, such as peer advocates. Survivorship navigators may benefit women with breast cancer during AET treatment, particularly those who have limited support networks or difficulties navigating long-term oncology and related care (Natale-Pereira et al., 2011; Pratt-Chapman et al., 2011). Differences in provider communication with Black breast cancer survivors highlight the continued need for provider trainings with specific focus on patient-centered communication practices with Black female patients.

Directions for future research

Race-based differences in patient-provider communication among Black cancer patients persist, despite more than two decades of scholarship identifying barriers and potential interventions. Findings from our study suggest that inadequacies in patient-centered communication for Black female breast cancer survivors (but less so for White patients) in the U.S. Mid-South also remain, contributing to what is known about how the intersectionality of race, gender, and geographic location influences communication practices between Black women with breast cancer and their oncology providers. Poor patient-provider communication may contribute to an already disproportionately risky environment for Black women in the region. However, challenges and barriers to Black breast cancer survivors' communication efficacy and patient engagement highlight opportunities for further research and intervention. Mixed-method research studies using critical theory and critical discourse studies (Unger et al., 2016) are needed to examine how patient-provider power dynamics, especially during race-discordant medical interactions, impact Black women's communicative efficacy with their providers. Objective measures of in-person provider communication patterns during clinic visits are needed to inform the development of interventions and “best practice” guidelines to increase patient-centered communication for Black women with breast cancer.

In a recent study, Black breast cancer survivors in Memphis reported that their providers did not want to give them adequate information regarding their treatment; however, providers thought patients could neither comprehend complex treatment-related information nor access and process online health information resources because of their perceived lack of digital skills and health literacy(White-Means et al., 2017). Additionally, Black breast cancer survivors described having to advocate for themselves to get clinicians to provide information about their treatment-related symptoms (Samuel et al., 2018). However, Gordon et al. (2006) found that when Black patients brought a companion to the clinic visits, Black patients and the companion received less information from the provider and were less active than triads that included White patients. Therefore, additional research is need to examine the impact of peer advocates who serve as communication interlocutors on patient-provider communicative patterns in oncological settings. Additionally, given the proliferation of technology-based healthcare, patient navigators may need to facilitate use of HITs for patient-provider communication for older women with breast cancer to make sure that these patients fully participate and benefit from HIT affordances that may improve their oncological care.

While HITs can increase and improve patient-provider communication and promote patient-centered care (Snyder et al., 2011), they require patients to take a more active role in their healthcare and decision-making. Because implicit bias, race-based differences in information provision, and other institutional barriers may not obvious to medical providers, HIT may be effective in reducing nonclinical factors and the impact of implicit bias that can be detrimental to clinical care (Lopez et al., 2011). Yet the impact of HIT on patient-provider interactions between Black women with breast cancer and their oncology providers is not neutral. Although the empowerment potential of HITs has been established in existing literature, so have challenges, particularly uneven access to web-based resources among different subpopulations (e.g., racial/ethnic minorities, older adults, patients with limited digital literacy) (Clauser et al., 2011). Although there is growing evidence that HITs can improve patient-provider communication, it is also likely that HITs can exacerbate racial disparities in communication and cancer care. Given known challenges of HIT use among minority patients (e.g., digital divide, mistrust and cultural barriers, language proficiency), research that examines differential impacts on patient-provider communication, information access, and health outcomes is important and necessary (Lopez et al., 2011).

Limitations

All participants were recruited from the WCCRI patient database; women with early-stage breast cancer in the study area who received care in other settings were not included. Thus, recruitment from a single patient pool limited generalizability of our findings. Furthermore, this study only examined the perspective of Black and White women with breast cancer, which limited generalizability to other racial and ethnic backgrounds. Still, the majority of patients treated at the WCCRI (>96%) are Black or White. Lastly, since we did not ask focus group participants about demographic characteristics of their WCCRI oncology providers (e.g., racial identity or gender) we also were unable to control for the effects of provider race and gender concordance. Thus, we did not examine the perspective of patients who have race- and gender-concordant providers, who may have different experiences than those who had race- and gender-discordant providers.

Conclusion

We found that women with early-stage breast cancer in adjuvant treatment, regardless of race, expressed similar needs for patient-centered communication with their oncology providers in online and offline contexts. Yet, Black women, compared to White women, experienced poorer patient-provider communication. Race-based differences in communication needs and preferences highlight the need for systemic interventions to bridge communication gaps between providers and their patients. Communication skills training programs should include cultural competency curricula that are sensitive to patient gender, race/ethnicity, and geographic culture and help oncologists identify and address social support challenges that Black female patients may face during adjuvant treatment. HITs have the potential to empower patients, regardless of race, to assume a more active role in their healthcare; these web-based technologies may be especially promising for reducing patient-provider communication hindrances that negatively impact cancer care for Black breast cancer survivors. Future research should continue to explore the impact of patient-centered communication, including patient-provider sexual communication, on information provision and psychosocial wellness among women with breast cancer.

Acknowledgements

A grant from the National Cancer Institute (R01CA218155) provided support for this research study.

Madelyn Gero, MS contributed to this report.

The entire study team would like to express gratitude to the breast cancer survivors who participated in this study and shared their personal stories and insights.

The authors would like to acknowledge the editorial assistance and support provided by Curtis Roby, MA, during the preparation of this manuscript.

Appendix A

Focus Group Moderator Guide

Good morning/afternoon and welcome to this focus group, sponsored by the West Cancer Center Research Institute (WCCRI) and the University of Tennessee Health Science Center. My name is [*name*], and I will serve as the moderator for today’s conversation. This is [*name*], and she’s here to take notes. We are here today to learn from you. Before we get started with the discussion, let’s go around the room and have each person introduce herself.

1. Tell us your first name and your favorite restaurant in the city.

The moderator will instruct each woman to introduce herself as well as write her name on a table tent (name facing the group). The moderator will inform the group that pseudonyms are allowed to maintain anonymity.

Today, you will be asked to provide feedback about the enrollment process for a new study as well as your thoughts and suggestions for improving the content of a web-based app used by the WCCRI. Your honest feedback is important to the study team. Your thoughts and feelings about the content we are going to present to you will help improve the intervention, including the web app, for women with breast cancer.

You should have a small notebook and a packet in front of you. The notebook is yours to keep. Use it to jot down notes or questions or exchange information with other focus group members. The packet has five sheets, labeled Sheet A through Sheet G. You will be given instructions pertaining to these sheets throughout the discussion.

1. The overall purpose of the [*study name*] is to improve adjuvant endocrine therapy (AET) medication adherence, patient-provider communication, breast cancer care, and patient quality of life through the use of web-based app. Sheet A provides examples of AETs, both generics and name brands.

What do you think the WCCRI team should know about women's physical/mental/emotional/spiritual needs after cancer diagnosis and/or treatment?

Probe #1: What recommendations would you make to the WCCRI team?

Now, I'd like to get your thoughts about the study enrollment process the team plans to implement.

[Moderator will read the short narrative about the general enrollment process]

A few days after being prescribed their first adjuvant endocrine therapy prescription, eligible women will receive a call from a research coordinator to tell them about the study and invite their participation. Interested individuals will schedule a time to meet in person with the research nurse shortly after picking up their AET pills. During this initial visit, women will be asked to bring in their AET pills and the nurse will (1) review the study consent form, (2) ask them to complete a brief, 10-minute survey, and (3) give them a new, electronic pill bottle monitor to be used with their AET prescription. The monitor looks just like a regular pill bottle. To compensate participants for their time and effort, they will receive $25 for each follow-up survey completed and pill bottle reading plus a $25 bonus for 100% completion for up to $200 for a year of study participation.

1. What do you think about the [*study name*] enrollment process, as I have described it?

1. Think back to when you first received your adjuvant therapy prescription. When would have been the best time to approach you for participation in a study?

Thanks for your feedback on the study enrollment process. Now let's switch gears and think about how technology can impact communication in the medical setting.

1. How do you think use of technology, like the tablet used in the WCCRI clinics, can increase communication between physicians and their patients?

Probe #1: What topics would you most like to discuss via an app with your healthcare provider?

Probe #2: Are there any topics you might feel MORE comfortable discussing electronically rather than face to face?

Probe #3: Are there any topics that you might feel uncomfortable discussing with your healthcare provider in any format?

Please direct your attention to the packet. What I've given you are examples of a web-based app that has been developed to help providers improve communication with patients about taking their medications according to the prescribed regimen and side effects. For the next few minutes, I'd like you to provide feedback on the existing app. Feel free to write on the packet; the more, the better. As I describe each item, circle aspects you like, put Xs over aspects you don't like, and write any additional feedback you think is helpful.

Participants will receive reminders by email or text message to use the study app. Sheet B provides examples of those reminder messages.

1. How frequently would you like to receive app reminders? How frequently is too frequently?

Probe #1: What would be the consequences of too much contact? Would you delete the app? Turn off notifications?

Now, let's take a look at Sheet C. Here you will see an example of the flow of questions a person will receive through the app if she takes her AET medicine as prescribed and has no new symptoms to report.

Is the language in the questions clear? Do you like the layout of the app messages? Are there other symptoms that should be included? Feel free to mark up the packets. We are grateful for any feedback and recommendations you provide, so we can improve the existing app.

Now let's take a look at Sheet D. Here you will see an example of the flow of questions a person will receive if she does not take her AET medicine as prescribed or has new or changing symptoms to report. Again, we would like you to provide feedback about the content of the app.

Now, let's take a look at Sheet E. Here are some examples of text messages patients may receive after using the app based on what they report.

> [Moderator will read the directions. Moderator will also read each message to participants and direct them to provide feedback. Remind them to score each message.]

Finally, please look at Sheet F. Here are some examples of graphic feedback messages patients may receive after using the app.

> [Moderator will read the directions. Moderator will also read each message to participants and direct them to provide feedback. Remind them to score each message.]

1. What do you think of the sample messages and what other kinds of content would be helpful in the messages a patient could receive through the app?
2. In addition to text-only feedback messages, would self-esteem/self-affirmations, photos, or video messages be effective? Why? Why not?

1. Thank you for your feedback. I'd like three or four volunteers to briefly describe what you liked best and least about this program you just viewed.

Probe #1: How could this study/program be improved?

[If there is duplication in answers, the moderator should probe participants to provide new feedback/evaluations.]

[Notetaker will collect the packets from participants.]

1. How do you think real-time communication with a provider would impact how you take your medication and your health care?

Probe #1: Do you think others would be completely honest in their answers knowing that their care team members are monitoring them? Why? Why not?

1. What are your thoughts about using this app?

Probe#1: How do you feel about using this app on your own?

Probe#2: Do you have family members or friends who are able to help you use the app?

1. Do you have data usage or privacy concerns? Would you worry about exceeding your data plan limit?

1. We have had a great discussion today about several important topics. Did I miss anything? Is there a topic or concern that you have that I didn't mention? Is there something that I should have asked but didn't? This is the open-format session of the conversation. Please feel free to add anything you think will help the WCCRI provide better care.

This concludes today's focus group session. Thank you so much for your time and great answers. Please leave your materials on the table. Please see the receptionist outside for your gift card incentive.

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Table 1:

Demographics and medical characteristics of study sample (N=28)[*], % (n)

Characteristics	Black women		White women	
	AET ≤ 6 months (N=5)	**AET > 6 months (N=8)**	**AET ≤ 6 months (N=8)**	**AET > 6 months (N=7)[*]**
Age (mean)	64 years	61 years	67 years	66 years
Breast cancer stage at diagnosis				
Stage 0	20% (1)	0% (0)	13% (1)	0% (0)
Stage I	40% (2)	50% (4)	38% (3)	43% (3)
Stage II	20% (1)	38% (3)	25% (2)	43% (3)
Stage III	0% (0)	13% (1)	13% (1)	14% (1)
Missing	20% (1)	0% (0)	13% (1)	0% (0)
AET medication				
Anastrozole	100% (5)	88% (7)	75% (6)	86% (6)
Letrozole	0% (0)	13% (1)	13% (1)	0% (0)
Exemestane	0% (0)	0% (0)	13% (1)	14% (1)
Mean months on AET (SD)	2.2 (2.3)	14.4 (6.6)	2.9 (2.0)	19.0 (6.4)
AET self-reported non-adherence [§]	50% (2)	62.5% (5)	37.5% (3)	
Overall health rating				
Very good or Good (vs. poor or fair)	75% (4)	87.5% (7)	62.5% (3)	0% (0)
Missing	20%(1)	0% (0)	0% (0)	100% (7)
Education				
High school	20% (1)	37.5% (3)	12.5% (1)	0% (0)
Some college	40% (2)	37.5% (3)	50% (4)	0% (0)
College degree or more	20% (1)	12.5% (1)	25% (2)	0% (0)
Missing	20%(1)	12.5% (1)	12.5% (1)	100% (7)
Income				
Less than $20,000	20% (1)	12.5% (1)	12.5% (1)	0% (0)
$20,000 - $39,999	0%	25% (2)	0% (0)	0% (0)
$40,000 - $59,999	40% (2)	0%	12.5% (1)	0% (0)
$60,000 - $99,999	20% (1)	25% (2)	25% (2)	0% (0)
$100,000 or more	0% (0)	12.5% (1)	25% (2)	0% (0)
Missing	20%(1)	25% (2)	25% (2)	100% (7)
Relationship status				
Single	20% (1)	12.5% (1)	50% (4)	0% (0)
Married	60% (3)	37.5% (3)	25% (2)	0% (0)
Separated/Divorced/Widowed	0% (0)	37.5% (3)	12.5% (1)	0% (0)
Missing	20%(1)	12.5% (1)	12.5% (1)	100% (7)

[*] Survey data for the focus group among White women on AET > 6 months was not collected (N=7).

[§] “Yes” to any on the four-item Medication Adherence Questionnaire

Table 2:

Participant recommendations for improved patient-provider communication

Communication during the initial breast cancer diagnosis

- Communicate serious news in face-to-face settings.
- Assess each patient’s capacity for information immediately after diagnosis. Post-diagnosis mental distress (e.g., anxiety, fear) can decrease comprehension.
- Implement a breast cancer diagnosis checklist
  - ✓ Have I scheduled a face-to-face office visit with my patient to deliver serious news?
  - ✓ Is my patient emotionally supported by a family member, friend, spiritual advisor, or patient advocate?
  - ✓ Do I have information materials adapted to meet a diverse patient population (e.g., low literacy, low health literacy, multiple languages, large print)?
  - ✓ Have I communicated the diagnosis honestly?
  - ✓ Have I allotted sufficient time for patient questions?
  - ✓ Does my tone communicate empathy and respect for the distressing nature of a breast cancer diagnosis?
  - ✓ Have I elicited patient questions or concerns and checked for information comprehension?

Communication about adjuvant treatment

- Provide detailed information about a patient’s individualized treatment regimen as soon as possible (e.g., adjuvant treatment length of time, medication side effects)
- Provide lifestyle maintenance information (e.g., physical activity recommendations, approved complementary and alternative treatment options).

General recommendations

- Communicate directly & honestly with your patients about their health condition.
- Create an opportunity during each clinic visit for patient-initiated questions.
- Elicit concerns from patients, so they will ask questions and seek clarification about their diagnosis and treatment.
- Encourage and support family involvement and participation when delivering serious news or providing treatment-related information.
- Ask patients if they would like to have religious/spiritual resources in the room.
- Routinely initiate discussions about patient sexual and mental health. Help your patients overcome discomfort, embarrassment or shame discussing sexual and mental health challenges.
- Create an environment of shared decision-making and shared control.