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A Qualitative Exploration of Race-based Differences in Social Support Needs of Diverse Women with Breast Cancer on Adjuvant Therapy

Andrew Paladino[1], **Janeane N. Anderson**[1], **Carolyn Graff**[2], **Rebecca Krukowski**[1], **Ryan Blue**[2], **Tameka Jones**[3], **Joanne Buzaglo**[4], **Mehmet Kocak**[1], **Gregory Vidal**[3], and **Ilana Graetz**[1,5]

[1]College of Medicine, University of Tennessee Health Science Center, Memphis, TN

[2]College of Nursing, University of Tennessee Health Science Center, Memphis, TN

[3]West Cancer Center, Germantown, TN

[4]Vector Oncology, Memphis, TN

[5]Rollins School of Public Health, Emory University, Atlanta, GA

Abstract

OBJECTIVE: Social support is a critical component of breast cancer care and is associated with clinical and quality of life outcomes. Significant health disparities exist between Black and White women with breast cancer. Our study used qualitative methods to explore the social support needs of Black and White women with hormone receptor-positive breast cancer on adjuvant endocrine therapy (AET).

METHODS: We conducted four focus group (FG) interviews (N=28), stratified by race (i.e., Black and White) and time on AET. FGs were audiotaped, transcribed, and analyzed according to conventions of thematic analysis.

RESULTS: Participants noted the importance of having their informational and emotional social support needs met by friends and family members. White participants reported support provided by others with breast cancer was crucial; Black women did not discuss other survivors as part of their networks. Notably, both White and Black participants used the FG environment to provide experiential social support to each other.

CONCLUSIONS: White participants noted that having other breast cancer survivors in their support network was essential for meeting their social support needs. However, Black participants did not reference other breast cancer survivors as part of their networks. Cancer centers should consider reviewing patients' access to experiential support and facilitate opportunities to connect women in the adjuvant phase.

Corresponding Author: Andrew Paladino; Department of Preventive Medicine, College of Medicine, University of Tennessee Health Science Center, 66 N. Pauline St., Suite 615, Memphis, TN 38163, Phone: (901) 448-1771; Fax: (901) 448-7041; apaladin@uthsc.edu.

Conflict of Interest Statement
The authors do not have any conflicts of interest to declare. There is no financial interest or benefit, either direct or indirect, which might influence authors' objectivity.

Keywords

cancer; oncology; breast cancer; adjuvant therapy; race-based differences; social support

Background

Breast cancer is a prevalent chronic disease affecting millions of women, with recent statistics indicating that approximately 1 in 8 women in the United States will be diagnosed in their lifetime.[1] For women with hormone receptor-positive (HR+) breast cancer, adjuvant endocrine therapies (AETs) are often needed for several years as prophylaxis against cancer recurrence following primary treatment.[2] Previous studies have mostly focused on addressing the social support needs of these women during initial diagnosis and primary treatment phases.[3] The adjuvant phase is much longer than the diagnosis/treatment phase and still understudied.

Completion of primary treatment coincides with a sudden decrease in healthcare encounters, from several times per month during active treatment to once every three to six months during the adjuvant phase.[4] This decrease results in patients having fewer occasions to obtain support from their healthcare teams.[5] Moreover, patients tend to underutilize their support networks and report receiving less social support from their friends and family a year following primary treatment.[6] Thus, for many women, the start of AET marks the beginning of a decline in social support, which may create new unmet social support needs.

Several studies show a positive association between social support and clinical health outcomes, such as medication adherence and mortality.[7–13] For women on AET, unmet social support needs are also associated with increased symptom burden,[14] higher leukocyte pro-inflammatory and pro-metastatic gene expression,[15] increased depressive symptoms,[16] and lower overall quality of life.[17] Specifically, social support from other survivors, referred to as experiential support, has been shown to improve a patient’s ability to appraise her breast cancer experiences while also reducing feelings of isolation and promoting optimism for the future.[18] While this type of support can be facilitated via formal support groups, less than 12% of women with breast cancer regularly attend formal meetings.[19] Accordingly, scholars and clinicians have called for examining new ways to improve access to social support, particularly experiential support, for women with breast cancer.[20]

Understanding racial differences in social support is especially important for regions with significant disparities, such as Memphis, Tennessee. The Memphis metropolitan region has high breast cancer mortality relative to other cities of its size[21] and significant Black-White disparities.[22] Black women in Memphis are more than twice as likely to die from breast cancer as White women.[23] Still, little is known about racial differences in social support and how they may contribute to these well-documented racial disparities. We conducted four focus groups (FGs) with women diagnosed with early stage HR+ breast cancer taking AETs to explore social support needs among Black and White women with breast cancer following primary treatment.

Methods

Participants

Participants were recruited from the West Cancer Center (WCC), a comprehensive oncology center providing a network of fully integrated cancer care that serves patients in the U.S. Mid-South. We recruited WCC patients who met the following criteria: women who were 18 years and older, diagnosed with early stage (I-III) HR+ breast cancer, and prescribed AET medication (e.g., tamoxifen or aromatase inhibitor).

Procedures

Following approval by the Institutional Review Board at the University of Tennessee Health Science Center (IRB # 17–05479-XP IAA), a WCC research nurse (TJ) reviewed electronic health records to identify women who met our eligibility criteria using purposive sampling. TJ confirmed participant eligibility and provided an overview of the study and topics to be discussed during one-time FGs.

Four 90-minute FG interviews were conducted between December 2017 and January 2018. Before starting each group, informed consent was obtained from each participant who also completed a survey assessing demographic and medical characteristics.[24] These groups were stratified by race (i.e., Black and White) and length of AET treatment (i.e., < 6 month AET use or ≥ 6 month AET use; see Appendix A). Each FG participant was compensated with a $40 gift card.

Race- and gender-concordant moderators, a clinical psychologist (RK) and a health communication scholar (JNA), led the FGs. Both moderators completed formalized FG training and have extensive backgrounds in facilitating FGs. A semi-structured moderator guide containing questions and prompts was drafted by JNA, which was reviewed and edited by the study team until a consensus was reached regarding content and phrasing. For consistency across FGs, moderators asked questions in the guide word-for-word, and follow-up probes were asked and clarifications were provided as needed. For instance, some interview questions included, “What do you think the team should know about women’s physical, mental, emotional, spiritual, and social support needs when taking your hormone therapy?” and “What recommendations would you make to the team?”

In order to ensure the accuracy of perspectives and to increase validity, moderators employed the strategy of member checking[25] by periodically summarizing participants’ comments throughout the FGs (e.g., “So what you’re saying is… Is that right?”). To reduce bias toward perspectives of more loquacious participants, moderators identified participants who were contributing less frequently and encouraged them to offer their perspectives (e.g., “I feel like I haven’t heard from this side of the room. Anything to add?”).

Analysis—We audio-recorded FG interviews and transcribed verbatim to obtain accurate data using a modified version of Silverman’s transcription conventions.[26] First, FG interview transcripts were analyzed separately by group. Two authors (JNA and CG) conducted line-by-line coding for each transcript. These authors used the qualitative strategy of constant comparison[27, 28] to identify emergent themes from the raw data. After these initial themes were identified, two authors (AP and IG) performed additional coding and analysis to assess race-based differences in social support. Inter-rater reliability between AP and IG via percent agreement was calculated to be 89.6%, with Cohen's $\kappa = 0.87$. Discrepant coding was resolved by a third party (JNA). Another author (RK) conducted an independent review of the final codebook and qualitative analyses.

Results

Table 1 in Appendix A describes FG participants' demographic and medical characteristics. Average age was 64 years, 48% were not married, and 19% had a 4-year college degree or higher. The majority of participants (86%) were prescribed the AET medication Anastrazole, and 48% reported not being fully adherent.

Across the FGs, participants identified family and friends as key sources of informational and emotional support from their initial breast cancer diagnosis through the adjuvant treatment phase. Importantly, the FG modality itself served as a source of support from which FG participants drew upon to address unanswered questions and receive emotional validation. White women (FG1 and FG2) often reported having support from other survivors. However, Black women (FG3 and FG4) did not make any references to providing or receiving social support from other breast cancer survivors outside of the FGs.

Informational and emotional support from family & friends—Participants from all FGs noted the importance of family and friends to accomplish varied instrumental support and information-seeking tasks and serve as additional listening ears during physician visits. One participant (FG3) noted the importance of family inclusion during provider visits, which can help facilitate the acquisition of necessary informational support. She said: "*And I had several questions and had my daughter, mother, my husband and my son—so it was like a family-like presentation to us because these are the people that are going to have to help you outside of the medical facility*." Another participant (FG2) expressed how her daughter, a pharmacist who had also been diagnosed with breast cancer, helped her navigate her own cancer. She said: "I *was blessed to have my daughter who… had been through breast cancer… to answer a lot of my questions*." One participant (FG4) reported that she maximized the knowledge and skills of her network to help her find the best plastic surgeon in her area, saying, *"I really literally called everyone that cares about me and I care about them, and I gave them assignments. I really truly did. You tell me you find me, your job is to find who the best plastic surgeon in […] is."*

Additionally, participants underscored the value of emotional support provided by networks of family members and friends. Participants in our study readily admitted to relying on spouses, children, and in-laws to provide comfort during medical visits, especially when serious or negative news from providers was anticipated. One participant (FG1) stated: "*My son-in-law was exceptional. He went with me every time I went to the doctor when my daughter couldn't go, so I feel so fortunate*." Another participant (FG1) added, "*…It's my husband. He's has been my strength through everything*."

Race-based Differences in Support

White women more likely to report having other breast cancer survivors in their social support networks—Despite having many similarities in needs, we observed some race-based differences in sources of support. White participants frequently noted the importance of relationships they had with other breast cancer survivors who provided informational support during participants' active and adjuvant treatment phases based on first-hand knowledge and insights from their own cancer experiences. For example, one White participant (FG2) expressed gratitude for the small network of long-term breast cancer survivors with whom she was able to talk and receive reassurance during her treatment. She said: "*I've got a lot of support in my work group and my sister has had breast cancer but she is 15 years older and she lives in Missouri…it's nice to be able to sit down and talk to people who have been through it recently."* Conversely, there were no explicit references made by Black women in our sample to receiving or providing support from other breast cancer survivors outside of the FG.

White women more likely to report addressing other breast cancer survivors' emotional needs—Unlike Black women, White women in our sample also reported finding mutual benefit in providing emotional support to other breast cancer survivors in their lives. Our participants noted the importance of having someone—even a complete stranger—minister to their emotional needs during temporal moments of fear, uncertainty or hopelessness. This was particularly the case among older White women in our study who often expressed the need for survivors to be sensitive to others' emotional needs. For instance, one participant (FG2) recounted an experience in which she was able to provide some comfort to another patient during a short elevator ride. She said: "*'Oh, we all you know, didn't know how to do and what to do.' And she looked so floored that I said, 'Would a hug help?' And she said, 'I think it would,' and so I hugged her, and she said she had been going through another type of cancer for 12 years and the breast cancer stuff was new.*"

Interestingly, all of the FGs created environments where participants were able to give and receive support. In fact, in every FG a spirit of sisterhood was fostered among some participants. Experiential support occurred more frequently as seeking and providing <u>informational</u> support to each other in FGs of Black participants (FG3 and FG4) and more frequently as seeking and providing <u>emotional</u> support to each other in FGs of White participants.

Black women more likely to provide informational support to each other during FG interviews—Some Black participants used FG discussions to query others about tumor growth (e.g.,*"Do everybody think that when they are being diagnosed with breast cancer it is always a lump in their breast?"*(FG4)) and genetic testing (e.g., "*Now was it a hormone that was causing the tumor or the cancer to grow faster in any of you? Did you have a hormone?"*) and to share tips and over-the-counter products for combating AET medication side effects. One Black participant who worked in a pharmacy made a point of providing medical information she knew by virtue of her occupation to other women in the FG. Sometimes, as was the case for one exchange in FG4, participants provided informational and emotional support concurrently. For example, Black participants (FG4) acknowledged the harsh effects of active treatment while providing affirming statements to one woman who felt self-conscious about her radiation burns:

Participant A I didn't have to go through the chemo. I went through just the harsh radiation. Ahhh Lord!

Participant B It will burn you up.

Participant A It burnt me up!

Participant B I had third degree burns.

Participant A Then I had to go on a cruise afterwards and sit there and look stupid.

Participant B I wouldn't say you looked stupid.

White women more likely to provide emotional support to each other during FG interviews—Study participants, regardless of race, noted that sharing their personal experiences with breast cancer and subsequent treatments in safe, supportive environments with other women "who are going through the same thing" was meaningful and spiritually helpful. Several women even suggested meeting monthly for lunch. Yet, White women were more likely than Black women to explicitly provide emotional support to other FG members during the interviews. For instance, one participant said to another (FG2): "*I just met you, what an hour ago? I'd hug you because sometimes you just feel like you need that, you just need somebody to say, 'Oh, I know what you mean. I've been through that, too.*"

The following conversation, sparked by one participant (FG2), about hair loss in the adjuvant phase is a telling example.

Participant A Is anyone else losing their hair?

Participant B My hair is coming out, and it's so thin now.

Participant C Mine was thin before.

Participant B But this is just from breast cancer not the Anastrozole. Mine is coming in thicker than I had before.

Participant A I just got a clip on (laughs). The top is mine.

Participant C Yeah, it looks good!

Similarly, White women in our study did not pass judgment when one participant admitted to being nonadherent to their AET (FG2).

Participant D How often I forget to take the medicine. (*Women make sounds of concern*). You know maybe once a week I forget it.

Moderator And that would be a little uncomfortable?

Participant D Well, yeah because it's to save my life! You know, what's my problem?

Participant E I think everyone forgets every once in a while.

White women more likely to report a desire for stage-specific support groups—White women in our study who had been newly prescribed an AET medication discussed the importance of sharing their experiences with other breast cancer survivors in similar stages of treatment. These women noted that their cancer experiences often differ from other family members who were diagnosed years prior because of new medical advancements; thus, they reported wanting opportunities to connect with women "who have been through it recently." For one participant (FG2), the absence of social support because of limited familial or friendship networks made experiential support provision from FG participants even more important. This was reinforced by another participant (FG2) who expressed concern about other women with breast cancer who might not have an extensive social network from which to derive support, saying, "*And you know you don't know who doesn't have anybody here in town. You don't know what we all are going through and how much we rely on other people or don't."* Participants suggested the WCC should facilitate monthly social support groups for newly diagnosed women with breast cancer in addition to general or topic-specific support groups.

Conclusions

Our study found that women with early-stage breast cancer have a variety of informational and emotional social support needs during AET. The presence of relatives and other allies to accompany patients during medical visits was a key factor in meeting participants' emotional and informational needs. Instances of this were recounted as crucial to processing information during encounters with healthcare providers, especially when family and friends functioned as emotional buttresses that made information more easily absorbed. Despite some similarities in experiences among all participants, White women frequently reported receiving and providing support from other breast cancer survivors, while explicit references to this type of support were absent for the Black participants. Experiential support provision among study participants was noted in all FGs. However, Black women were more likely to provide informational support and White women more frequently provided emotional support to each other.

In each group, participants developed camaraderie and sisterhood with each other. They provided informational support by asking questions about treatment and giving advice about symptom management and expectations. They provided emotional support by validating commonalities in symptom experiences and by extending gestures of affection and care to each other. Consistent with our findings, previous research of Black survivors found that they often utilized support from friends and family, and never referenced support from other survivors. They also note that Black women are more likely to rely on God for support.[29,30] Still, it is possible that having a more limited support network drives Black women to rely on God. Another study among primarily White participants found that support from formal groups with other survivors and informal support from family and friends are essential to post-primary treatment well-being.[31] Our study expands upon the previous research by juxtaposing needs and illuminating differences in the manifestation of social support among both White and Black patients.

The importance of experiential social support in the form of reassurance and validation from others with breast cancer was a central theme in other qualitative studies examining the lived experiences of breast cancer survivors.[31, 32] Though all participants in our study acknowledged that they relied on a network of family, friends, and even relative strangers to meet their informational and emotional supports needs, Black women did not bring up other survivors as part of the support they received. In several instances among White participants, family members and friends were also breast cancer survivors, and the support they provided was essential to FG participants during the challenges of cancer diagnosis and treatment. In FGs of Black women, participants readily exchanged experiential support with each other, but they did not explicitly mention other cancer survivors as being part of their existing networks. The seeking and provision of informational support by Black women is also consistent with past research that suggests that individuals from racial/ethnic minority groups are less likely than White patients to report having their informational needs met.[33, 34] This suggests that convening breast cancer support groups for Black women comprised of other Black survivors could be particularly beneficial in meeting their social support needs. Perhaps, connections with other survivors are not being accessed as easily for Black women compared to their White peers because of sociocultural factors unexplored in the current study.

Past research suggests that formal breast cancer support groups that include participants with a significant range of treatment phases and experiences may be less helpful in meeting patients' needs.[35] Our participants expressed similar sentiments, stating that meeting with women going through the same phase of treatment was more helpful than having discussions with women who had gone through it years ago. While there are some support groups that target specific race/ethnicities,[36] few target specific treatment phases. Given that social support is important for cancer outcomes and social networks and social support groups are underutilized, our findings suggest that providing smaller, race- and treatment phase-specific groups might be a more effective and impactful way of reducing deficits in support. By leveraging experiential support, prior literature suggests that adopting and encouraging peer mentorship programs leads to greater satisfaction and fulfillment of needs.[37] Thus, women might also benefit from one-on-one peer mentors[38] to fully capitalise on empowering experiential support. Women with limited social networks and fewer personal resources may especially benefit from experiential peer support.[39] Digitally connected technologies and online support groups[40] might be a novel way to connect patients in similar phases of treatment and life experiences who may not be able to connect locally.

Limitations and Strengths

This paper is the first to qualitatively analyze the social support needs of women in the adjuvant phase of their breast cancer treatment, with a specific focus on race-based differences in experiential support. Moreover, this study incorporated the perspective of a group not usually well represented in research and employed race-stratified FGs, using race-concordant moderators, to facilitate and enrich discussions. Therefore, this study offers valuable insights into the shared and different needs that arise from diverse viewpoints among survivors in the adjuvant phase of treatment. Future research should approach this research question quantitatively and experimentally to assess the degree to which experiential support from women of similar backgrounds might be associated with improvements in outcomes.

Still, this study also had some limitations. Despite endeavors to mitigate this, some of the more assertive personalities of the group might have dominated over others and influenced the results and themes that emerged from conversations. Some women might have agreed with some of the discussion but might not have spontaneously shared the same perspective if the methodology were different (e.g., one-on-one interview). Finally, generalizability is limited due to the nature of qualitative research.

Clinical Implications

Our findings highlight the importance of assessing social support needs in the adjuvant phase and offering resources to meet deficiencies in support. Prioritizing ways to foster and encourage experiential support could be a way to fill the gap left by decreased healthcare encounters following primary treatment. Our findings suggest that support groups that are more homogeneous and targeted to specific treatment phases may be better suited to meet the varying needs of patients. This can be accomplished through healthcare and community-based organizations and online communities creating formal and informal support groups or one-on-one peer groups targeted to treatment phase.

Social support from friends and family as well as experiential support from other breast cancer survivors are needed to help women navigate their adjuvant care. Knowing and understanding the nuances of support needs are crucial first steps to developing novel interventions that capitalise on the saliency of experiential support to fill unmet needs for these populations. Ultimately, such interventions should address needs by facilitating connections among survivors, offering more avenues to receive support from the healthcare team, and encouraging women to utilize their existing networks by inviting family and friends to be active contributors in their care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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