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**ORIGINAL ARTICLE**

# Peer support preferences among African-American breast cancer survivors and caregivers

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**Abstract**

*Purpose* Breast cancer mortality rates continue to improve due to advances in cancer control and treatment. However, gains in breast cancer survival rates vary by race. Psychosocial support systems can lead to improved health outcomes among cancer survivors. This study was a part of a larger study exploring the challenges that both African-American cancer survivors and caregivers face across the cancer continuum. The objective of this paper was to explore African-American breast cancer survivors' and caregivers' preferences regarding characteristics and qualities of Peer Connect guides to inform the development of a peer support program.

*Methods* Forty-one African-American cancer survivors and caregivers participated in five focus groups lasting approximately 90 min. Participants were asked about what qualities or characteristics they would prefer in a peer support guide to make them feel comfortable talking with them. Focus group transcripts were analyzed using thematic content analysis, an iterative coding process. Themes were identified based on the research team's integrated and unified final codes.

*Results* Twenty-two cancer survivors, 19 caregivers, and 3 individuals who were both survivors and caregivers participated in the focus groups. Participants discussed five preferences for peer support guides: (1) competency, (2) gender, (3) age, (4) cancer role status, and (5) relationship to participant.

*Conclusions* This study highlights cancer survivors' and caregivers' perceptions of characteristics needed for peer support providers that in turn can influence whether and how they participate in cancer support programs.

**Keywords** Cancer survivors · Cancer caregivers · Cancer support · African-American · Breast cancer · Peer support

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## Introduction

Since the 1990s, breast cancer incidence and cancer mortality rates in the USA have continued to improve due to advances in cancer control and treatment [1]. However, significant disparities in screening, diagnosis, treatment, and survival persist [2]. Research has shown that racial/ethnic minorities are more likely to be diagnosed with later stages of cancer than white women [2]. Additionally, gains in breast cancer survival rates vary by race and ethnicity: 5-year survival rates for white women are 92% while they are only 79% for African-American women [3]. This disparity has been attributed to higher prevalence of co-occurring chronic diseases and challenges with obtaining timely cancer screening and high-quality cancer treatment [4–7].

The emotional and physical effects of breast cancer increase women's need for support [8]. Studies have shown that psychosocial support systems can lead to improved health outcomes among cancer survivors [9, 10]. Racial/ethnic

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minorities have been shown to have less access to organized cancer support groups, and African-Americans are less likely than white women to communicate with other cancer patients and more likely to want to have contact with cancer patients [11]. Cancer survivors are in most need of counseling and support groups to serve their emotional support immediately following the post-acute care stage [12]. One option for addressing the emotional support needs of survivors and caregivers is through peer support. Peer support has been used in a variety of health conditions, including cancer. Peer support interventions have been effective particularly with underserved, minority populations [13]. Peers can effectively reach survivors and caregivers to help facilitate a range of healthcare and psychosocial needs. Peer support can be leveraged to provide information, advocacy, and practical, emotional, and spiritual support [13]. Previous studies have found that characteristics of a good peer support include those that share similar health experiences, are approachable, and have time to meet with peers [14]. However, beyond these general characteristics used to match or include peers in support programs, there is a limited understanding of what the targets of peer support want, need, or prefer.

Although cancer is a dyadic stressor—affecting both the patient and caregiver, cancer support interventions focus primarily on the support needs for either the cancer survivor or caretaker—but rarely examine both [15]. This qualitative study explored both perspectives in tandem to gain a greater understanding of the issues that are different and/or similar for each group to help us better meet survivor and caregiver needs. Additionally, this study helped inform the development of a larger peer support program ("Peer Connect") in collaboration with two community-based organizations in rural North Carolina.

Peer Connect is a patient-centered program developed as part of the University of North Carolina at Chapel Hill's (UNC-CH) LIVESTRONG Survivorship Center of Excellence (http://carolinawell.org/connecting.do) to help survivors cope with their cancer diagnosis, treatment, and life after treatment [16, 17]. Since 2010, the program has been connecting post-treatment volunteer cancer survivors and caregivers (guides) with those currently experiencing cancer-related issues and needing support (partners). Cancer survivors and caregivers who wish to be guides to other survivors or caregivers are trained using a DVD and manual-based training program and matched to partners. The focus is providing patient-centered support: listening, reflecting, and avoiding unsolicited advice. Peer Connect trains volunteer guides in motivational interviewing (MI) techniques, i.e., asking open-ended questions, reflective listening, building motivation (importance, confidence, and value clarification), moving toward change (overcoming barriers and matching resources with participant interests), summarizing, and goal setting. MI helps individuals to work through their ambivalence about behavior change, master their own barriers, and explore potential untapped sources of motivation [18].

This study was a part of a larger study exploring the challenges that both African-American cancer survivors and caregivers face across the cancer continuum, including their support needs [15]. This paper focuses on African-American breast cancer survivors' and caregivers' preferences regarding characteristics and qualities of Peer Connect guides, which, in the main study, was a much-desired peer support program connecting cancer survivors and caregivers with other survivors and caregivers.

## Methods

Focus groups were used to examine what qualities and characteristics African-American breast cancer survivor and caregivers wanted in Peer Connect guides delivering peer support. Focus groups encourage participants to present and defend their views and beliefs about a certain phenomenon to others in the group [19, 20]. They also have the potential to uncover group norms through social interactions between participants, providing researchers information that would have not been obtained through individual interviews or surveys. Since little is known about African-American breast cancer survivor and caregiver preferences for Peer Connect guides, focus groups were considered the most appropriate research method which could inform the development of Peer Connect.

Participants were recruited through flyers, emails to local hospitals, community health centers, and organizations that served cancer survivors in North Carolina. Interested individuals contacted the study coordinator, completed screening questions and, if eligible, were invited to participate. Inclusion criteria included the following: (1) ages 18 or older, (2) self-reported diagnosis of breast cancer and/or a caregiver to someone diagnosed with breast cancer, and (3) spoke and understood English. While cancer survivors and caregivers were recruited separately, almost all of the caregivers accompanied the survivor during the focus group. This study was approved by the UNC-Chapel Hill's institutional review board.

Five focus groups were conducted between April and May 2013. Focus groups were approximately 90 min long. Four focus groups were held at a church and one at a university. Prior to the focus group, participants completed a brief demographic questionnaire. Informed consent was obtained from all individual participants included in the study. Participants received a $25 cash incentive. All groups were moderated by an African-American female trained in qualitative methods (MA). Cancer caregivers were mixed within focus groups with cancer care survivors. Using a semi-structured moderator guide, cancer survivors and caregivers were asked about previous experiences with cancer support services, level of interest in an African-American-only peer support program, and what

qualities or characteristics they would prefer in a peer support guide to make them feel comfortable talking with them. Specifically, the moderator asked, "What qualities/characteristics are most important for you for a Guide to have to make you feel comfortable talking with them?" and then probed specifically about gender, age, and similar cancer diagnosis by asking the following questions: "Do they need to be of a certain age group?", "Do they need to have had a similar cancer diagnosis or similar number of years of caregiving?", and "Do they need to be of the same gender?"

### Data analysis

Focus group recordings were transcribed verbatim and uploaded into ATLAS.ti version 7.0. A qualitative approach was used to analyze the focus group data. The authors used thematic content analysis, which uses an inductive approach to identify common preferences for peer support guides as they emerged from the data [21]. One strength of using thematic content analysis is that it goes beyond just code counting and focuses more on the interpretation and meaning of themes [22]. The authors (LHM and MA) independently reviewed transcripts and discussed participants' (both survivor and caregiver) preferences for guides. For participants that were both a cancer survivor and caregiver, the authors analyzed their responses based on which role they associated with in their response to the moderator. The authors then applied open coding to the transcripts to develop the initial codebook. After discussing the open codes and agreeing on a final code list of preferences, the authors (LHM and MA) coded all transcripts independently. Any code discrepancies were discussed until consensus was reached [23]. Based on the final codes, the authors then identified broad themes based on similar and related codes [22].

### Results

A total of 41 African-American adults (37 women and 4 men) participated in five focus groups. Demographic characteristics of the 41 participants are shown in Table 1. Over half the participants were cancer survivors ($N = 22$); 16 were caregivers and 3 were both a cancer survivor and a caregiver. All cancer survivors had been diagnosed with breast cancer. On average, cancer survivors had been diagnosed 8 years previously. Caregivers comprised mostly of spouses, children, and friends. A majority of participants were married (46%), had some college education or more (90%), and were retired (46%).

Across all focus groups, participants discussed five aspects regarding preferences for guides that would help build rapport and make them feel more comfortable confiding with them: (1) competence, (2) gender, (3) age, (4) cancer role status, and (5) relationship to participant (see Table 2).

### Competence

The majority of focus group participants focused on the guide's personality and demeanor. Most participants described wanting a guide to be compassionate, optimistic, emotionally capable, and non-judgmental. As one cancer survivor cautioned, "Guides need to feel comfortable with whatever people may come with…Because I never know what conversation is going to bring me to tears." In addition to being compassionate, a caregiver also discussed the importance of having a guide with good communication skills: "If they can communicate well, and are compassionate and can share information with me and they provide me with some coping skills – the skills you need for your journey and being a caregiver – that would be important for me." Although the peer support guide and survivor/caregiver have been both touched by cancer, this shared characteristic does not mean that cancer should always be the topic of conversation in peer support sessions. Additionally, several survivors mentioned they wanted guides to be "non-judgmental" as there was concern of being judged for having cancer—as in past life decisions that brought on their cancer diagnosis or judgment about any current situation they may be facing. One female survivor was worried that even after peer support training, some guides would still have a "she brought this on herself" mentality.

### Gender

Most focus group participants acknowledged the importance of same gender matching (women with women and men with men). Two caregivers did not have preferences for matching based on gender. For those who preferred gender matching, one male caregiver commented, "There are some gender factors that need to be taken into consideration. As open as we have become with sexual conversations, I believe that gender could inhibit communication between different sexes." Another male said, "I just think for males, if they talk to a guy, they'll probably be more comfortable saying, 'Well, man, what is that?'" A female survivor discussed how losing one's breasts might be a sensitive topic that is better understood between two females, with someone that has "all the same body parts as me."

### Age

When asked if participants would prefer that the guide be of a certain age, all survivors agreed that they would not feel comfortable speaking with guides younger than themselves. One survivor felt that someone with a similar age or older would be an important quality for her: "I would say my age to older. I would not have a problem with an older person, but I would not want a 25-year old talking to me." Some survivors felt that younger guides would not have the life experiences necessary

**Table 1** Demographic characteristics of breast cancer survivors and caregivers (*N* = 41)

| Characteristics | Survivors Number (%) | Caregivers Number (%) | Survivor and caregiver Number (%) |
|---|---|---|---|
| *N* | 22 | 16 | 3 |
| Age (mean, SD) | 63.6 (12.2) | 61.6 (14.2) | 59.3 (5.4) |
| Gender | | | |
| Female | 19 (100.0) | 12 (75.0) | 3 (100.0) |
| Male | 0 (0.0) | 4 (25.0) | 0 (0.0) |
| Cancer type | | | |
| Breast | 22 (100.0) | – | 2 (75.0) |
| Colon/rectal | 0 (0.0) | – | 1 (25.0) |
| Years since cancer diagnosis (mean, SD) | 8.0 (7.4) | – | 2.8 (3.0) |
| Years of caregiving (mean, SD) | – | 3.8 (3.4) | 5.1 (4.0) |
| Marital status | | | |
| Married | 7 (31.8) | 9 (56.3) | 2 (66.6) |
| Divorced | 5 (22.7) | 2 (12.5) | 0 (0.0) |
| Widowed | 3 (13.6) | 3 (18.8) | 1 (33.3) |
| Other | 6 (27.3) | 2 (12.5) | – |
| Education | | | |
| High school/GED | 3 (13.6) | 0 (0.0) | 1 (33.3) |
| Some college | 8 (36.4) | 5 (37.5) | 1 (33.3) |
| College graduate | 4 (18.2) | 4 (25.0) | 0 (0.0) |
| More than college | 7 (31.8) | 7 (43.8) | 1 (33.3) |
| Employment status | | | |
| Full time | 6 (27.3) | 8 (50.0) | 0 (0.0) |
| Part time | 2 (9.1) | 1 (6.3) | 0 (0.0) |
| Retired | 10 (45.5) | 6 (37.5) | 1 (33.3) |
| Unemployed | 1 (4.5) | 1 (6.3) | 2 (66.6) |
| Other | 3 (13.6) | 0 (0.0) | 0 (0.0) |

to serve as peer supporter. In response to why age was important, another survivor commented, "Because the older they are, the more experience you would expect them to have or to already have – and a little bit more understanding." Two caregivers did not have an age preference.

**Cancer role status**

All participants agreed that cancer survivors should be matched with other survivors and cancer caregivers be matched with other caregivers. One survivor commented,

"It's important for me that the Guide also be a survivor. To have firsthand understanding of some of the things you can go through. And the only way you can do that is to have come through it." Several survivors preferred being matched with peers that had a similar cancer type. As one survivor said, "Talking to someone who had the same cancer type as me is important, especially if it is a type that they are still doing a lot of research on." She felt that the guide might have a better connection if they could discuss the latest research for that cancer type. Lastly, one survivor even preferred being matched someone who had similar years of cancer diagnosis.

**Table 2** Focus group preferences for Peer Connect support guides

| Theme | Sub theme | Sub-theme total | Theme total |
|---|---|---|---|
| Qualities and characteristics | Competence | 13 | 36 |
| | Gender | 7 | |
| | Age | 6 | |
| | Cancer status | 6 | |
| | Relationship to participant | 4 | |

Total references were calculated based on the number of times participants made statements about Peer Connect preferences

### Relationship to participant

While all participants acknowledged the importance of having family support, most felt they needed a non-family member to serve as their guide. For cancer survivors sharing intimate details about their cancer journey, many wanted to protect family from their own fears about their diagnosis: "That's why I think it's better to talk to someone other than family, because you're sometimes scared to how a family member is going to react to what the situation is, so you hold a lot back." As one caregiver said: "I'm not saying family is not the best support, but seeing her [cancer survivor] go to the support groups, she's more open to talk to strangers because they've been there and they know a little bit more than what family would really know." Another survivor commented, "I think it's important to be able to talk to someone who's not a family member. You know, you might be a little more open – and maybe not as a therapist wanting to solve your problems, but just to talk and feel better by opening up." Overall, participants did not want to burden or worry family members about their feelings—and sometimes fears—pertaining to their cancer diagnosis, treatment, and post-acute care.

### Discussion

In our larger study exploring the challenges that both African-American cancer survivors and caregivers face across the cancer continuum, participants expressed the need for more African-American peer support groups [15]. Going beyond race, this study presents new insight into the preferences that African-American breast cancer survivors and caregivers have for peer support guides. Participants indicated strong preferences for competent individuals that are compassionate, optimistic, and non-judgmental. These competencies should be a key element of a peer support training. In terms of gender and age, most participants, with the exception of two caregivers, preferred to be matched with guides that were of the same gender and older in age. All participants preferred to be matched with a guide that shared similar health experiences, i.e., matching survivor to survivor and caregiver to caregiver. This is similar to other studies that indicate patients wanting to be matched with individuals that could understand their experiences [23, 24]. Being able to confide in a guide that is non-family is consistent with other studies focusing on peer support preferences [25]. However, in contrast to other studies on peer support among cancer patients from racial/ethnic minority group showing the importance of faith and spirituality [26–28], only one of our study's 41 participants preferred to have a guide that shared a similar faith.

In general, survivors were more interested in getting emotional support in the moment—from individuals of similar age and cancer role status, whereas caregivers were more focused on talking with someone as a mechanism for stress relief. Caregivers were less focused on age, gender, and years of caregiving. The preferences discussed by our focus group participants provide specific directions for cancer support program development. First, selecting peer support guides who can approach service provision in a compassionate, non-judgmental way is essential. Therefore, screening processes should take into account how to assess, monitor, and evaluate that care is being provided in this way. Additionally, training methods should incorporate strategies that provide guides with the tools and techniques to offer compassionate, non-judgmental care that encompasses a more humanistic framework. One therapeutic approach is motivational interviewing (MI). Because of MI's counseling approach, using it for peer support trainings would be an appropriate technique. MI operates from the viewpoint that the patient has a central role in determining his or her own behavior change and has freedom of choice in treatment or life challenges. The peer support provider collaborates with the patient to determine which approach is most suitable. Thus, MI's orientation is interpersonal, egalitarian, and empathic.

The second direction this study offers for cancer support program development is that gender, age, and cancer status matching should be a feature of programs so that cancer survivors and caregivers receiving support can readily build rapport with the peer support guide. In terms of participants preferring that guides be up-to-date on current cancer research, future peer support programs should consider incorporating this information into their trainings. Finally, the need to use non-family members as support providers suggests that families may only have a particular set of experiences, expertise, and information to serve the needs of survivors and caregivers. This study also found that survivors recognized that their cancer diagnosis often posed a significant care burden on their families and support services by an outsider would alleviate some of the caregiving burden. It is relevant to know what services and resources are needed that families are unable to provide so that a peer support program can fill this void.

This study has four limitations. First, asking about participants' preferences for Peer Connect guides was not the study's main research question; therefore, the moderator did not ask more specific, in-depth questions about qualities and preferences due to time constraints. Asking more open-ended questions would have helped gain a deeper understanding of support preferences. Going forward, researchers should ask more about these specific traits to uncover a deeper understanding. Second, the study's location and sample size may limit the generalizability of its results. Third, views from the cancer survivors and caregivers in this study may differ from African-Americans who chose not to—or were unable to—participate. Lastly, our sample included predominately educated women. Their views may differ from males or less educated African-Americans. Future studies with African-American cancer

survivors and caregivers should be conducted to confirm participants' perceptions about peer support providers here.

This study is among the first to describe the corresponding peer support preferences of *both* African-American survivors and caregivers. Since African-Americans have lower cancer survival rates, and support services have been shown to promote positive outcomes among survivors [29, 30], it is important to understand African-American's preferences for peer supporters.

## Practice implications

Previous research has shown that African-American cancer survivors and caregivers have strong preferences for peer support [15]. Public health researchers and clinicians should recognize that when developing peer support programs, they should understand what those preferences are. This study highlights the importance of competence, gender, age, cancer diagnosis, and non-familial relationship of peer supporters for cancer survivors and caregivers. Further, these findings have implications about the selection and training of peer supporters in the Peer Connect program.

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