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Permalink

<https://escholarship.org/uc/item/3jb731fs>

Journal

Cancer nursing, 41(6)

ISSN

0162-220X

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Publication Date

2018-11-01

DOI

10.1097/ncc.0000000000000522

Peer reviewed

Perceptions of support groups among older breast cancer survivors: “I’ve heard of them, but I’ve never felt the need to go”

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Acknowledgement: Our gratitude extends to Nancy Jo Bush, RN, MN, MA, AOCN, FAAN for her input into the preparation of this manuscript.

Funding Acknowledgement: This work was funded by the National Cancer Institute (R21CA167218-01A1).

Disclosures: The authors have no funding or conflicts of interest to disclose.

Abstract

Background: Cancer survivors transitioning from active treatment to posttreatment may lack critical support and information about their posttreatment care. Support groups have the potential to address this gap.

Objective: To describe how breast cancer survivors 65 years and above perceived professionally-led, in-person support groups.

Methods: Individual interviews with 54 women were analyzed using grounded theory informed by constructivism.

Results: Strong negative assumptions about cancer support groups were described.

Tension existed between two opposing categories: participants' preconceptions of support groups and characterizations of their members, and the women's perceptions of their own informational and emotional needs. Participants also described what sources of support they utilized in lieu of professionally-led support groups.

Conclusion: Despite awareness and availability, the majority of participants did not use support groups as a resource during their primary or post-cancer treatment.

Implications for Practice: Structural changes can benefit existing models of support groups including how and when support needs and services are discussed with survivors and a shift toward the inclusion of practical information.

It has long been known that support groups are a forum where cancer survivors address psychosocial needs¹ and high levels of satisfaction and quality of life benefits have been reported.^{2,3} There are many existing cancer support groups, including those specific for breast cancer, the most common cancer among women. Support groups vary in their structure from peer or professionally led to online forums. Effective breast cancer support groups have been found to increase empowerment, provide information about cancer, foster a sense of control³, improve cognitive function, body image, fatigue, and future perspective⁴. Learning from others in a group setting provided key emotional and psychosocial support.⁵ However, mixed results regarding whether support groups led to long-term positive outcomes or satisfied breast cancer survivors have been found in various types of group models.⁶⁻⁸ Problems with support groups have also been reported, such as non-attendance because of reluctance to share private matters with strangers in a group.⁹ Other reasons given for discontinuing or non-attendance of breast cancer support groups included wanting to move on from the cancer experience, seeing groups as a place for those with less support, wanting more “people like me” in the group, convenience, and lack of awareness about an existing group.^{10(pp24)}

Cancer survivors transitioning from active treatment to posttreatment lack support and information regarding their posttreatment care, which is critical to their long term health.¹¹ For many breast cancer survivors, the posttreatment phase is associated with premature discontinuation of anti-hormonal treatment, a potentially life-saving oral medication.¹² Contact with oncology clinicians, and potentially as a result with supportive clinical information, declines sharply in the posttreatment phase during which information and support can be helpful. The important role of support groups is further emphasized by the foreseeable shortage of oncologists. It was posited that by 2025 the United States may face a 40% increase in demand for

oncologist services, whereas supply will only increase by 25%.¹³ Furthermore, it has been found that older breast cancer survivors specifically deemed it difficult to ask or seek out support.¹⁴ Therefore, as part of a study focused on the decision-making processes related to persistence with anti-hormonal medications by breast cancer survivors 65 years and older in the posttreatment phase, this paper helps to update and add to the literature as we discuss how the women perceived professionally-led, in-person support groups.

Design and Methods

Grounded theory, an inductive, qualitative methodology informed by constructivism, directed all data collection and analysis.¹⁵ Grounded theory especially guided our research because the methodology is strongly focused on interactions and process.¹⁵ Our sample included women who were at least 65 years old when they were diagnosed with loco-regional (Stage I, II or III) breast cancer. All participants initiated anti-hormonal treatment. The total sample of 54 women co-incidentally consisted of two equal groups: 27 women continuing with an anti-hormonal treatment and 27 women who had prematurely discontinued the medication within the 15 months preceding the interview.

After approval by Institutional Review Boards, participants were recruited through mailings to potential participants provided by three cancer registries in Southern California and flyers posted in breast clinics, hospitals where support groups met, and at community support organizations. After informed consent was obtained, individual, in-depth interviews were conducted by the senior author (HP), an experienced qualitative interviewer. Interviews were conducted in a private place of the participant's choosing, usually her home. In the interviews, women were asked about support groups. (see Table 1 for examples of questions.) While other

types of support were mentioned (such as online forums or peer support), the findings presented here are related to the in-person, professionally-led support groups that were locally available. Participants received a cash compensation of \$60 after the interview was completed. Additional data collection consisted of a purposefully designed demographic questionnaire that was administered before the start of the interview and the abstraction of relevant characteristics from medical records.

INSERT TABLE 1 HERE

Interviews, averaging 97.2 minutes, were transcribed verbatim, checked against the audio-recording for accuracy, de-identified and transferred to Atlas.ti, a program used for data management and analysis. In addition to systematic rounds of coding by three team members experienced in grounded theory methodology, self-reflexive memo-writing, diagramming and situational analysis¹⁶ were used to track the developing conceptualizations. Methodological rigor was facilitated by regular meetings to compare codes, discuss discrepancies, and enhance deeper understanding of the data. Data collection and analysis occurred simultaneously for the purposes of constant comparison.

Sample Characteristics

The 54 women were an average age of 71.9 years at diagnosis. Most participants self-identified as white (n=44), were at least college graduates (n=38), identified her husband (n=21) or daughter (n=17) as her main support person, and spoke with friends daily (n=43). All participants lived independently either with a spouse (n=24) or alone (n=23) (Table 2).

INSERT TABLE 2 HERE

All participants reported that they were told about professionally-led, in-person cancer support groups at one point in the course of her treatment by either a treating clinician or friend, and most knew where a local group was located. A subset of participants had exposure to support groups prior to their cancer diagnosis through either attending a non-cancer related support group or by facilitating a group in a professional capacity as registered nurses, social workers, psychologist or as a non-professional volunteer at her church. No participant reported inconvenience, travel, or cost as barriers to attending support groups.

However, despite awareness and availability, the majority of participants did not use this type of support group as a resource during their primary or post-cancer treatment. With the exception of two participants (one who was continuing with the aromatase inhibitor and the other who had stopped), no participant was attending a cancer support group at the time of the interview, nor considered joining a group in future. Seven women had attended one session of a breast cancer support group, but had not returned. Additionally, while most women used online resources for information retrieval, none participated in an online support group.

Results

The importance of support and supportive people over the course of their cancer experience was naturally described across participants. Typically, the women identified either their husband or daughter as their main support person during the primary treatments. Support was described as an integral part of the cancer experience, through practical assistance and/or emotional support, by talking in person or via the phone and generally ensuring that the woman

did not feel alone. Following primary treatments, a shift was evidenced where out-of-town support sources were less present and/or participants tended to lean on and share less with their previously identified main support person. In addition to family and friends, most women also shared their diagnosis and treatment experiences with at least one other cancer survivor. Rich descriptions evidenced that valuable information was exchanged, such as referrals to doctors, treatment-related expectations, and tips on how to manage side-effects. Other survivors were also a source of emotional support, including the ways they validated participants' experiences and were perceived to understand the experience, having been there themselves. However, while our participants valued support, supportive people, and mutual sharing with other survivors, their appreciation of support and sharing did not translate into utilizing a professionally-led support group. A participant who was especially satisfied with her overall care illustrated this sentiment particularly clearly when she referred to the free support group at the local medical center close to her home where she was continuing to receive cancer treatments, "I've heard of them, but I've never felt the need to go".

Why available support groups were underutilized by this sample of older participants can be explained by a tension that existed between two categories that emerged in the data: 1) participants' preconceptions of support groups and characterizations of their members, and 2) the women's perceptions of their own informational and emotional needs. Participants also described what sources of support they utilized in lieu of professionally-led support groups.

Assumptions about Support Groups

The majority of our participants described groups as a negative space mostly intended to meet emotional needs. Characterizations of a typical group member was someone who enjoyed

group activities, had a limited support system, or was diagnosed with more advanced cancer. In contrast, participants voiced confidence in their knowledge of themselves as someone different. Knowing themselves over decades, this sample of older women clearly self-identified as someone who did not meet their idea of a typical woman who might benefit from a support group.

Assumptions about What Occurs in Support Groups

Despite their inexperience attending a breast cancer support group, women confidently described what they assumed happened in a group. Many participants held strong negative assumptions that one member usually dominated a group, and how attending the group was consequently not beneficial. A participant who had never attended a support group illustrated this finding when she said, “people that are more talkative often dominate the conversation. And it's just hard for me to express ... myself. I don't mind one-on-one, but to a room full of people, it would be very hard to tell them.” (See Table 3 for more quotes.)

INSERT TABLE 3 HERE

Another common misunderstanding was that groups were designed to primarily provide emotional support as opposed to also meeting informational needs. Many participants thought of groups as a place where people shared their fears and grief, sadness was pervasive and the mood was negative. When asked what she thought happened in a support group, one woman replied, “A bunch of old women sitting around crying”. Women described how, when they discussed their diagnosis or experience with others, it was upsetting to see others get upset. Therefore,

participants wanted to actively avoid that negative space, and not attending a support group was a way to protect themselves. Thus, the perception of groups as a negative space where members were emotional and upset was a deterrent to seek out a breast cancer support group.

Assumptions about Who Needs to Attend a Support Group

Based on their perceptions, the participants in our sample did not see themselves as the type of person to attend a support group. Some women shared that they would never seek out group support since they were not a “joiner” or a “group person”, while others had a certain depiction of which women need and benefit from support groups and it was a dissimilar profile from who they saw themselves to be.

Breast cancer support groups were understood to be a place to “vent” for women who did not otherwise have supportive people in their lives. In contrast, participants in our sample frequently described gratitude for strong existing support systems from family, their social circle (including friends in a quilting circle, gym, or church group) and trusted physicians, such as their primary care doctor. The existing and long-standing support were understood to mean that external social or emotional support with strangers was unnecessary. As one participant stressed, “I have too much family and church to think that I needed that kind of support.” Interestingly, the two participants who attended a support group at the time of interview did not fit this profile of a woman without support. One woman was married and described an extensive existing support system, while the other was an unmarried woman with close friends and family. However, the unmarried woman explained why she was still attending the group, “One reason is I don’t talk about it with my friends... my kids don’t talk about it with me. My friends don’t. [The group] is my only opportunity to do it”.

Similar to the participant who attended the group described above, a select number of participants who had never attended expressed a parallel sentiment and explained how they had family and other support, yet their journey with cancer was a lonely experience. Despite receiving support from both of her children and reporting a good relationship with her oncologist, one participant felt strongly that she did not want to burden her children with her cancer-related concerns and that her oncologist did not comprehend her level of vulnerability, nor had the time to address her emotional needs in their short posttreatment appointments. Finding herself “really affected” by the diagnosis, this participant was seeking “some base of security” to establish that “I have this horrible thing, but I'm still okay. I'm still an A person. I'm not a B minus or a C person.” While a professionally-led support group was likely a place to share this self-doubt and find reassurance, this woman felt she had adequate support and did not seek out a group. Another participant described that while she knew other survivors within her existing support system, these other survivors became a source of negative support in the sense that she compared herself to them and felt “they had it worse” and she feared that her friends thought hers was “not as big of a deal” since they had more advanced cancer. This dynamic harmed their friendship and she chose not to utilize these friends as sources of support. Thus, whether or not women were of the opinion that their existing support systems met their needs, they maintained that they would not benefit from a support group.

For some participants, membership in a support group was perceived to require a certain degree of sickness that translated into worthiness to attend. Groups were seen as a place for other women who had more advanced cancer or were suffering greatly. Participants in this study were all diagnosed with early stage breast cancer, and many felt their diagnosis was less severe and their complications or concerns were somehow less deserving than those of other women. For

example, while one woman was interested to hear about the experiences of others, she decided not to try out a support group because she thought, “I’m in here and, oh, all I have to do is take this pill. You know what I mean? I just didn’t feel worthy to a degree, I guess, I guess that held me back.” A participant who attended one group meeting, but decided not to go to another, said “the women there had been through so much more than I did...I didn’t feel like I belonged there”. Some women made reference to how they may have considered going if they were “doing poorly” or were “more badly off” showing their impression that if they were “doing ok” they would likely not benefit from a support group. One participant shared why she had not attended a support group:

No, I haven’t, because I feel like I’m fortunate enough to have had such a good experience that... I don’t think I’d be good hearing really bad stories at this point...I would feel terrible for them and feel guilty that mine was such a good experience. And also fearful that maybe there is something else in store for me.

In our sample composed of women 65 years and above, many participants described their breast cancer experience in comparison to other chronic illnesses they had been managing for years, if not decades. Their breast cancer experience was, in comparison, minor or quick or less life-altering. Furthermore, in this sample of survivors over age 65 years, most women knew others who had had breast or other cancers and had a more difficult treatment course or even lost their life to cancer. This uniquely played into participant’s understandings of their own cancer experience. Thus, overall not only did the women in our sample perceive that what happens in support groups would not benefit them, they also compared themselves to the theoretical members of a support group. This comparison led them to determine that they would not be an appropriate candidate to seek out membership.

Perceived Personal Needs

Participants described their informational and instrumental support needs, their need to move on from cancer, and the importance of establishing a connection and having shared qualities with fellow survivors. Weighing their needs with the perceived value of support groups led our participants to conclude that support groups were not a good match for their needs.

Informational needs

Participants clearly valued being informed and many women spontaneously reported that they specifically asked for more information related to cancer treatment from several clinicians. However, most of the women also voiced confusion based on conflicting information about various aspects of cancer, recurrence of the disease, and the purpose and management of anti-hormonal treatments. While disease uncertainty, fearing recurrence, and managing new medications and side-effects all caused anxiety about cancer, women did not ask questions or reach out for information from their oncology clinicians. Most participants appreciated and trusted their oncologist and wanted this prescribing specialist to give them the answers, yet they also knew the clinician was busy and had other sicker patients. Across cases, participants described that posttreatment visits was shorter and less individually focused. While women wanted more contact with their oncology providers to get their questions answered, only a few called with questions, emailed providers, or used available online portals. Instead participants planned to ask at the next appointment which could be months away. Participants easily listed many questions and issues about which they would like to get more information, though none felt that a support group would be a place to obtain this information.

Various components of informational support were evidenced in the narratives, with emotional and social support clearly separated from informational and practical support. In comparison to the emotional support that the participants assumed would be gained from a support group, they voiced their preferences for informational and concrete support. With regards to what she would prefer in terms of support, one participant suggested, “You know, it’s more than an empathetic approach. It’s got to be a problem-resolution type of approach.” Another woman described the difference between monthly support groups that she perceived to be focused on emotional support and the type of meeting where the practical information she preferred was presented, “I went and saw that [group presentation about estrogen] ... But going to monthly meetings and stuff, no. I don’t go to any of that.”

Thus, while most participants in our sample identified their socio-emotional needs as being satisfied outside of the medical system in the context of their own lives, the women associated informational and concrete support as areas of need that could be met through educational forums or more time with a medical professional. However, these women did not see support groups as a place to gain practical knowledge.

Importance of Moving Forward

At the transition to posttreatment, participants clearly described the importance of getting back to life as they knew it before cancer. The need to move beyond cancer was particularly well illustrated by the woman who said, “You’re re-establishing your connection to life, and that’s the way I see it because you’ve dropped out... you’re re-establishing, you’re also trying to get your footing. And you’re trying to re-establish some of your confidence.” Upon initiation of the anti-hormonal medication, participants described their rituals of taking the medication with very little

fanfare. Both the women who were taking an anti-hormonal medication and those who had stopped prematurely did not share issues or concerns related to their medication with their family and friends to the same degree that they had shared treatment experiences during primary treatment. For this sample, moving into their posttreatment phase marked a time when they were ready to move forward. While it was important for these participants to leave the cancer experience behind, the women perceived support groups as a mechanism for keeping cancer in their lives at a time when they described being “done” with cancer. The decision whether to attend a group, involved balancing their need for a connection to other survivors with the desire to return to their family role as cook or caregiver, or re-engage with valued activities such as exercise. Most participants understood their anti-hormonal treatment as playing a role in preventing cancer recurrence and this motivated women to initiate and persist with the medication. Dissimilarly, support groups were seen as prolonging the cancer journey and reminded the participants of challenges, limitations, and an experience that pulled them away from life apart from cancer.

Needing a Connection

Sharing with and helping other breast cancer survivors who had been through similar treatments or who were encountering similar side-effects from the anti-hormonal medication were seen as especially valuable during the primary and posttreatment phases. One participant described the value in obtaining information from other survivors as follows:

She said, "Oh. I am too!" And we discovered we had the same doctor and so got a little bit of a kinship. And we went out to dinner with them once. She was already on the medication and had been on it for a year, so she was telling me a little bit about it as I was about to go on it.

The importance of a genuine connection with another survivor before a supportive relationship would be considered helpful, was emphasized. Support group settings were seen to be a difficult forum to forge a relationship with other women, because others would be in different stages of cancer treatment and so they were unlikely to benefit from each other given their varying experiences. As one woman reflected, “They said, “Go to a cancer support group.” I don't want to go there and listen to other people's problems, not unless they're exactly like me with the hormone.” Other participants described how groups are primarily made up of younger women and how their experiences, values, and perceptions are entirely different. Women assumed that these differences meant they would be unable to find people they could relate to and with whom a genuine connection could be established.

What Women Were Doing Instead

Participants did not see groups as fitting their needs and therefore did not attend professionally-facilitated support groups that were available. Instead, informal networks were utilized as a tool for informational and emotional support. These informal networks were composed of other cancer survivors and their friendships that spanned decades, familial relationships, groups of women (such as neighbors), and acquaintances met during treatment. In addition, many participants saw trusted non-oncology physicians with whom they had consulted for many years such as a primary care doctor or OB/GYN as a valuable resource. Participants sought motivation, encouragement, and validation from fellow breast cancer survivors and shared how they managed symptoms or procedures and how well they were doing now. Others found that tip-sharing from other survivors was valuable because “you're just more likely to believe them” and was beneficial in simply “knowing more what to expect”. Sharing their

experiences with supportive others found in the course of their own lives was useful in employing a previously established connection and a sense of comradery upon which to build a system of support. Thus, despite the value seen in both informational and emotional support, participants did not seek out professionally-led in-person support groups, an accessible and potentially suitable resource that could provide consistent and accurate information.

Discussion

Breast cancer survivors in this sample valued and sought information and support, yet their perceptions of support groups were such that accessible groups were underutilized. In fact, when asked about in-person, professionally-led support groups, many participants had not even considered looking into a group, but automatically dismissed the idea as evidenced by the woman who said that she had heard of support groups but simply “never felt the need to go.”

One contributory reason for the disinterest of our participants in attending a group was the certainty that groups were intended for those without existing support systems who needed emotional support, whereas participants perceived that their existing support was sufficient. Two studies examined an earlier finding¹⁷ that the benefit of group support interventions may be different for those with varying levels of personal support. The first study found that support groups offered a separate social space to gather information, make decisions, and find hope, even to members with existing support systems.¹⁸ A subsequent study confirmed the earlier findings, also adding that groups led to increased confidence, agency, sense of control, a unique sense of community, and a place to obtain information about cancer and its treatment.³

Our findings with a sample of older breast cancer survivors support earlier results among younger participants with various types of cancer.¹⁰ Factors that influenced participation in

support groups included practical issues, resisting an identity as a cancer patient, presence of adequate existing support, mismatches between the group and the individual, groups seen as a negative place, and dissatisfaction with the group members and/or facilitator. Three of these four older studies^{3,9,17,18} on participation in support groups are somewhat dated. Our findings confirm and shed new light on the complexity surrounding how older women currently perceive the purpose of groups and who should attend.

Another reason for the underutilization was that support groups were seen as a place for those with more advanced disease and serious treatment concerns, whereas our sample had been diagnosed with early stage breast cancer and many described that their concerns were not worthy of or suitable for support groups. Furthermore, groups represented a connection to cancer at a time when participants wanted to move away from their cancer experience and return to their life before cancer. Finally, participants identified that sharing with their own informal networks was the way they met their informational and emotional needs. In sharp contrast to the rest of the sample, the two participants who were attending a support group described it as a place where they exchanged valuable tips and information.

The underutilization of an accessible resource happened despite the fact that most of our participants could potentially have benefitted from the emotional, instrumental and informational resources that available support groups usually offer during the posttreatment phase of their cancer journey. One reason these women could have benefitted from attending a professionally-led support group was that their transition into posttreatment marked the initiation of a new medication that often resulted in bothersome side-effects and resultant new informational and emotional needs.¹⁹ This happened at a time associated with fewer appointments with oncology specialists, when the women perceived that providers were too busy to be contacted with

concerns about side-effects. Another reason why attendance of a support group could have facilitated informed decision-making for the participants of our sample was that the main support person that the women identified commonly had less of a presence during the transition from active to posttreatment care. The few participants who continued to receive quality and consistent emotional support, often did not tell this support person about her concerns with the anti-hormonal medication and she still felt alone in the cancer experience. Thus, in addition to being a resource at the time of diagnosis and during primary treatments, support groups can potentially serve as a setting to learn from and help others to transition from active treatment to the posttreatment phase of survivorship and share tips with specific challenges such as persisting with anti-hormonal treatments.

In addition to professionally-led support groups, the availability and integration of psychosocial care options for cancer survivors is expanding to include self-help programs and education programs.²⁸ As with professionally-led support groups, specialist cancer nurses are well-positioned to play key roles with these services in continuing to meet the array of psychosocial and educational needs of breast cancer survivors managing an anti-hormonal treatment.

Strengths and Limitations

This is the first study to describe how a sample of breast cancer survivors, 65 years and above, perceive professionally-facilitated, in-person support groups. Ours is a robust sample size for a grounded theory study with women from a large geographical area receiving medical treatment at various medical institutions in both urban and less populated settings. The length and depth of the interviews resulted in well-developed, multi-faceted concepts. Another strength

of this work is that perspectives are represented from both participants that were continuing their anti-hormonal treatment and those who had discontinued the treatment prematurely. Our sample of older women also uniquely highlights the perspectives of older survivors as opposed to previous research on support group engagement with participants of all ages. However, a constraint of this research is that our sample mostly included Caucasian women while support-seeking literature suggests differences among individuals from different cultural backgrounds.^{20,}

²¹ Additionally, while different models of support exist utilizing various therapeutic and leadership styles, formatting, setting and components, all of which may impact patient benefit,^{3,}

²² we focused singularly on professionally-run support groups.

Implications for Practice and Research

Three implications for clinical practice emerged from the personal accounts of our participants that may positively impact engagement in cancer support groups by older cancer survivors: how groups can be structured, enhanced promotion, and how and when referrals are made. Structuring a group can include our finding that, across participants, supportive others were highly valued. A group can be structured to invite a support person such as a spouse, family member, friend or fellow survivor to some group meetings. Such inclusion can acknowledge the role of the support person in the ongoing cancer experience and open lines of communication about cancer-related concerns that may have ceased when primary treatments were completed. An invitation to occasionally include a support person could also provide a space to learn about coping skills for both survivors and supportive others. Support groups are one example of a logical, feasible, and accessible place where people living with cancer and their families and friends can learn about the posttreatment phase of the cancer journey.

Efforts to promote support groups would benefit from accentuating the following facts about the content and outcomes of groups: instrumental and informational support are provided, all members can benefit despite the phase of survivorship, type of disease or the severity of the diagnosis, and represents an opportunity to help other attendees. While it is known that support groups provide informational, emotional and instrumental support,²³ the participants of this study were only aware of or focused exclusively on the emotional component. This perception made groups unattractive because the participants valued concrete support, specifically sharing practical tips, but they did not associate this opportunity with support groups. Thus, our data suggest that promoting support groups as meetings where practical information is exchanged could make them more appealing. For example, recent developments in breast cancer support group formatting has had success in presenting monthly, hour-long, nurse practitioner-led sessions as group education and support sessions.²⁴ Therefore, given that the women in our sample highly valued information and instrumental support, organizers of support groups may promote that an important objective of the group is information gathering. Instrumental tip-sharing amongst survivors could be included as a constructive activity and groups can be presented as an opportunity to validate those tips with a professional facilitator present. Presenting groups as an opportunity to receive information from a clinical specialist about side-effect identification and the concrete aspects of the ongoing management of cancer's impact on daily life would likely also add to the perceived benefits of existing group models. Our sample, composed of women diagnosed with early stage disease transitioning to posttreatment, frequently described themselves as less deserving to be in a support group compared to members with more advanced diagnoses. This finding supports previous research where women who considered attending a group were reluctant to face the difficult experiences of fellow group members and

felt survivor's guilt when comparing themselves to members who had worse prognoses.¹⁸ The concern that one type of cancer or complication makes a person more deserving of support resources should be dispelled in an effort to encourage any cancer survivor to attend a support group, even if they were diagnosed with an early stage breast cancer and whose sole treatment at present is taking an oral adjuvant treatment in the home-setting.

Also, given that support groups allow for an exchange of information, mutual helping and giving back, regardless of disease severity, others may benefit simply by engaging in a space where they can reciprocate.²⁵ In fact, altruism was valued among our sample, but the participants were unaware that support groups provide an opportunity to give back. Thus, another way that cancer support groups can be promoted is as an opportunity to give back to other survivors. An example of a flyer based on our findings that can be customized for different settings is presented in Table 4.

INSERT TABLE 4 HERE

How and when support groups are presented to patients are of crucial importance. Both participants who were regularly attending support groups in our study received the information from clinical sources. Promoting a support group in the clinical setting gives the suggestion more gravity compared to the patient hearing about a group from another cancer survivor. During appointments, clinicians can present a range of formats, such as in-person vs online, professional-led groups such as those found in medical centers, peer-to-peer programs, psycho-educational series, or community models such as the Cancer Support Community. Information about support groups can also be promoted with a flyer that is handed to the patients during

clinical appointments. Regarding when support groups are presented, support resources should be addressed at every interaction with an oncology provider because cancer survivors' needs shift and change throughout a cancer journey.²² It has been over ten years since the Institute of Medicine published a landmark call for attention to the transition from primary to posttreatment cancer care¹¹ with ongoing appeal from the scientific community for special consideration to the transition to posttreatment.²⁶ Starting an anti-hormonal treatment and transitioning to posttreatment care presents an especially good time to remind the patient of the match between professionally-led support groups and a patient's evolving support needs.

Our work starts to describe an understudied area of cancer survivorship research. The many opportunities for future research include a specific focus on cultural diversity to capture commonalities and differences in seeking out cancer support groups. Furthermore, the available literature typically includes wide age ranges. We found no studies from a lifespan perspective that considered how to modify the way support groups are presented to cancer survivors of different ages. Future research should address age related differences and perceptions of support groups. For example, the finding that a cancer survivorship identity is perceived differently among women 70 years and older,²⁷ may uniquely influence how support groups are promoted among seniors. While our work focused on the perceptions of women who were not attracted to support groups, a future study can research women who are actively attending a group and gain their perspectives about what is helpful. Another opportunity for future research is how the degree, source and role of established support networks prior to a cancer diagnosis impact support seeking behaviors.^{3, 10, 18}

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Table 1. Examples of Interview Questions and Potential Follow-Up Questions

Example of Questions
<p>Have you heard of support groups? <u>Follow-up question:</u> Some women go to support groups for cancer to get information. Is there such a group around where you live here?</p>
<p>Please tell me what have you heard about support groups? <u>Follow-up question:</u> What do you think happens in a breast cancer support group? <u>Follow-up question:</u> What do you associate with a support group for breast cancer? <u>Follow-up question:</u> How do you think women could benefit from a support group?</p>
<p>So, for someone like you who has been diagnosed with breast cancer, do you think women sometimes go to support groups? <u>Follow-up question:</u> Did you ever go to such a group? <u>Follow-up question:</u> Have you ever thought of going?</p>
<p>(For participants who are attending a group): What prompted you to go to a support group? <u>Follow-up question:</u> Please describe what, in your case, helped you to decide to attend a group? <u>Follow-up question:</u> In what ways are the group helping you?</p>
<p>(For participants who never attended or attended a group only once): So you have never attended (attended a group only once), please tell me how you made the decision not to attend (not to return after you went the one time). What about groups or that group did not attract you? <u>Follow-up question:</u> So, in your case, even though there was a support group not too far away, what in your way of thinking prevented you from going to a support group? <u>Follow-up question:</u> Are there any other reasons why support groups do not attract you?</p>
<p>Is there anything else about a support group that for you in an ideal world may have been helpful? <u>Follow-up question:</u> In what way could a support group now be a good idea? <u>Follow-up question:</u> Is there anything else about support groups that you may want to add to our discussion?</p>

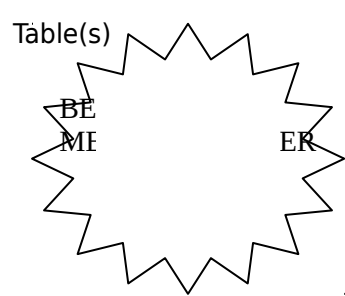
Table 2. Sociodemographic Characteristics (N=54)

Age at diagnosis (yrs)	Avg =71.9 (65-93)
Age at interview (yrs)	Avg = 73.4 (66-94)
Time from diagnosis to interview (mths)	Avg = 19.6 (8.17-44.77)
Setting of where received treatment (may be more than one setting)	NCI-designated comprehensive cancer center 20 private practice 16 community medical center 13 HMO 7 clinic 1
Self-identification of race/ethnicity	White 44 Latina 3 Japanese 3 Chinese 3 African American 1
Born outside the US to parents who were not US-born	9 (average age of arrival in the US = 25.7 yrs)
Marital status	married 24 never married 2 widowed 16 divorced 10 separated 2
Education level (yrs completed)	high school graduate 9 some college 7 college graduate 19 some graduate school 5 graduated from graduate school 14
Licensed to drive with access to automobile	51
Living situation	with spouse 24 alone 23 with friends 1 in family member's home 1 family member(s) live with woman 3 tenants/boarders live with woman 2
Personal contact with children	daily 12 several times a week 5 once a week 12 several times a month 7 less often 13 does not have children 5
Talking with friends	daily 43 several times a week 10 once a week 1
Main support person(s) (may be more than one)	husband 21 daughter 17 other family members 12 friend 15 "no one" or "myself" 2

Table 3. Representations of Assumptions and Perceptions about Professionally-led, In-person Breast Cancer Support Groups

Assumptions about Support Groups	
Properties	Exemplars
Assumptions about what occurs in support groups	<u>Woman who was not attending a group</u> : I knew I didn't need that [a support group] because I don't want to be going into a negative feeling...I didn't want to go down. I needed to go up. ("Simone" #09)
Assumptions about who needs to attend a support group	<p><u>Woman who was not attending a group</u>: I think the support groups are wonderful. And if I didn't have the support that I've had, it's possible that I would have joined one of those. So, for me, it's a personal issue, personal preference. ("Beaumont" #30)</p> <p><u>Woman who was not attending a group</u>: My issues are so small, they don't require, you know, these resources are there for people who are in more trouble than I am. ("Rosario" #29)</p>
Perceived Personal Needs	
Informational needs	<p><u>Woman who was attending a group</u>: (The group) was helpful. Everybody had something to contribute. And if you had questions, most likely one of the other members went through what you're questioning or had an answer or said, "Try this oil on your skin." So, that was very helpful. ("Pakki" #21)</p> <p><u>Woman who was not attending a group</u>: It would be so much easier for you to go to this class and have all your questions answered because you have a lot of questions afterwards. And lots of times, the doctor doesn't take the time. ("Nilebos" #53)</p>
Importance of moving forward	<u>Woman who was not attending a group</u> : I'm trying to think of myself as normal and well and not a cancer patient. Dr. (oncologist) told me, he said, "Take your pill and forget about cancer." That's what he told me, "Live your life and forget about cancer." So, I'm doing my best to do that. And to go to one of those support groups would not be. I'd be remembering cancer if I did that. ("Nicey" #17)
Needing a connection (with another cancer survivor)	<u>Woman who was attending a group</u> : We say our name, when we were diagnosed, when we had surgery, and did we have a lumpectomy, did we have a mastectomy [etc]... So, each woman says those things. So, if someone's new, they can say, "Oh. I've been diagnosed that I'm going to need a lumpectomy. (name of participant) over there has had that. Perhaps I want to ask her a question...someone that was diagnosed with something quite similar to my situation, and ... it was very helpful when she came over. She just, after the class, came over and spoke with me about it...And I think it helped calm her that I'm now (number) amount of months

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