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Medical Advocacy Among African American Women Diagnosed with Breast Cancer: From Recipient to Resource

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Abstract

Purpose—Medical advocacy at multiple levels (self, community/interpersonal, national/public health interest) may be helpful to address the disproportionate burden of breast cancer African American women encounter. Little however is known about the interplay of medical advocacy at different levels.

Methods—We analyzed qualitative data from two studies focused on the psychosocial experiences of breast cancer among 38 African American women living in Western Washington State.

Results—Emergent themes suggested that survivors received community/interpersonal advocacy from different members of social networks in the form of social support (appraisal, emotional, informational, instrumental). Survivors indicated that receiving this advocacy was associated with greater self advocacy in terms of their own care experiences as well as greater community/interpersonal advocacy on their part as resources to other women diagnosed with breast cancer, their family, friends, and larger communities.

Conclusion—Our findings suggest that community/interpersonal advocacy, including providing different types of support, may lead to improved self advocacy as well as health-protective impacts for the networks in which survivors are embedded. Future quantitative research is warranted to support these findings and assess how this interplay is associated with improved outcomes among this marginalized and resilient population.

Keywords

breast cancer disparities; African American; cancer survivor; medical advocacy

Introduction

African American women have higher mortality rates from breast cancer than non-Latino White American women, despite having lower incidence [1,2]. Inequities are conceptualized to result from intrapersonal (e.g., biological factors, mistrust), community/interpersonal (e.g., clinical management, provider bias), and societal factors (e.g., access to high quality care) [3-11]. Given multiple levels contribute to inequities, multilevel solutions may be optimal [12,13]. Ashing and colleagues [14] provide one such framework through the concept of medical advocacy (see Figure 1). Medical advocacy is defined as “focused actions and work of supporters from various walks of life, including cancer survivors and their loved ones, civil society organizations, clinicians, and researchers”[14]. Below we define each level of advocacy.

Self advocacy has been conceptualized as the efforts of survivors to engage their own health experiences and overlaps with constructs such as healthcare-related self-efficacy and proactive postures [15-17]. Self-advocacy has been associated with improved cancer-related care outcomes among African American patients [17-21], potentially due to increased awareness of and responses to intrapersonal, interpersonal and systemic factors affecting them specifically (e.g., own distrust; discriminatory experiences with their providers), as conceptualized by social cognitive theories [22]. *Community/interpersonal advocacy* has been conceptualized as the efforts of individuals and organizations to optimize cancer care experiences of specific patients with whom they are connected and overlaps with skill building, self-management, and navigation strategies [14,23]. For example, healthcare professionals, family, and friends may provide different forms of social support, including “emotional (love, concern, understanding, reassurance, encouragement), instrumental (aid, assistance), informational (advice, problem-solving information), and appraisal (approval)” [24]. There is a substantial body of literature, begun and led by experts such as Cohen, House, Thoits, and Berkman, concerning these different types of social support and their relationships to healthcare, mental health, and physical health outcomes among breast cancer patients [24,25]. In addition to informal interactions, there have been successful examples regarding community organizations who support African American women diagnosed with breast cancer, including the Cierra Sisters, Witness Project, Sisters Network, Black Women's Health Imperative, African American Breast Cancer Alliance, African American Breast Cancer Coalition, Reach to Recovery, Metropolitan Chicago Breast Cancer Taskforce and the Harold P Freeman Patient Navigation Institute [14]. Conceptually, this type of community/interpersonal advocacy functions, in part, through decreasing distrust and increasing self advocacy in patients via actively working on intrapersonal factors associated with one's role as an advocate (e.g., biases, role in power dynamics) and facilitating health protective interpersonal factors (e.g., building trust; providing information; demonstrating technical expertise; sharing decisional control) [16,20], as noted within Cox's Interaction Model of Client Health Behaviors [26]. Other forms of community/interpersonal advocacy

include interactions between other stakeholders, including healthcare professionals, family, and friends (e.g., patient navigation; care coordination) [14]. *National/public health interest advocacy* has been conceptualized as the efforts of individuals and organizations, including those described above, to address inequities some populations face [1,2,5]. The current study represents such a scenario, with multiple author/advocates involved in population health narratives. This active interface with policymakers and researchers can include affecting policy development and participating in community engaged research. National/public health interest advocacy can be understood as a useful strategy targeted toward change at the population level. For example, advocates can serve as catalysts for needed research and policy efforts that recognize and address bias embedded in medical systems and reactive distrust at community levels [14, 27-29].

Notably, survivors can participate in all three levels of medical advocacy: they can decide to 1) advocate for themselves, 2) participate in peer navigation and support of others, and 3) become patient advocates in research and policy-related projects [30-35]. What is less understood is the interplay between different levels of advocacy. While there is extensive research concerning how social support and other forms of community/interpersonal advocacy result in improved patient outcomes [24], less is known about how they pertain to patients' self advocacy. To date, one study has examined this gap in the literature among African Americans and their findings suggested complex patterns between support and patients' self advocacy [21]. Little is also known about if and how promoting self advocacy may result in an increased interest in other levels of advocacy for survivors. One study to date has explored how a sample of African American women diagnosed with breast cancer perceive themselves as advocates for their communities across different stages of cancer treatment [34]. This study did not explore if and how previous experiences as a recipient contributed to future opportunities as a resource.

Current Project

The current project addresses these gaps in the literature with regard to the interplay of medical advocacy among a sample of African American women diagnosed with breast cancer. This work begins to assess how being a recipient of advocacy might have not only on patients, but also the networks in which they are embedded, through augmenting survivors' decisions to engage in all three forms of medical advocacy. Our efforts provide a platform for future research to enumerate if and how these different levels intersect.

Methods

Procedures

The current project combines findings from two studies ([BLINDED FOR REVIEW – Study 1 and Study 2]) focusing on the breast cancer diagnosis and treatment experiences of African American women in Western Washington. All methods and materials were approved by Institutional Review Boards. Between February and May 2013, African American women throughout the Puget Sound area were recruited through paper flyers distributed by community advocates, community-based organizations, and faith-based organizations, and the local National Breast and Cervical Cancer Early Detection Program grantee in King

County. Eligibility criteria were: 1) self-identification as being African American, Black, and/or of African descent; 2) age of 18 years or older; and 3) a definitive diagnosis of invasive breast cancer. A sample question for interviews and focus groups was “What could have been done by the doctor, the nurse, your partner, your family, or your friends, to make your treatment go more smoothly?” Each audio-recorded interview lasted 60-90 minutes. Participants received \$25-40 incentives.

Qualitative data analysis

The study team's approach was derived from multi-faceted content analysis approaches [36,37] and has been successfully employed by the team in the past (BLINDED FOR REVIEW). Two authors (KWR, RMC) ensured verbatim, high-quality transcription of audio-recordings and uploaded files into ATLAS.ti version 7 (Berlin, Germany). Two other authors (YM, THC) independently read each transcript. The team used deductive and inductive analysis approaches, in which themes were explored that had been previously identified from extant literature and new themes were identified from raw interview data. Coders met regularly to review codes and coding strategies and to maintain inter-rater reliability. The coders clustered similar concepts together into categories representative of each emergent theme and discussed preliminary findings with the study team. When there was a disagreement, coders discussed perspectives until a consensus was reached and then texts were re-coded to ensure consistency.

Results

Descriptive information for the thirty-eight participants is provided in Table 1. To understand participants in the context of broader populations, we also offer all available relevant data for Behavioral Risk Factor Surveillance System Survey (BRFSS) [38] and Surveillance, Epidemiology, and End Results (SEER) [39] participants within Washington State who identify as African American, aged 18 years and older, and female. In relation to two objectives of this project, emergent themes were grouped as: 1) recipients of community/interpersonal advocacy; and 2) community/interpersonal advocacy resources. We note that, while our work is focused on different levels of medical advocacy, participants also noted challenging experiences with healthcare professionals, family and friends, including experiencing non-empathic communication, lack of informational support, and microaggressions.

Recipients of community/interpersonal advocacy

The majority of participants declared different types of community/interpersonal advocacy enabled their self advocacy (Table 2). This was often framed within the context of social support provisioned by healthcare professionals, family, and friends to respondents.

Family and friends were perceived to provide four types of support that encouraged self advocacy (Table 2). Notably, emotional support appeared to be intertwined with appraisal, informational, and instrumental support, as exemplified by representative quotes below. First, family and friends provided *appraisal support* through emphasizing women's information-seeking abilities and the need to use these skills to confront problems associated

with breast cancer diagnoses. Study 2 Respondent #9 reported, “My sisters encouraged me, saying, you need to seek a second opinion.” Study 1 Respondent #4 laughingly enthused, “My friends teased me about how I didn’t...accept it...I was going all the time...I can talk to people...talk and interchange different strategies.” Family and friends also offered *informational support* through identifying resources that could help women throughout diagnostic and treatment periods. Study 1 Respondent #14 noted, “My friends...I was trying to make a decision between a mastectomy and lumpectomy. Someone pointed me to the [community patient navigation organization]...which helped...[having] all of the suggestions and taking someone with you to appointments to take notes.” In addition, those with personal cancer experiences offered informational support in terms of what to anticipate, as exemplified by Study 2 Respondent #7, “Mostly support came from my group of friends...people just calmed me and shared their stories to help me make my decision.” Similarly, Study 1 Respondent #18 noted, “Cancer...when you say that word to me, I see the strength of my sister Gwen. She’s 12 years free now...she taught me how to walk through those shoes.” *Instrumental support* manifested often in terms of family and friends attending appointments and supporting women’s efforts to self-advocate during visits. Study 2 Respondent #3 described a range of supports: “I had my cousin for support and he went with me to all my meetings...also my sisters and some of my friends... I learned research and look and listen.” Such support often enabled not only self advocacy but also was perceived to affect care through direct interface between family, friends, and healthcare professionals, as indicated by Study 2

Respondent #1:

Sisters [called] to ask my behalf... ‘Don’t you have any more resources to help her [respondent] out?’ They [clinical staff] said, ‘Well, we can’t share any information with you.’ But then I did see a change in their demeanor. They have been more forthcoming. When they see that you have people supporting you and backing you up and that you’re not out there by yourself, it seems like that gets them motivated to start doing something.

Healthcare professionals’ support was largely perceived as informational in nature and particularly effective when professionals offered information in the context of women’s preferences and emphasized women leading roles in decisions about treatment and treatment staff. For example, Study 2 Respondent #5 warmly reported, “The cancer clinic we chose had a team of doctors looking at my situation. We had a meeting and met each of those team members. They made recommendations and allowed us time to get a second opinion.” Study Respondent #17 described, “They didn’t rush me. They took their time and answered the questions that I had thoroughly...I appreciated that they understood what I was going through...and made sure I understood everything.” Healthcare professionals also encouraged women to provide input and give as much information as possible, as exemplified by Study 2 Respondent #2:

My doctor got on my case, very nicely, very professionally, because I’d be going through all these differ things but I never call...my philosophy is, ‘Oh, I can ride this out. It’s not that bad.’ When I finally went into his office...he asked me how things were going and I just kind of broke down and told him how things are going.

He said, ‘Well why haven't you been telling me this?’ I said, ‘Because I don't want you to think I'm a hypochondriac.’ He told me, ‘If you don't tell me, how am I to know? How can I help you? You're patient.’

Community/interpersonal advocacy resources

While discussing these experiences, respondents indicated their inspiration to “give back” and support women from their communities in the context of breast cancer (Table 2). This was largely in the context of community/interpersonal advocacy. Their role in helping other women diagnosed with breast cancer was largely framed as being emotionally supportive, based on their previous experiences and perceived benefits of reciprocity. When asked what would improve her situation as a cancer survivor, Study 1 Respondent #11 noted, “My thing is encouragement. Encourage others that they don't have to be afraid and they can go on with their lives.” Similarly these respondents enthused:

I need to go help support this sister who has cancer...we become one after what we have walked into or voyaged into...Because of this, I'm going to be a support to anyone who needs me. It doesn't matter who you are. – Study 2 Respondent #13

That's part of me being a cancer survivor that I can give back to another cancer survivor to show that, yes it's not going to be easy, but you can make it...at least you can give them a part of the hope. – Study 1 Respondent #6

Similarly, providing informational support seemed to correspond closely with the informational support received, as exemplified by Study 1 Respondent #16, “I think I've gained information. I've gone through what I've gone through and now I need to share it with someone else.” Indeed, women largely noted specific resources based on their own experiences and resources they had used, as indicated by these respondents:

[Cancer center] also had some information like the type of cancer and how the cancer should have been treated and handled. That information I received was helpful because when my sister was diagnosed I was able to share that information with my sister. – Study 1 Respondent #7

Dr. [Oncologist] referred me to the [Community patient navigation organization]. So, when my sister got diagnosed, I called [Founder of community patient navigation organization]...and told her about it. [Founder of community patient navigation organization] called my sister in Florida, prayed with her, and got her through it. – Study 2 Respondent #15

Women also offered appraisal and instrumental support closely related to their personal experiences. For example, Study 2 Respondent #14 reported, “They [Hospital staff] offer you blankets and that's when I got the idea that I should start making quilts and blankets for the ladies in treatment. Those treatment rooms are so cold.” Similarly, Study 1 Respondent #5 indicated:

I had seen her [Oncologist] a few times prior to discuss the biopsy findings and all that...I had a lot of questions. What should I do after this? Do I need chemotherapy? Radiation?...so then I have a friend that went...through radiation and she had a lumpectomy...and she's not followed which concerns me. I tell her

[breast cancer patient friend] she doesn't have to stick with the medication... 'If it's not working for you, let the Doctor know. I'm the one that's telling her...you need to follow through.

Although largely framed in the context of other women diagnosed with breast cancer, participants also described their efforts in prevention and early detection within their communities. They noted the importance of sharing their stories and their ongoing conversations to promote awareness and knowledge of breast cancer, as described by Study 1 Respondent #15, "I try to be an advocate to women about get your mammogram. I've told my daughters now with family history...that they need to be diligent about getting their mammograms also. Don't delay it. Prevention is the key." Similarly, Study 2 Respondent #14 reported:

I took pictures of it [cancer]...I had my friends take pictures with my camera phone. I burnt it to a CD so I said this is part of my history that I want to share and let everybody see this. Don't let this happen to you. Advocate for yourself.

Discussion

Interventions that promote medical advocacy among African American women diagnosed with breast cancer may have widespread implications for women themselves, other patients, and their broader social networks [14]. The current project offers preliminary data that suggest family, friends, and providers may facilitate self advocacy for some women and consequently influence these women's engagement to become advocates. Overall, this work provides insight into some potential mechanisms underlying ongoing successful programs invested in community/interpersonal advocacy and, potentially, national/public health advocacy [14].

Our work aligns with the large body of research regarding social support as a protective factor along the cancer continuum [24]. Simultaneously, our findings highlight unintended health-protective consequences: our participants' experiences in supportive environments resulted in a strong desire to "give back" and offer support. Such work clarifies findings from other research, wherein African American women described the process as 'cyclical' between their personal cancer experiences and subsequent roles within their communities [34]. Further, our work indicates that the type of support women receive during their journey may directly pertain to their perceived roles as resources. For example, women often reported receiving informational and emotional support from family and friends who had personal experiences with cancer; these women also described providing similar support to women diagnosed with breast cancer. Such work aligns with the increasingly multi-faceted role in which survivors engage in interpersonal and national/public health interest advocacy outside of their own personal cancer care experiences [14,27,28]. It further highlights opportunities wherein medical and nonmedical sources of advocacy may enable powerful agents of population-level change through supporting African American patients during their cancer care experience.

Notably, our study did not result in data to describe the relationship between self and national/public health advocacy. It is important to note that while such a relationship may

have existed, it might not have been captured due to the guides designed for other foci. The lack of emergent data relative to community/interpersonal advocacy may be due to a few reasons, which need to be studied in the future. First, the perceived impact of national/public health advocacy on self advocacy may not be as visible or salient for patients, especially those not affiliated with research and policy. Second, national/public health advocacy may be a ‘last step’, wherein patients first begin with self advocacy, proceed to their local communities’, and finally proceed to engage the population health narrative.

Limitations

The current project has several limitations. The current study focused on medical advocacy, but there are other determinants of breast cancer disparities [5, 7, 8]. Relatedly, while our work was focused on positive social experiences, there is evidence to suggest that negative social experiences are more predictive of patient-centered outcomes [40]. This study was focused on the experiences of African American women. Nonetheless, themes and relationships identified in this work may exist for other racial/ethnic groups and should be explored through multiethnic samples. We conducted a secondary analysis of two projects that were not designed to measure the multiple levels of medical advocacy. Given that, as described above, we may not have captured all relevant perspectives and experiences related to all levels of advocacy and are not able to compare which types of support were most helpful (e.g., information from who/when/how). Our two studies used convenience-based sampling by community advocates. This may have resulted in a substantial number of women being recruited with high amounts of experiences across different levels of medical advocacy. Although we provided information from SEER and BRFSS respondents, neither database had both detailed socioeconomic and cancer-related information at the individual level. Given this, we were unable to assess fully how our samples compared with local populations of African American breast cancer patients. Our participants appeared to exhibit relatively positive prognoses and were relatively socioeconomically advantaged. Their perspectives may not align with perspectives of African American women diagnosed at later stages or who are socioeconomically disadvantaged. Our findings may not be generalizable. Indeed, it is worthwhile to emphasize that African American culture is not monolithic and the need to explore distinct perspectives within this population through techniques such as maximum variation sampling [36,41]. While these studies were very similar in nature, there may have been differences that may have biased results. The majority of our participants had undergone diagnosis and treatment five years before the point of this project, which may have resulted in confirmation and recall bias. Our study was not designed to enumerate associations, but rather to qualify *if* and *how* community/interpersonal advocacy intended to promote self advocacy may also result in patients transforming into advocates for their family, friends, and larger communities [42]. Thus providing percentages would lead to misleading counting for ours (e.g., 50% of 38 participants is 19) [43].

Implications

Despite these limitations, the current project has implications for next steps. Our study identified associations that should be quantified in future population-based research to confirm the generalizability of our findings as well as to expand on them. For example, we should quantify how different types of community/interpersonal advocacy are associated

with survivors' engagement across levels of advocacy and compare the relative magnitude of associations. Such findings may provide insight into which types and who should be provisioning such community/interpersonal advocacy (e.g., provider versus family/friends). Finally, our and others' work [14,24,27,28,30-35] suggests that programs that enable survivors to discuss their personal narratives [44,45] may be helpful to improve survivors' well-being and outcomes as well as may result in community wide impact through greater recruitment and retention of volunteers with a history of breast cancer.

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Figure 1.
Conceptual framework, informed by Ashing et al., 2014[14].

Table 1

Sample characteristics

	Study 1 (n = 21)		Study 2 (n = 17)		SEER 1995-2012 Sample ¹ (n= 1573)		BRFSS 2013 Sample ² (n = 109)	
	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)
Age in 2013	55.7 (9.6)		59.9 (11.2)		64.9 (15.0)		50.8 (16.9)	
Age at diagnosis	48.4 (9.5)		53.6 (12.2)		56.7 (14.6)		**	
Years since diagnosis/treatment in 2013	8.9 (5.9)		5.8 (3.4)		8.3 (5.2)		**	
Number of treatments	2.4 (0.8)		1.9 (1.0)		**		**	
Education		n (%)		n (%)		n (%)		n (%)
<12 years of education or high school degree	1 (5)	1 (6)		*				7 (6)
12 years of education or high school degree	17 (81)	16 (94)		*				102 (94)
Household income								
<\$35,000	9 (43)	9 (53)		*				40 (37)
\$35,000	9 (43)	8 (47)		*				54 (50)
Insurance status								
No insurance	0 (0)	0 (0)						13 (12)
Any type of insurance	18 (86)	17 (100)						96 (88)
Late stage diagnosis								
0/I/II	14 (64)	12 (71)						**
III/IV	4 (22)	4 (24)						**
Procedures								
Surgery	18 (86)	14 (82)						**
Radiation	13 (62)	9 (53)						**
Chemotherapy	12 (57)	10 (59)						**

¹ SEER 1995-2012 female participants lived within the study state and met all criteria from both studies (self-identification as being African American, Black, and/or of African descent; age of 18 years or older; a definitive diagnosis of invasive breast cancer).

² BRFSS 2013 female participants lived within the study state, self-identified African American, Black, and/or of African descent; and were 18 years or older. Only 6% of the sample (n = 7) indicated they had obtained cancer diagnosis within their lifetime that was not skin cancer.

* Estimates are only available at the county-level and are thus not provided currently.

*Data not available.

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Table 2
Participants' reports of receiving and providing different types of community/interpersonal advocacy.

	Experiencing supportive environments when undergoing diagnosis and treatment	Becoming a supportive environment for other women	
	Family/friends	Healthcare Professionals	With breast cancer
Without breast cancer			
Appraisal			
Emotional			
Informational			
Instrumental			