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Post-treatment problems of African American breast cancer survivors

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Abstract

Purpose—African American breast cancer survivors (AABCS) have a lower survival rate across all disease stages (79 %) compared with White survivors (92 %) and often have more aggressive forms of breast cancer requiring multimodality treatment, so they could experience a larger burden of post-treatment quality of life (QOL) problems. This paper reports a comprehensive assessment of the number, severity, and domains of problems faced by AABCS within 5 years after treatment completion and identifies subgroups at risk for these problems.

Methods—A population-based random sample was obtained from the Pennsylvania Cancer Registry of African American females over 18 years of age who completed primary treatment for breast cancer in the past 5 years. A mailed survey was used to document survivorship problems.

Results—Two hundred ninety-seven AABCS completed the survey. The median number of survivor problems reported was 15. Exploratory factor analysis of the problem scale revealed four domains: emotional problems, physical problems, lack of resources, and sexuality problems. Across problem domains, younger age, more comorbid conditions, and greater medical mistrust were risk factors for more severe problems.

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Conclusions—The results demonstrated that AABCS experienced significant problem burden in the early years after diagnosis and treatment. In addition to emotional and physical problem domains that were documented in previous research, two problem domains unique to AABCS included lack of resources and sexuality concerns. At risk groups should be targeted for intervention. The study results reported in this manuscript will inform future research to address problems of AABCS as they make the transition from cancer patient to cancer survivor.

Keywords

Cancer survivor; Disparities; Breast cancer; African American; Quality of life; Medical mistrust

Introduction

Nearly 14.5 million Americans are living with a history of cancer, about three million of them are breast cancer survivors [1]. African Americans have the shortest survival after cancer of any racial or ethnic group in the U.S. [2]. Among breast cancer survivors, the 5-year survival rate across all disease stages is 79 % for African American versus 92 % for White females [1]. Lower survival for African Americans has been attributed to later stage of disease at diagnosis, delays in the initiation of treatment, and fewer opportunities for definitive treatment [3]. There is also evidence of more aggressive tumor characteristics in African Americans. From a quality of life (QOL) perspective, women with aggressive disease are more likely to receive multimodality treatment with greater risk for late and long-term effects. Together, these factors suggest that African American breast cancer survivors (AABCS) may be living with a large burden of physical and psychosocial problems after primary treatment completion. The goal of this paper is to describe a comprehensive assessment of the number, severity, and domains of current problems of AABCS after completion of treatment and identify subgroups at risk for these survivor problems.

Although a body of research has documented quality of life for AABCS, much research has compared African American with White survivors or healthy controls [4–7]. However, knowing the relative differences between racial groups does not provide a clear understanding of the scope of problems experienced within a specific group or the diversity within that group. Few studies have examined differences among AABCS, which our study aimed to accomplish. Another issue is that some QOL research has focused on specific problems such as physical functioning [8], upper extremity disability [9], obesity [10], social disconnection [11], or follow-up care [12]. While this approach has yielded valuable information, it does not provide a comprehensive view of the survivor experience of AABCS. Mollica [13] has called for the use of a multidomain approach to document QOL problems to achieve a deeper understanding of the survivor experience.

The current study of AABCS builds on past research documenting survivor problems in a mixed group of 752 adult cancer survivors (9 % African American, 60 % female, 14 % with breast cancer) during the first year after diagnosis. The previous study used the Cancer Problems in Living Scale which documents a wide range of common and distressing survivor problems [14]. Fear of recurrence was the most commonly reported problem

(68 %); other prominent concerns included fatigue (67 %), sleep problems (48 %), and difficulties with sexual intercourse (41 %). Women reported more problems than men; non-Whites had more problems than Whites. A limitation was the mixed group of cancer diagnoses that did not adequately describe the experience of subgroups such as AABCS.

A factor analysis of 5155 completed surveys using the Cancer Problems in Living scale examined the underlying dimensions of the scale. [15] Results showed four domains of cancer problems: physical, emotional, economic, and fear of recurrence. These domains indicated the classes of problems that were of greatest concern to a mixed group of cancer survivors. However, the sample was only 8 % African American and 25 % breast cancer; again, the low representation of AABCS was a limitation in understanding their specific problems.

Past research has shown that QOL differs by a variety of demographic and clinical factors including age and comorbid conditions. With regard to age, a review of 28 studies of younger survivors (younger than age 51) identified menopause and infertility as key issues [16]. However, the racial composition of the studies was not described. Young AABCS ($n = 33$) identified concerns about employment, romantic relationships, fertility, and sexual dysfunction [17]. Younger AABCS ($n = 82$) also reported high levels of anxiety and depression [18]. Concurrent comorbid chronic health conditions have been shown to heighten cancer survivor burden and increase risk for poor health outcomes [19–23]. Medical mistrust, the tendency to distrust the dominant medical system and personnel [24], has been tied to prior discrimination and poor health outcomes in non-cancer populations [25–27].

The current study adapted the Cancer Problems in Living Scale to reflect the experiences of AABCS. Our previous research included three preliminary focus groups of 22 AABCS to evaluate the comprehensiveness of the Cancer Problems in Living scale to document survivor problems, and assess the extent to which the scale should be adapted to fit the needs of AABCS. Focus group participants suggested the addition of 20 new problems to the scale. The issue of medical mistrust also came up spontaneously in all three groups. Participants perceived that being Black meant that you were treated differently in medical situations, received inferior information, and needed to advocate for ones' self. This reinforced our interest in exploring medical mistrust as a predictor of problems experienced by AABCS.

Two hypotheses were examined in this research: (1) AABCS will identify problems and problem domains (physical, emotional, and financial problems, and fear of recurrence) described previously in a cancer survivor group with mixed diagnoses [15]; and (2) demographic, medical, and cultural (medical mistrust) factors will be associated with problem severity.

Design and methods

A survey of current problems reported by AABCS was conducted in collaboration with a Community Advisory Board, approved by the Institutional Review Board at Thomas Jefferson University, and participants signed an informed consent. A random sample of 3498

AABCS was obtained from the Pennsylvania Cancer Registry, a population-based registry and member of the North American Association of Central Cancer Registries and the National Cancer Institute SEER program. African American females treated for breast cancer who were age 18 or older at the time of diagnosis and were diagnosed with local or regional disease were eligible to be included. Registry information was not available for research until 3 years after diagnosis. Because of the lag time, this study was conducted from 2009 to 2011 using contact information for women diagnosed between 2006 and 2008. Women who were 3 to 5 years post-diagnosis were surveyed.

Procedures

The survey employed several best practices from past research to maximize accrual of AABCS [28, 29] including pre-testing and modifying the survey based on feedback from focus groups and our Community Advisory Board. The research coordinator who followed up with respondents was African American. Survey procedures were based on principles of Dillman [30] allowing for five contacts with each participant. The first contact was a personalized ethnically tailored letter to alert survivors to expect the survey using an approach that included pictures of African American women and an appeal to contribute to a better understanding of their survivor experience [31]. The second contact included a similarly formatted cover letter with consent, survey, and \$2.00 cash gift. A postcard was sent 2 weeks later as a thank you to those who completed the survey and reminder to those who had not completed it (third contact). Two weeks later, a replacement survey was sent to individuals who did not respond (fourth contact). Two weeks later, individuals who did not respond were contacted by telephone; in the absence of a phone number, a final letter and survey was sent (fifth contact).

Measures

Survivor problems were measured with the adapted version of the Cancer Problems in Living Scale. The original scale of 31 items [14] was expanded to 51 items for this research based on focus group recommendations (items shown in Table 2). Ratings for each item ranged from 0 (not a problem) to 2 (a severe problem). The medical mistrust scale, [24] measuring suspicion of health care professionals and medical care based on racial differences, is a 12-item Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). A sample item is "The medical complaints of my ethnic group are not taken seriously."

Demographic, medical, and socio-economic covariates obtained from the participant survey included education, marital status, employment status, comorbid conditions, treatment completion, and type of cancer therapies.

Statistical analysis

The number of cancer problems was calculated as a count of items that were scored >0. A total severity score was calculated as the sum of the severity of the 51 items. For comparison with the past research which used a shorter version of the scale, the number of problems and total severity were calculated for the original 31-item scale [15]. Exploratory factor analysis was used to investigate the latent structure of the scale in this sample. Factor loadings were

considered salient if they were ≥ 0.4 . Three-, four-, and five-factor models were compared to determine the optimal number of domains with theoretical relevance. Factor scores of problem severity were computed as the unweighted sum of responses to survey items salient to each factor. Multiple linear regression analysis was used to test the association between each factor and the covariates. Covariates were chosen a priori and were retained in the model regardless of significance. Because the type of treatment is thought to have a major influence on survivor morbidity, this variable was analyzed in two different ways: as a sum of the number of treatment modalities and as treatment with or without chemotherapy. Analyses were performed in SAS 9.4 (SAS Institute Inc., Cary, NC).

Results

From the list of 3498 names provided by the cancer registry, surveys were mailed to 1056 AABCS. Two hundred ninety-seven surveys were completed representing a completion rate of 28 % of all mailed surveys, lower than we anticipated (Fig. 1). Non-responders to the mailed survey included incorrect addresses (11 %) and unreturned mailings (48 %). Considering only the group for whom we had correct addresses who responded to the mailings ($n = 430$), survey completers comprised 69 % of this group; refusals comprised only 8 % of total mailings or 19 % of responders. Comparing zip code and age of responders with non-responders, the two largest cities (Philadelphia and Pittsburgh) had fewer survey completers than the rest of PA, 26 % versus 30 % with an equal percent of refusals. The lowest response rate was among women age 31–40 (19 %) and highest in the 61–70 age group (35 %).

The mean age of participants was 57.5 years ($SD = 11.5$); 37 % worked full- or part-time (Table 1). Income data, coded by category of earnings, showed that 31 % had annual incomes of \$25–50,000 with 13.5 % declining to answer. Most respondents (99 %) received surgery, (52 %) chemotherapy, (77 %) radiotherapy, and (40 %) hormone therapy. Most (95 %) reported at least one health condition such as hypertension (68 %) or diabetes (25 %); 22 % reported five or more comorbid conditions. With regard to medical mistrust, the scale mean was 28.7 ($SD = 7.4$); 25 % endorsed the belief that people of their ethnic group did not get the same medical care as members of other ethnic groups.

The top five problems reported by this sample were physical symptoms including aches and pains (74 %), muscle stiffness (71 %), fatigue (63 %), sleep difficulty (62 %), and hot flashes (61 %). The most frequently reported problem in the previous mixed cancer sample [14], fear of recurrence (68.1 %), was less commonly endorsed by this sample (58.6 %); likewise, discomfort with physical appearance, endorsed by 39.6 % of the previous sample, was endorsed by 53.9 % of this sample.

Using the 51-item scale, the median number of survivor problems reported by this sample was 15 (IQR = 9, 25), the mean number of problems was 17.5 ($SD = 11.6$), and total problem severity score was 21.6 ($SD = 17.5$). Using the original 31-item scale, the mean number of problems in this sample (9.6) and total severity score (11.8, $SD = 11.3$) were comparable to the mixed group of survivors [14] (mean = 9.4; total severity score = 11.4, $SD = 10$).

Factor analysis

Of the three-, four-, and five-factor models with promax rotation that were considered, the five-factor model had the best fit (AIC for the three-, four-, and five-factor models were 1303.1, 964.4, and 657.6, respectively). However, the four-factor solution was judged to have the best fit conceptually (Table 2). In the four-factor model, the emotional domain (15 items, Cronbach's alpha = 0.94) included the same items as the previous research but also subsumed the fear of recurrence items that were a separate domain in that research [15]. The physical domain (11 items, Cronbach's alpha = 0.88) was congruent with the previous research. Two new domains of survivor problems were identified for AABCS: lack of resources (10 items, Cronbach's alpha = 0.88) including both economic and informational resource problems and sexuality problems (4 items, Cronbach's alpha = 0.80). Eleven items did not meet the criterion for salience (factor loading ≥ 0.4); these were excluded from the multivariable analysis. The mean factor scores were the following: emotional problems, 6.5 (SD 6.7, observed range 0–30); physical problems, 7.5 (SD 4.9, range 0–22); lack of resources, 2.6 (SD 3.8, range 0–20); and sexuality problems, 1.7 (SD 2.0, range 0–8).

Multivariable analysis

Younger age, being unmarried, having less education, not working, having more comorbid conditions, and a higher level of medical mistrust were predictive of more severe *emotional problems* (Table 3). For example, women under age 50 reported emotional problem severity scores that were three times higher than women over 70 (data not shown). More severe *physical problem* scores were predicted by younger age, unemployment, more treatment modalities, three or more comorbid conditions, and higher levels of medical mistrust. In this case, having three or more comorbid conditions was associated with physical problem severity scores that were twice as high as having no comorbidities. *Resource problem* severity scores were highest for younger, unmarried, unemployed women with more comorbidities and higher medical mistrust. Women with medical mistrust scores in the highest quartile reported resource problem severity scores that were eight times higher than those in the lowest quartile. *Sexual problems* were greater for younger, unmarried women with more comorbidities and higher medical mistrust. Again, medical mistrust scores in the highest quartile were associated with sexual problem scores that were three times higher than the lowest quartile. Looking across problem domains, younger age, more comorbid conditions, and higher level of medical mistrust were consistently associated with more severe problems across all four problem domains. Examining treatment with or without chemotherapy as the treatment variable, chemotherapy was a significant predictor of physical and sexual problems (both $p < .001$) but not of emotional or resource problems (data not shown).

Discussion

This research demonstrated that AABCS experienced significant problem burden in the early years after cancer diagnosis and treatment. The number and mean severity of problems were comparable to a previously studied mixed group of cancer survivors [14]; however, the survivor problem domains we identified were only partially congruent with that research [15]. This sample was more likely to report sexuality concerns and lack of economic and

informational resources than the mixed group of cancer survivors [15]. The presence of two problem domains that differed from mostly White survivors with mixed cancer diagnoses suggests that the concerns of AABCS differ substantively from the broader group of survivors; these differences suggest the need to address different problems in this population [32, 33].

The multivariable analysis revealed that age, comorbid conditions, and medical mistrust were risk factors for more severe problems across the four cancer problem domains, findings congruent with past research. Past research has also shown that younger women are at risk for more distress and difficulty coping than older women, perhaps due to the unique challenges they experience including body image changes, relationship strain, sexual dysfunction, and fertility concerns [16, 34] in addition to their youth and ethnicity [17]. Interventions to improve the QOL of young AABCS must take into consideration this “double jeopardy” of age and ethnicity.

Our findings for the influence of comorbidities as a risk factor for increased problem severity in this sample are in agreement with past research showing an association with poorer QOL [35, 36] and reduced survival [22]. Future research should address modifiable problems such as obesity and inactivity that are associated with comorbid conditions such as diabetes.

The influence of medical mistrust in this sample is consistent with previous research showing that individuals with higher levels of medical mistrust perceived that the information they received was inferior, providers were less forthcoming, and information was sometimes conveyed in an insensitive manner [37, 38]. Acknowledging African American women's experience with racism and discrimination and understanding its influence on perceptions of health and illness are crucial steps for health providers in developing trustworthy relationships with AABCS. Future research should explore strategies to lessen mistrust by including culturally appropriate survivor care, information, and resources in a timely manner [39, 40].

A limitation of this research is the low overall response rate that could have resulted in selection bias. However, our response rate fell within the range of several respected community surveys including the California Health Interview Survey (CHIS) and the Behavioral Risk Factor Surveillance System (BRFSS). A sample of AABCS obtained from CHIS had a 30 % response rate [28]. A mailed survey of African Americans accrued from two tumor registries yielded a completion rate of 35 % of all mailed surveys or 70 % of eligible individuals who responded [29]. Viewed in this light, our results are comparable to other studies that reached out to African Americans. Interestingly, we obtained a higher response rate from women who lived in rural areas than those who lived in urban areas. This has been seen in other statewide surveys [41] and may speak to lower literacy levels in urban populations and difficulties in completing self-administered surveys. Another limitation of this research is the cross-sectional design that did not allow for documentation of changes in the presence or severity of survivor problems over time. Finally, we cannot fully comment on clinical predictors of problem domains for AABCS because limited information was

available from the cancer registry, and survivor self-report is subject to recall and informational deficits.

The results of this study will inform the development of a future educational program addressing the problems identified by AABCS in this research and evaluate its benefit in reducing survivor problems and increasing self-efficacy during the transitional years after completion of breast cancer treatment. Knowing that AABCS have an increased risk of cancer recurrence and often disproportionately suffer from late and lingering long-term effects after treatment completion, there is a need for culturally tailored interventions. While there is growing literature on survivor interventions [42], there is a paucity of intervention research focused on AABCS who may have unique needs for support after treatment. We are working with our Community Advisory Board to develop educational resources and a tailored intervention based on these research findings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Fig. 1. Response rate for mailed survey of African American breast cancer survivors

Table 1
Demographic characteristics (*n* = 297)

	All	
	<i>N</i>	%
All	297 ^a	100.0
Age at diagnosis		
25–49	77	25.9
50–59	87	29.3
60–69	83	27.9
70–89	50	16.8
Ethnicity		
Not Hispanic or Latino	287	96.6
Hispanic or Latino	3	1.0
Race		
Black or African American	286	96.3
More than one	11	3.7
Marital status		
Not married	170	57.2
Married	126	42.4
Education level		
High school or less	99	33.3
Some college or more	196	66.0
Employment status		
Working	111	37.4
Not working	185	62.3
Income		
<\$15,000	53	7.8
\$15,001–25,000	54	18.2
\$25,001–50,000	93	31.3
\$50,001–100,000+	57	19.2
Declined to answer	40	13.5
Number of comorbid conditions		
0	15	5.1
1	42	14.1
2	48	16.2
3	66	22.2
4	31	10.4
5+	91	21.5
Number of additional therapies		
0 (surgery only)	22	7.4
1	96	32.3

	All	
	N	%
2	114	38.4
3	54	18.2
4	10	3.4

^aVariability of sample size is due to missing data

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Table 2
Four-factor solution with factor loadings after promax rotation

CPILS Item	Factor 1	Factor 2	Factor 3	Factor 4
Feeling less feminine	83 [*]	−26	−4	3
Feeling less attractive	77 [*]	−9	−3	8
Feeling less sexually desirable	70 [*]	−10	−4	24
Feeling emotional vulnerable	62 [*]	27	7	−7
Feeling sad	61 [*]	27	−1	−1
Uncomfortable with changes in my physical appearance	60 [*]	19	−18	6
Feeling angry	60 [*]	9	11	5
Guilt feelings	57 [*]	13	17	−3
Feeling helpless	56 [*]	14	25	−13
Problems communicating with my spouse or partner	56 [*]	−9	−1	28
Feeling isolated	55 [*]	10	21	4
Feeling anxious	55 [*]	27	7	−5
Having difficulty in making long-term plans	48 [*]	30	17	−7
Feeling dependent	48 [*]	25	12	−17
Fears about the future	41 [*]	26	20	−8
Problems with my family/children	32	5	17	21
Difficulty in returning to former roles	32	21	27	7
Aches and pains	−11	85 [*]	−1	−5
Muscles or joint stiffness	−17	85 [*]	−7	2
Fatigue, loss of strength	−2	74 [*]	−10	1
Forgetfulness	−2	58 [*]	2	11
Trouble concentrating	16	55 [*]	4	7
Sleep Difficulties	4	55 [*]	−8	19
Hot flashes	−3	49 [*]	−12	29
Tenderness at surgical site	15	46 [*]	1	8
Major problems with my health	21	45 [*]	10	2
Preoccupation with being ill	37	42 [*]	0	−4
Sweating	5	41 [*]	−4	26
Feeling fearful that my illness will return	26	38	13	−7
Eating difficulties	7	34	8	13
Arm swelling	3	30	10	24
Being concerned about infection and crowds	25	25	19	10
Difficulty in meeting my medical expenses	−23	10	91 [*]	2
No money for cost or co-payment for medical visits	−10	2	86 [*]	−6

CPILS Item	Factor 1	Factor 2	Factor 3	Factor 4
No money for cost or co-payment for medicine	-1	5	79 [*]	3
Difficulty in obtaining adequate insurance	-14	1	77 [*]	8
Unable to get info I need to for myself after treatment	26	-10	54 [*]	0
Unable to get the information I need about cancer	12	-12	53 [*]	2
No regular doctor or medical provider	19	-13	49 [*]	1
Being less able to provide for the financial needs of my family	15	19	48 [*]	4
Being treated as different from others	32	-10	42 [*]	9
Job discrimination	22	-15	41 [*]	12
No transportation to/from medical visits	15	9	35	-11
Difficulty in pursuing the career of my choice	16	4	34	21
Unable to change jobs for fear of losing insurance	26	-13	31	3
Dryness in vagina	-5	6	5	70 [*]
Pain during sexual intercourse	-6	14	3	69 [*]
Being physically unable to have sexual intercourse	10	8	9	65 [*]
Less sexual desire	15	5	-6	59 [*]
Discharge in vagina	5	11	6	32
Being physically unable to have children	12	-1	13	21

All factor loadings were multiplied by 100 for presentation as whole numbers

* Indicates items that loaded on each factor

Table 3
Summary of multivariable linear models of factors: emotional, physical, resource, and sexual problems

	Emotional problems		Physical problems		Resource problems		Sexual problems	
	Difference in factor score (95 % CI)	p value	Difference in factor score (95 % CI)	p value	Difference in factor score (95 % CI)	p value	Difference in factor score (95 % CI)	p value
Age at diagnosis		<0.0001		<0.0001		<0.001		<.0001
Increasing by 1 decade	-2.47 (-3.17, -1.77)		-1.57 (-2.05, -1.09)		-0.76 (-1.18, -0.34)		-0.47 (-0.69, -0.24)	
Marital status		0.047		0.103		0.001		0.029
Not married compared to married	1.41 (0.02, 2.80)		0.80 (-0.16, 1.75)		1.39 (0.55, 2.22)		-0.50 (-0.95, -0.05)	
Education level		0.026		0.096		0.238		0.903
HS or less compared to at least some college	1.76 (0.22, 3.30)		0.90 (-0.16, 1.96)		0.55 (-0.37, 1.48)		0.03 (-0.46, 0.53)	
Employment status		0.040		<0.001		0.004		0.106
Not working compared to working	1.74 (0.08, 3.40)		2.06 (0.92, 3.20)		1.49 (0.49, 2.48)		0.44 (-0.09, 0.97)	
Number of comorbidities		<0.0001		<0.0001		0.007		0.001
Increasing by 1 comorbidity	0.77 (0.42, 1.11)		0.90 (0.66, 1.13)		0.29 (0.08, 0.49)		0.20 (0.09, 0.31)	
Number of cancer therapies		0.999		0.002		0.840		0.085
Increasing by 1 treatment	0.0 (-0.75, 0.75)		0.81 (0.30, 1.33)		0.05 (-0.40, 0.50)		0.21 (-0.03, 0.45)	
Group-based medical mistrust scale		<0.0001		0.007		<0.0001		0.002
Increasing by 1 point	0.22 (0.13, 0.32)		0.09 (0.03, 0.15)		0.14 (0.08, 0.19)		0.05 (0.02, 0.08)	

N = 289 complete cases

CI confidence interval