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RESEARCH

The role of breast cancer-related arm lymphedema in physical functioning and physical activity participation among long-term African American breast cancer survivors

Sarah Nechuta[1] · Wendy Y. Chen[2,3] · Ally Goerge[1] · Deepika Boopathy[1,4] · Maureen Sanderson[5]

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Abstract

Purpose Breast cancer-related arm lymphedema (BCRL) is a common chronic and debilitating condition that involves accumulation of lymphatic fluid in the arm or hand. Limited data are available on BCRL in African American women. Lack of physical activity (PA) and poor physical functioning (PF) are both associated with increased morbidity and mortality among breast cancer survivors. We examined the association of BCRL with PA and PF among African American breast cancer survivors.

Methods 323 African American women who previously participated in a case-only study in three states (TN, GA, SC) completed a survivorship-focused questionnaire (mean: 4.2 years post-diagnosis) in 2015–2016. Validated measures were used to determine BCRL, PF, and PA. Adjusted binary logistic regression models estimated ORs and 95% CIs for the association of BCRL and meeting PA guidelines ($\geq$150 min/week), while multinomial logistic regression was used for PF and PA (minutes/week) categorized based on tertiles.

Results Approximately 32% reported BCRL since diagnosis; 25.4% reported BCRL in the last 12-months. About 26% and 50% reported that BCRL interfered with exercise and ability to do daily activities, respectively. The mean PF among those with BCRL was 51.0(SD:29.0) vs. 68.5(SD:30.1) among those without BCRL. BCRL was associated with lower PF (adjusted-OR for tertile 2: 2.12(95% CI:1.03–4.36) and adjusted-OR for tertile 1: 2.93(95% CI:1.44–5.96)).

Conclusions BCRL was associated with lower PF among long-term African American breast cancer survivors. Continued monitoring by health care professionals and increased education and behavioral interventions to support PA and improved PF among survivors living with BCRL are warranted.

Keywords Breast cancer · Lymphedema · Cancer survivorship · Minority health · African American · Physical health

Abbreviations

SF-36	36-Item Short Form Survey
AABL	African American Breast Cancer Long-Term Survivorship Study
AJCC	American Joint Cancer Committee
BMI	Body mass index
ER	Estrogen receptor
IRB	Institutional Review Board
PA	Physical activity
PF	Physical functioning
PR	Progesterone receptor
QOL	Quality of life
STSBHS	Southern Tri-State Breast Health Study
BCRL	Breast cancer-related arm lymphedema
REDCap	Research Electronic Data Capture
OR	Odds ratio
CI	Confidence Intervals

✉ Sarah Nechuta
nechutas@gvsu.edu

[1] School of Interdisciplinary Health, College of Health Professions, Grand Valley State University, 500 Lafayette Street, Grand Rapids, MI, USA

[2] Channing Division of Network Medicine, Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, USA

[3] Deptartment of Medical Oncology, Dana Farber Cancer Institute, Boston, MA, USA

[4] Department of Public Health Sciences, Henry Ford Health, Detroit, MI, USA

[5] School of Medicine, Meharry Medical College, 1005 Dr. DB Todd Jr. Blvd, Nashville, TN, USA

Introduction

Breast cancer-related arm lymphedema (BCRL) is a common chronic condition in survivors that involves accumulation of lymphatic fluid in the arm or hand, and can persist many years after primary cancer treatment [1, 2]. While estimates of BCRL vary due to differences in the definition of lymphedema, the type of breast cancer treatment provided, and timing of lymphedema onset, BCRL may affect up to one-third of survivors [2–10]. Risk factors for BCRL include axillary lymph node dissection, radiotherapy, and obesity [2, 3, 7, 8, 10–18]. For women living with BCRL, the swelling associated with fluid retention can cause pain, discomfort, and decreased function in the affected arm [19, 20]. Further, women may struggle with body image and anxiety about the appearance of the affected limb as well as increased emotional distress [21–24].

Lymphedema has been shown to impact physical and mental health-related quality of life (QOL) [8, 24–26]. However, results are limited among long-term (> 5 years) breast cancer survivors [27, 28] and African American breast cancer survivors. African American women have been shown to have increased prevalence of BCRL compared to White women [3, 12, 29, 30], and be less likely to receive sentinel lymph node biopsy, compared to White women [5]. Using data from the Carolina Breast Study that included women diagnosed with breast cancer between 2008 and 2013, investigators reported that 26% of African American breast cancer survivors in the study self-reported BCRL [30].

Decline in physical function (PF), which includes ability to walk, climb stairs, and participate in normal activities of daily living [31], can negatively impact employment and QOL and lead to permanent disability [32–34]. Reduced patient-reported PF has been associated with increased risk of mortality among breast cancer survivors [35, 36]. Studies have shown that African American breast cancer survivors may have lower patient-reported PF and physical health compared to other race/ethnicities [37–40]. While some studies have examined risk factors for BCRL among African American women [3, 5, 7], no studies have specifically examined BCRL and physical health among African American long-term breast cancer survivors. Data is needed to understand the role of BCRL on PF among African American breast cancer survivors.

Despite initial concerns that exercise may not be safe in women with BCRL, substantial research has now demonstrated that exercise is safe and can improve symptoms [41, 42]. Exercise has many benefits for breast cancer survivors regardless of BCRL status and is important for improving QOL and reducing risk of mortality overall [43, 44]. Therefore, it is important to understand if BCRL impacts physical activity (PA) participation, in particular among African American breast cancer survivors who may be less likely to participate in PA [45] and face unique barriers to PA related to the social determinants of health and social inequities [46]. In summary, lower levels of PA and poor PF are both associated with increased morbidity and mortality among breast cancer survivors. To address gaps in knowledge, we examined the association of BCRL with PA and PF among African American breast cancer survivors using data from the African American Breast Cancer Long-Term Survivorship (AABL) Study.

Materials & methods

Study design and study population

The AABL Study is a cross-sectional study of lifestyle and QOL outcomes with a particular focus on PA, sleep quality, and issues of importance to long-term African American breast cancer survivors. The study included 323 African American women who were previous participants of a case-only breast cancer etiology study in three southeastern states (Tennessee, Georgia, South Carolina) [47]. The case-only study (the Southern Tri-State Breast Health Study (STSBHS)) was conducted by Meharry Medical College and Vanderbilt University Medical Center. The STSBHS included a questionnaire on breast cancer risk factors and cancer registry data including stage and tumor characteristics. The detailed methods of the STBHS are published previously [48].

Recruitment for the AABL survivorship study began in September 2015 and ended in September 2016. The initial eligible population for the AABL study included cases from the STSBHS who consented to be contacted for further research. Women who were deceased or too ill to participate were excluded (n = 23). Recruitment to the AABL study occurred initially via a mailed introductory packet with consent form and study brochure. A similar study introduction letter was sent via email (when available) in addition to the mailed introduction packet. The AABL study interviewer began calling women within seven days after sending the introductory packet to conduct the interview (or women could have requested to complete the study online at any time). Among a total of 480 eligible women, 44 could not be contacted (confirmed disconnected phone, wrong phone number, incorrect mailing address). Another 67 women were nonresponsive to all forms of contact (email, mailing, phone) and 46 women refused participation. Among the 323 women that completed the AABL study interview, most (51.1%) completed the AABL study questionnaire by phone, (43.3%) completed via the web-based questionnaire, and 5.6% completed by mail.

For recruitment, data collection and management, we used Research Electronic Data Capture (REDCap), a secure web application for building and managing online questionnaires and study databases developed at Vanderbilt University Medical Center [49]. All questionnaire data was entered into the REDCap online survey by the study interviewer for phone interviews and for mailed questionnaires. For mailed questionnaires, all data was entered by two independent members of the research team and any discrepancies were reviewed by the team. A comprehensive breast cancer survivorship-focused questionnaire was developed for the AABL study to assess lifestyle factors, cancer treatment (surgery, radiotherapy, chemotherapy, adjuvant hormonal therapy), major comorbidities, PF outcomes, and psychosocial factors. The questionnaire was developed based on our prior research among breast cancer survivors, literature review, consultation with experts, and reviewing online databases [50–55]. We used only validated and well-established measures implemented previously in studies of breast cancer survivors or African American women to design our questionnaire. The development of the AABL questionnaire was also guided by feedback from breast cancer survivors and advocates. Initially, we obtained feedback through a focus group meeting. Pilot testing of a preliminary paper version of the questionnaire was conducted by individual survivors and/or advocates. We utilized participant feedback during the first several months of the study to make questions more clear, applicable and culturally sensitive, and to reduce participant burden. For the AABL study, all participants provided written informed consent and the study was approved by the Institutional Review Boards (IRB) at Vanderbilt University Medical Center and Meharry Medical College. For the present analysis which utilized de-identified data from the AABL study, IRB approval from Grand Valley State University was obtained.

Breast-*cancer* related lymphedema

We used questions based on a self-report validated measure developed by Norman and colleagues to assess BCRL among breast cancer survivors [1]. We also used selected questions from the a detailed BCRL questionnaire used in the Pathways study [55], which captured information similar to previous studies of BCRL [11]. The questionnaire used in AABL for BCRL is provided in Online Resource 1. Information collected included BCRL since diagnosis of breast cancer (ever BCRL), in the last 12 months (current BCRL), location of swelling, impact of swelling on daily life, and treatment receipt.

Physical functioning

PF was assessed using the 10-item PF subscale of the RAND 36-Item Short Form Survey (SF-36) [56]. The SF-36 is a standardized health survey including items on physical and mental functioning that has been used extensively in health research, including among breast cancer survivors [25, 37, 57–60]. General PF is measured via the 10-item SF-36 subscale (measures ability to complete moderate and vigorous intensity activities, bathing/dressing oneself, lifting groceries, climbing stairs, and walking various distances). The specific questions are provided in Online Resource 2. Low subscale scores indicated low functioning and high subscale scores indicated high functioning. PF score was classified based on tertiles, similar to previous work [61] (tertile (T)1: ≤ 45, T2: > 45- < 85; T3: ≥ 85).

Physical activity

PA was measured via a validated questionnaire used previously in studies of breast cancer survivors [54]. We modified the questionnaire slightly after feedback from African American breast cancer survivors with detailed methodology previous reportedly [47]. Briefly, activities reported were in one of three categories: household, recreational, or transportation. Participants reported the frequency of participation in each activity and the amount of time each activity was performed. Frequency and duration were multiplied for each activity to obtain an estimate of weekly minutes of PA for each activity. PA was categorized as recreational PA and total PA minutes per week [47]. For the present analysis, total and recreational PA were also classified based on tertiles (T) for analysis with values for each tertile category show in Table 3. We also created a PA variable based on meeting the United States (U.S.) PA recommendations of ≥ 150 min per week of exercise [62, 63].

Covariates

Age at diagnosis was available from the case-only study (originally calculated using date of birth and date of diagnosis). Additional demographics were collected on the case-only study questionnaire and included health insurance (Medicare or other insurance, Medicaid alone, other insurance neither Medicare nor Medicaid), education (high school education or less, some college, graduated college/received education higher than college), and annual household income (< $15,000, $15,000-$24,999, $25,000-$49,999, $50,000-$99,999, and $100,000 and over). Treatment and

lifestyle data were collected on the AABL survivorship study questionnaire and included type of surgery (lumpectomy, mastectomy, or none), lymph nodes removal (yes, no), chemotherapy (yes, no), radiotherapy (yes, no), aromatase inhibitors (yes, no (types included Anastrozole, letrozole, and exemestane)), selective estrogen receptor modulators (yes, no (types included raloxifene and tamoxifen)), smoking status (never, former, or current) and ever diagnosed with selected comorbidities (type II diabetes, hypertension, high cholesterol, and arthritis). Pre-diagnosis body mass index (BMI) was calculated using self-reported height and weight from the original case-only study. Post-diagnosis BMI was calculated using self-reported height from the original case-only study and self-reported current weight from the AABL questionnaire. Women were defined as postmenopausal if they reported no menstrual period in the last six months on AABL questionnaire (otherwise they were classified as premenopausal). Bodily pain and bodily pain that interferes with daily tasks were assessed using two questions from the SF-36 that asked about pain experienced in the last 4 weeks. Higher scores for the pain questions indicate less pain (100 = no pain, 0 = very severe pain, for example) [56]. Tumor characteristics and stage were available from the cancer registries in each state. American Joint Cancer Committee (AJCC) stage at diagnosis categories included stage 0, stage I, stage II, stage III, and stage IV. Due to small sample sizes, stage 0 and I were combined into one category and stage III and IV (n = 5) were combined into one category. Tumor characteristics included estrogen receptor (ER) positive status (yes/no) and progesterone receptor (PR) positive status (yes/no).

Statistical analysis

The percentage and frequency of women who reported current BCRL and ever BCRL, and BCRL characteristics were assessed overall. Frequencies and percentages for categorical covariates and means with standard deviations (SDs) for continuous covariates were examined by current BCRL status. Descriptive statistics were also estimated for PA variables, and PF in tertiles by both current BCRL and ever BCRL status. P-values were obtained from Wilcoxon tests for continuous variables and χ^2 test for categorical variables. Binary logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (CIs) for the association of BCRL and not meeting PA recommendations (reference: meeting PA recommendations). Multinomial logistic regression was used to estimate ORs and 95% CIs for the association of BCRL and recreational PA minutes/week (reference: highest tertile) and low PF (reference: highest tertile). Based on the bivariate analysis and considering both previous literature [2, 14, 28, 60] and sample size, the models were adjusted for age at diagnosis, health insurance, chemotherapy, and stage. P-values < 0.05 and 95% CIs that did not contain 1.0 were considered statistically significant. All analyses were conducted in Statistical Analysis Software version 9.4.

Results

Table 1 displays the prevalence and characteristics of BCRL in the study population. About 32% of the women reported BCRL since their cancer diagnosis and about 25% reported BCRL in the last 12 months (hereafter referred to as current BCRL). Most women had swelling on the same side as their breast cancer surgery (96.2%). Nearly half of women with current BCRL had constant swelling (47.5%). Half of the women with current BCRL reported their swelling interfered with the ability to do routine activities, and 39% reported that their swelling interfered with clothes. Around a quarter of women with current BCRL reported that their swelling interfered with exercise (25.6%) and appearance (26.8%). Just under half of the women with current BCRL received treatment in the last 12 months (46.3%). The open text responses of the 12 women who reported other are provided as Online Resource 3.

Table 2 displays clinical factors, demographics, and lifestyle factors by current BCRL status. Among those with current BCRL, the mean age at diagnosis was 54.5 years and the mean years since diagnosis was 4.2 years. PF, bodily pain, and bodily pain that interfered with daily tasks differed statistically significantly between those with and without BCRL, with lower PF and higher pain in those with BCRL. For example, the mean (SD) for the PF score was 51.0 (29) among women with current BCRL (compared to 68.5 (30.1) among women without current BCRL). Compared to women without current BCRL, a higher percentage of women with current BCRL had Medicaid as insurance (21.3% versus 9.4%), income of < $15,000 (38.8% versus 24.6%), and ≤ high school education (34.2% versus 25.8%). A greater percentage of women without current BCRL had a lumpectomy (60.9%), while a greater percentage of women with current BCRL had a mastectomy (51.3%) and chemotherapy (70.7%). Most women with current BCRL reporting having their lymph nodes removed (97.5%). Compared to women without current BCRL, a higher percentage of women with current BCRL had a pre-diagnosis and post-diagnosis BMI of ≥ 35 kg/m^2 (35.8% and 38.3%, respectively).

Table 3 presents PF and PA by BCRL status. A higher percentage of women with BCRL were in the lowest PF group for both current and ever BCRL, 45.7% and 46.1%, respectively. Differences for PA participation by BCRL status were larger for recreational PA (compared to total PA) and for ever BCRL (compared with current BCRL). For

Table 1 Breast cancer-related arm lymphedema in the AABL Survivorship Study, n = 323[a]

	n	%
BCRL since diagnosis		
No	220	68.1
Yes	103	31.9
BCRL in the last 12 months		
No	21	6.5
Yes	82	25.4
Not applicable	220	68.1
Swelling on same side as breast cancer surgery[a]		
No	3	3.8
Yes	76	96.2
Missing	3	
Frequency of swelling[a]		
Constantly	38	47.5
Occasionally	35	43.8
Other	7	8.8
Missing	2	
Does swelling interfere with[a]		
Clothes		
No	50	61.0
Yes	32	39.0
Exercise		
No	61	74.4
Yes	21	25.6
Appearance		
No	60	73.2
Yes	22	26.8
Ability to do routine activities		
No	41	50.0
Yes	41	50.0
Other		
No	70	85.4
Yes	12	14.6
None		
No	57	69.5
Yes	25	30.5
Received treatment for BCRL in the last 12 months[a]		
No	44	53.7
Yes	38	46.3

Abbreviations: breast cancer-related arm lymphedema (BCRL)

[a]Among women with current BCRL (n = 82)

example, about 25.5% of women who reported ever BCRL were in the highest tertile of recreational PA (compared to 38.1% for those without BCRL) and 31.4% of women who reported ever BCRL met PA recommendations (compared to 43.1% of those without BCRL).

Table 4 displays results on the association of ever and current BCRL with low PF. Women with current BCRL had

Table 2 Clinical factors, demographics, and lifestyle by current BCRL status, AABL Survivorship Study (n = 323)

	Current BCRL (last 12 months)				
	Yes (n = 82)		No (n = 241)		P-Value[a]
Age at diagnosis, mean (SD)	54.5	(9.9)	54.9	(9.9)	0.68
Missing	2		9		
Years since diagnosis, mean (SD)	4.2	(0.78)	4.3	(0.85)	0.74
Missing	2		9		
Physical Functioning, mean (SD)	51.0	(29.0)	68.5	(30.1)	< 0.01
Missing	1		2		
Bodily Pain, mean (SD)	44.7	(28.0)	60.8	(28.3)	< 0.01
Missing	1				
Bodily Pain Interferes with Daily Tasks, mean (SD)	56.5	(32.1)	73.2	(30.7)	< 0.01
Missing	1		2		
Menopausal status					
Premenopausal	7	(8.5)	23	(9.5)	
Postmenopausal	75	(91.5)	218	(90.5)	0.77
Health Insurance, n (%)					
Medicare (alone or with other insurance type)	27	(33.8)	85	(36.3)	
Medicaid alone	17	(21.3)	22	(9.4)	
Private/other type alone	36	(45.0)	127	(54.3)	0.02
Missing	2		7		
Education, n (%)					
≤ High school	28	(34.2)	62	(25.8)	
Some college	28	(34.2)	89	(37.1)	
≥ College graduate	26	(31.7)	89	(37.1)	0.34
Missing			1		
Income, n (%)					
< $15,000	31	(38.8)	58	(24.6)	
$15–24,999	9	(11.3)	31	(13.1)	
$25–49,999	18	(22.5)	55	(23.3)	
$50–99,000	15	(18.8)	65	(27.5)	
≥ $100,000	7	(8.8)	27	(11.4)	0.15
Missing	2		5		
AJCC Stage, n (%)					
0/I	27	(32.9)	137	(58.1)	
II	34	(41.5)	79	(33.5)	
III/IV	21	(25.6)	20	(8.5)	< 0.01
Missing			5		
Surgery, n (%)					
Lumpectomy	34	(42.0)	145	(60.9)	
Mastectomy	43	(53.1)	82	(34.5)	< 0.01
None	4	(4.9)	11	(4.6)	
Missing	1		3		
Lymph nodes removed,[b] n (%)					
No	2	(2.6)	58	(25.4)	
Yes	74	(97.4)	170	(74.6)	< 0.01

Table 2 (continued)

	Current BCRL (last 12 months)				
	Yes (n = 82)		No (n = 241)		P-Value[a]
Missing	2		2		
Chemotherapy, n (%)					
No	24	(29.3)	115	(47.7)	
Yes	58	(70.7)	126	(52.3)	< 0.01
Radiotherapy, n (%)					
No	30	(37.0)	77	(32.0)	
Yes	51	(63.0)	164	(68.1)	0.40
Missing	1				
Aromatase Inhibitors, n (%)					
No	48	(60.0)	151	(62.9)	
Yes	32	(40.0)	89	(37.1)	0.64
Missing	2		1		
Selective Estrogen Receptor Modulators, n (%)					
No	56	(69.1)	159	(66.3)	
Yes	25	(30.9)	81	(33.8)	0.63
Missing	1		1		
ER Positive, n (%)					
No	30	(37.0)	65	(28.3)	
Yes	51	(63.0)	165	(71.7)	0.14
Missing	1		11		
PR Positive, n (%)					
No	34	(42.0)	93	(40.4)	
Yes	47	(58.0)	137	(59.6)	0.81
Missing	1		11		
Pre-diagnosis BMI (kg/m^2), n (%)					
< 25	13	(16.1)	33	(13.8)	
25- < 30	22	(27.2)	81	(33.8)	
30- < 35	17	(21.0)	62	(25.8)	
≥ 30	29	(35.8)	64	(26.7)	0.34
Missing	1		1		
Post-diagnosis BMI (kg/m^2), n (%)					
< 25	10	(12.4)	28	(11.8)	
25- < 30	18	(22.2)	76	(31.9)	
30- < 35	22	(27.2)	77	(32.4)	
≥ 35	31	(38.3)	57	(24.0)	0.07
Missing	1		1		
Smoking status, n (%)					
Never	61	(74.4)	186	(77.2)	
Former	11	(13.4)	37	(15.4)	
Current	10	(12.2)	18	(7.5)	0.41
Type II Diabetes, n (%)					
No	56	(68.3)	183	(75.9)	
Yes	26	(31.7)	58	(24.1)	0.17
Hypertension, n (%)					
No	27	(32.9)	88	(36.5)	
Yes	55	(67.1)	153	(63.5)	0.56
High cholesterol, n (%)					
No	45	(54.9)	141	(58.5)	
Yes	37	(45.1)	100	(41.5)	0.57
Arthritis, n (%)					
No	42	(51.2)	136	(56.7)	
Yes	40	(48.8)	104	(43.3)	0.39
Missing			1		
Recurrence/new cancer (after breast cancer diagnosis)					
No	76	(92.7)	227	(94.2)	
Yes	6	(7.3)	14	(5.8)	0.62

Abbreviations: American Joint Committee on Cancer (AJCC), breast cancer-related lymphedema (BCRL), body mass index (BMI), estrogen receptor (ER), progesterone receptor (PR)

[a]P-values were from Wilcoxon tests for continuous variables and general χ^2 test for categorical variables

[b]Excludes women who did not have surgery (n = 15)

increased odds of low PF in both unadjusted and adjusted models. For example, the adjusted OR (95% CI) for the lowest tertile of PF was 3.98 (1.77–8.96) for current BCRL. The association was less strong but remained statistically significant for ever BCRL. For example, the adjusted OR (95% CI) for ever BCRL in association with the lowest tertile of PF was 2.93 (1.44–5.96).

Table 5 displays results for the association of BCRL and PA. A positive association between BCRL and not meeting recommendations of >=150 min per week of PA (reference: meeting the PA recommendations) was observed, but results were not statistically significant after adjustment for covariates (adjusted OR (95% CI for ever BCRL: 1.61 (0.93–2.79)). Lower levels of PA (tertile 1 and 2) in minutes per week (versus tertile 3) were non-significantly positively associated with BCRL. Adjusted ORs (95% CIs) for ever BCRL and tertile 2 and tertile 1 were 1.86 (0.97–3.55) and 1.52 (0.75–297), respectively.

Discussion

In this cross-sectional study of long-term African American breast cancers across three states, approximately 32% of women reported BCRL since diagnosis and 25.4% reported BCRL in the last 12 months. BCRL symptoms were constant for many women (48% of those with current BCRL) and BCRL interfered with ability to do routine activities for half of women with current BCRL yet less than half (46%) had received any treatment for BCRL in the last 12 months. Both current BCRL and ever BCRL were statistically significantly

Table 3 Physical functioning and physical activity by current and ever BCRL status, AABL Survivorship Study (n = 323)[a]

	Current BCRL					Ever BCRL				
	Yes (n = 82)		No (n = 241)		P-Value[b]	Yes (n = 103)		No (n = 210)		P-Value[b]
Physical functioning										
≤ 45	37	(45.7)	70	(29.3)		47	(46.1)	60	(27.5)	
> 45- < 85	31	(38.3)	62	(25.9)		33	(32.4)	60	(27.5)	
≥ 85	13	(16.1)	107	(44.8)	< 0.001	22	(21.6)	98	(45.0)	< 0.001
Total PA (minutes/week)										
< 340.75	30	(37.0)	74	(31.0)		38	(37.3)	66	(30.3)	
340.75- < 681	27	(33.3)	80	(33.5)		34	(33.3)	73	(33.5)	
≥ 681	24	(29.6)	85	(35.6)	0.21	30	(29.4)	79	(36.2)	0.13
Recreational PA (minutes/week)										
< 33.75	27	(33.3)	71	(29.7)		33	(32.4)	65	(29.8)	
33.75- < 192.25	33	(40.7)	80	(33.5)		43	(42.2)	70	(32.1)	
≥ 192.25	21	(25.9)	88	(36.8)	0.12	26	(25.5)	83	(38.1)	0.09
Meeting PA recommendations[c]										
No	56	(69.1)	138	(57.7)		70	(68.6)	124	(56.9)	
Yes	25	(30.9)	101	(42.3)	0.05	32	(31.4)	94	(43.1)	0.03

Abbreviations: physical activity (PA), breast cancer-related arm lymphedema (BCRL)

[a]Table excludes women 3 missing physical functioning data

[b]P-values from chi-square analysis

[c] ≥ 150 min/week of exercise

Table 4 Ever and current BCRL in association with physical function, AABL Survivorship Study (n = 320)[a]

	Unadjusted				Adjusted[b]			
	> 45- < 85		≤ 45		> 45- < 85		≤ 45	
	ORs	(95% CI)	ORs	(95% CI)	ORs	(95% CI)	ORs	(95% CI)
Current BCRL								
No	1.00	(reference)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Yes	4.12	(2.01–8.45)	4.35	(2.16–8.76)	3.94	(1.74–8.90)	3.98	(1.77–8.96)
Ever BCRL								
No	1.00	(reference)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Yes	2.45	(1.31–4.59)	3.49	(1.92–6.36)	2.12	(1.03–4.36)	2.93	(1.44–5.96)

[a]Table excludes three women missing data on physical function

[b]Models are adjusted for age at diagnosis, surgery type, receipt of chemotherapy, AJCC stage, and insurance type. Adjusted models exclude women missing covariates (n = 29 missing)

associated with lower PF, with women who reported ever BCRL having about 2 times the odds of low PF compared to women without BCRL. While findings for BCRL and PA were not statistically significant, there was a suggestive pattern of increased odds of lower recreational PA participation (minutes per week) and not meeting physical activity recommendations of ≥ 150 min per week for women with BCRL.

Few previous studies of BCRL and QOL have included African American women, despite studies that have shown that Black women may be more likely to develop BCRL[5, 30]. A previous review summarized the literature on BCRL and QOL among cancer survivors and noted only one study including non-White breast cancer survivors [26]. Data is particularly limited for studies of BCRL and physical health among African American women. Two reports from the HEAL study evaluated risk factors for self-reported BCRL and included an analysis among African American women (n = 225), but did not examine BCRL in association with PF or PA [3, 7]. A more recent report from the HEAL study examined BCRL in association with QOL including physical and mental health using the SF-36 survey [60]. While African American women (n = 155) were included in the overall sample, analyses were not conducted by race/ethnicity.

Our study fills a gap in knowledge among long-term African American breast cancer survivors on the role of BCRL in physical health. The AABL study had detailed

Table 5 BCRL in association with recreational PA, AABL Survivorship Study (n = 323)

	Not Meeting PA Recommendations							
	ORs[a] (95% CI)				ORs[b] (95% CI)			
Current BCRL								
No	1.00 (reference)				1.00 (reference)			
Yes	1.70 (1.00–2.91)				1.59 (0.88–2.86)			
Ever BCRL								
No	1.00 (reference)				1.00 (reference)			
Yes	1.72 (1.05–2.82)				1.61 (0.93–2.79)			
Recreational PA								
	33.75- < 192.25 (minutes/week)		< 33.75 (minutes/week)		33.75- < 192.25 (minutes/week)		< 33.75	
	ORs[c]	95% CI	ORs[c]	95% CI	ORs[d]	95% CI	ORs[d]	95% CI
Current BCRL								
No	1.00	(reference)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Yes	1.73	(0.93–3.22)	1.67	(0.88–3.19)	1.59	(0.80–3.17)	1.45	(0.71–2.95)
Ever BCRL								
No	1.00	(reference)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Yes	1.96	(1.10–3.50)	1.69	(0.92–3.09)	1.86	(0.97–3.55)	1.52	(0.78–2.97)

[a]Models are unadjusted with results from binary logistic regression. Reference group is meeting PA recommendations

[b]Models are adjusted for age at diagnosis, surgery type, receipt of chemotherapy, AJCC stage, and insurance type with results from binary logistic regression. Reference group is meeting PA recommendations. Adjusted models exclude women missing covariates (n = 26 missing)

[c]Models are unadjusted with results from multinomial logistic regression. Reference group is the highest tertile of minutes per week of PA

[d]Models are adjusted for age at diagnosis, surgery type, receipt of chemotherapy, AJCC stage, and insurance type with results from multinomial logistic regression. Reference group is the highest tertile of minutes per week of PA. Adjusted models exclude women missing covariates (n = 26 missing)

data available on lifestyle factors, comorbidities, sociodemographics, cancer treatment, and other key covariates of interest. In addition, validated and well-established measures were used, which reduced the potential for information bias. Despite these strengths, our study had several limitations. First, we did not have data on number of lymph nodes removed or whether women had axillary dissection or sentinel lymph node biopsy, which are important risk factors for BCRL. Second, the study outcome was based on self-reported BCRL. This could have resulted in misclassification of women for BCRL status. However, previous studies have noted the importance of patient reported outcomes, in particular for BCLR [26]. Third, this was a cross-sectional study with information collected retrospectively and future studies with prospective follow-up and repeated measures of PF and PA are needed.

An important clinical implication of our study findings is that BCRL remains a key concern (about 50% reported constant swelling) among African American women many years after diagnosis of breast cancer and completion of primary treatment. About 26% of women with BCRL noted that it interfered with their ability to exercise and 50% noted it interfered with their ability to do routine activities, while less than half reported receiving any treatment. A recent small qualitative study (n = 11) examined the lived experiences of African American breast cancer survivors living with lymphedema [64]. A key theme identified was distrust of health care providers which hindered support and treatment. Future larger studies focused on African American women living with BCRL that examine barriers to treatment access and also barriers and preferences for interventions [65] to reduce symptoms and improve PF are needed to inform future interventions.

Conclusions

BCRL was common and associated with lower PF among long-term African American breast cancer survivors. Our study shows how regular assessments of BCRL are important in the long-term and should be part of cancer survivorship care plans. Clinicians should try to address BCRL symptoms, even after the primary treatment for breast cancer is completed. Continued monitoring by clinicians and increased access to support for exercise, BCRL treatment, and culturally sensitive and supportive interventions to improve PF among African American breast cancer survivors living with BCRL are needed.

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Author contributions SN, WYC, and MS contributed to the study conception and study design. The data analysis was performed by SN and replicated by AG. The first draft of the manuscript was written by SN. All authors contributed to interpretation of results and revising the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Data availability The data used for this research study is not available to external researchers at this time. The statistical code used for the analysis is available from the corresponding author upon request.

Declarations

Ethics approval Institutional Review Board (IRB) approval for the AABL study was obtained from Vanderbilt University Medical Center and Meharry Medical College, and all study participants provided written informed consent.

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Competing interests The authors declare no competing interests.

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