CLINICAL TRIAL

Possible socioeconomic and ethnic disparities in quality of life in a cohort of breast cancer survivors

Deborah J. Bowen · Catherine M. Alfano · Bonnie A. McGregor · Alan Kuniyuki · Leslie Bernstein · Kathy Meeske · Kathy B. Baumgartner · Josala Fetherolf · Bryce B. Reeve · Ashley Wilder Smith · Patricia A. Ganz · Anne McTiernan · Rachel Ballard Barbash

Received: 1 December 2006 / Accepted: 4 December 2006 / Published online: 27 January 2007 © Springer Science+Business Media B.V. 2007

Abstract

Background This paper describes the ethnic and socioeconomic correlates of functioning in a cohort of long-term nonrecurring breast cancer survivors.

Methods Participants (n = 804) in this study were women from the Health, Eating, Activity, and Lifestyle (HEAL) Study, a population-based, multicenter, multiethnic, prospective study of women newly diagnosed with in situ or Stages I to IIIA breast cancer. Measurements occurred at three timepoints following diagnosis. Outcomes included standardized measures of functioning (MOS SF-36).

Results Overall, these long-term survivors reported values on two physical function subscales of the SF-36

L. Bernstein · K. Meeske Department of Preventive Medicine and USC/Norris Comprehensive Cancer Center, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA

K. B. Baumgartner · J. Fetherolf Department of Internal Medicine, Cancer Research and Treatment Center, University of New Mexico, Albuquerque, NM, USA

B. B. Reeve Outcomes Research Branch, ARP, DCCPS, National Cancer Institute, Bethesda, MD 20892-7344, USA

A. W. Smith · R. B. Barbash Applied Research Program, National Cancer Institute, Bethesda, MD, USA slightly lower than population norms. Black women reported statistically significantly lower physical functioning (PF) scores (P = 0.01), compared with White and Hispanic women, but higher mental health (MH) scores (P < 0.01) compared with White and Hispanic women. In the final adjusted model, race was significantly related to PF, with Black participants and participants in the "Other" ethnic category reporting poorer functioning compared to the White referent group (P < 0.01, 0.05). Not working outside the home, being retired or disabled and being unemployed (on leave, looking for work) were associated with poorer PF compared to currently working (both P < 0.01).

P. A. Ganz Schools of Medicine and Public Health, University of California, Los Angeles, CA, USA

P. A. Ganz Division of Cancer Prevention and Control Research, Jonsson Comprehensive Cancer Center, Los Angeles, CA, USA

Present Address: K. B. Baumgartner J. Fetherolf Department of Epidemiology and Clinical Investigation Sciences, University of Louisville, Louisville, KY, USA

D. J. Bowen · C. M. Alfano · B. A. McGregor · A. Kuniyuki · A. McTiernan (⊠) Fred Hutchinson Cancer Research Center, 1100 Fairview Avenue N, M4-B402, Seattle, WA 98109, USA e-mail: amctiern@fhcrc.org

A. W. Smith

Cancer Prevention Fellowship Program, Division of Cancer Prevention and Applied Research Program, Division of Cancer Control and Population Science, National Cancer Institute, Bethesda, MD, USA

Conclusion These data indicate that race/ethnicity influences psychosocial functioning in breast cancer survivors and can be used to identify need for targeted interventions to improve functioning.

Keywords Breast cancer survivorship · Fear of recurrence · Race disparities · SES disparities

Introduction

Recovery from breast cancer diagnosis and treatment is a multifaceted process. Several decrements in women's functioning have been documented in the short term, including reduction in overall quality of life and in more specific aspects of quality of life, such as increases in physiological and psychosocial symptoms including fatigue, mood disturbance, and a range of social and occupational changes [1]. Recent key papers [1–4] indicate that many of the QOL difficulties experienced by survivors in the short term (i.e., during the first two years post diagnosis) resolve over time. However, there MIGHT BE a subgroup of approximately 20–25% of women who still report decrements in several aspects of QOL up to four years after diagnosis [1, 5, 6].

Why does a subgroup report lower QOL after the first year of treatment? Several disparity-based explanations are explored in this paper. First, it is likely that demographic differences exist in long term functioning of cancer patients, although very little has been published on the survivorship experience of a demographically diverse group of women. The quality and experiences of survival could be quite different in women who differ by race or ethnicity [3], or by socioeconomic status [1], given the importance of these variables in determining survivorship. Other areas of research comparing women from varied ethnic and socioeconomic groups, including such outcomes as chronic disease, screening, health behavior, and general functioning, have found differences by sociodemographic variables [7, 8], but little is known about the experience of survivorship across ethnic or sociodemographic groups.

Second, it is likely that continued presence of symptoms related to cancer and cancer treatment reduces overall QOL. Continuing experience of symptoms, including hormone related symptoms [5], lymphedema [1, 9], and fatigue [10], could interfere with functioning. True differences in disease profile and even perceived prognosis might play a role too. Finally, the worry and fear of cancer recurrence would be another type of reminder of the initial experience, of vulnerability, and of potential mortality. There is qualitative evidence that better functioning over time is reported by women who are able to view and label themselves as survivors, and who consider their cancer diagnosis as a past experience rather than continuing to view themselves as cancer patients [11]. Worry about recurrence and its meaning could interfere with women's ability to put the cancer experience behind them and could interfere with their overall functioning. These potential psychosocial explanations (worry, symptoms) may also be related to the differences among demographic subgroups, providing clues to explain any disparities found.

The research aims of this paper are: (1) to describe the ethnic and socioeconomic correlates of functioning of a diverse cohort of long-term nonrecurring breast cancer survivors and (2) to determine the contribution of ongoing difficulties, including symptoms and concerns about cancer, to the ethnic and socioeconomic differences in functioning levels.

Methods

Study design

Participants were enrolled in the Health, Eating, Activity, and Lifestyle (HEAL) Study, a populationbased, multicenter, multiethnic, prospective study of women newly diagnosed with in situ or Stages I to IIIA breast cancer. HEAL study participants are being followed to determine the impact of weight, physical activity, diet, hormones, and other exposures on breast cancer prognosis. All study protocols were approved by the Institutional Review Boards of each participating center. The baseline interview occurred on average 6.1 months following diagnosis, followed by a 24 month and a 35 month post baseline assessment. Women with new primary cancer or recurrent cancer were excluded from all analyses.

Eligibility and recruitment

Female patients diagnosed with their first primary breast cancer were recruited from National Cancer Institute sponsored Surveillance Epidemiology and End Results (SEER) registries in three geographic regions of the United States, and data on two of the sites have been previously published [12]. Incident breast cancer patients at the third site (Los Angeles County, California) were initially recruited to participate in one of two population-based case-control studies, a study of in situ breast cancer [13,14] and a study of invasive breast cancer [15,16]. Women were eligible to participate in these two case control studies if they were age 35 to 64 years at diagnosis, Caucasian or Black, and born in the United States. Los Angeles County participants in these studies were included in the HEAL study if they were (1) Black, (2) diagnosed between May 1995 and May 1998, and (3) satisfied the HEAL stage eligibility criterion. Overall, less than 2.4% of the participants were beyond the 12-month window.

Measures

General functioning

We used the Medical Outcomes Study short form 36 (SF-36) health status measure created to measure physical and mental health functioning in healthy populations [17, 18]. This widely used measure includes 36 items, scored into eight subscales: Physical Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE), and Mental Health (MH), and a physical component and a mental component summary scale, with high alpha coefficients (0.78–0.91).

Menopausal status

Menopausal status was determined at the 24-month assessment using an algorithm that assigned women into pre, post, or unclassifiable menopausal status based on the following data: age, date of last menstruation, hysterectomy and oophorectomy status.

Stage of breast cancer and treatment

Stage of disease was based on SEER data. Treatment data were recoded as: surgery only; surgery with chemotherapy; surgery with radiation, or the combination of all three treatments. Tamoxifen use was categorized as use between baseline and 24-months, use at or before baseline only, or no use during the study period.

Antidepressant use

Self-reported use of antidepressant medication was collected at the 24-month assessment and categorized as currently taking at 24 months versus not currently taking at 24 months.

Hormone-related symptom checklist

Hormone symptoms were measured with 14 items representing the most relevant symptoms for a population of breast cancer survivors [19].

Lymphedema

We constructed an index of self-reported lymphedema, with three levels: currently experiencing lymphedema (current lymphedema, 13.9%), did experience lymphedema, but not currently experiencing lymphedema (no current lymphedema, 6.1%), and never experienced lymphedema (never had lymphedema, 80.0%).

Fatigue

We constructed a simple three-level index of fatigue duration: fatigued for weeks or months (longer-term fatigue, 37%), fatigued for minutes, hours, or days (short-term fatigue, 27.4%), and no fatigue (35.6%).

Impact of cancer

Impact of cancer was measured with four scales measuring the impact on four separate domains of life: Caregiving/finances ($\alpha = 0.77$), Exercise/diet ($\alpha = 0.63$), Social/emotional ($\alpha = 0.75$), and Religiosity ($\alpha = 0.80$) [20].

Fear of recurrence

For the current study we used a 5-item version of the Fear of Recurrence scale [21]. Confirmatory CFI = 0.99, Tucker-Lewi factor analysis indicated that all items loaded onto one common factor (Comparative Fit Index s Index TLI = 0.99). The single factor accounted for 66% of the scale variance. Cronbach's α in the present sample was 0.82.

Analysis plan

The analyses presented in this paper use data collected through November 18th, 2004. The data were analyzed using SAS/STAT software, version 9 of the SAS System for Windows. Copyright ©2002 SAS Institute Inc and version 3.01 of MPlus, which is a specialized software that is designed for analyzing ordinal level data [22]. SF-36 subscales with missing item responses were imputed following standard scoring methods [23]. Missing hormone-related symptoms and BCIA scale scores were imputed (for less than 3% of participants) based on the average of non-missing item responses, when at least 50% of the scale items were not missing; no imputation was necessary for the FOR scale responses. Imputation of missing values was not considered for any other measure. See Alfano et al. [19] for a figure of the enrollment process. For the analyses that are presented here, 1 woman did not have complete data sufficient to compute psychosocial scales; thus, the final sample size available for analysis was 804 women.

We fit linear regression models to evaluate the associations between race/ethnicity and socioeconomic variables with the study's QOL measures. Indicator variables representing the three HEAL sites were not included in our models due to their strong associations with the racial/ethnic groups recruited by each site. In addition, we did not use 24-month household income (collected at the 24-month follow-up interview) as a socioeconomic predictor in the regression models due to the extent of missing data reported. We used these intermediate outcomes of symptom reporting, impact of cancer, and fear of recurrence, along with fatigue and lymphedema, to predict the overall physical and mental functioning variables.

Results

Table 1 presents demographic and medical characteristics of the 804 participants who provided data at the QOL measurement point, compared to the 304 participants who did not provide QOL data at the follow-up period. As shown in this table, there were key differences in the distributions between the two groups of women. Non-completers were significantly more likely to be younger or older (P < 0.01), of lower educational attainment (P < 0.01), and either Black or Hispanic (P < 0.01). Also, non-completers were slightly, but significantly, more likely to be diagnosed at a more advanced breast cancer stage (P < 0.01) and more likely to have received treatment (P < 0.01).

Data on physical and MH functioning summary scores by socioeconomic level and by race/ethnicity are provided in Table 2. Race/ethnicity was a significant correlate of physical (P = 0.01) and mental (P < 0.01) summary scores. Black women reported statistically significantly lower PF scores, compared with White and Hispanic women, but higher MH scores compared with White and Hispanic women. Employment status was also significantly associated with PF (P < 0.01). Restricting the analyses to women aged 35–64, the age of the Black women, or conducting analyses without the "other" race category, did not alter the pattern of findings.

Figure 1 presents data on the specific and independent eight subscale scores for the SF-36, compared to national norms [23]. As seen in this figure, HEAL participants reported lower scores on most of the subscale scores, but particularly the PF, RP, and RE scores. The largest differences were in PF and RP subscales, where the scores for these breast cancer survivors were approximately one standard deviation below population means.

Tables 3 and 4 present the results of analyses to determine the relationships between demographic variables and both hormone-related symptoms and BCIA scale scores. Significant relationships between symptom level and sociodemographic variables were reported for Black women versus other women in cognitive/mood (P < 0.01), incontinence (P < 0.01), and weight/appearance (P < 0.01) symptoms. Table 4 contains the results of the BCIA on five scales, each representing a different dimension of life. Scores for the Exercise/Diet subscale differed significantly by educational levels (P < 0.01). Higher education level was associated with a more positive impact of breast cancer on exercise/diet subscale (P for trend < 0.01). White and Black women reported a greater negative impact of cancer on the caregiving/finances domain, compared to Hispanic women. Hispanic women reported significantly greater positive impact of cancer on religiosity compared with both Black and White women. Employment levels were significantly related to the Caregiving/finances (P < 0.01) and Social/emotional (P = 0.05) scores, with women who were unemployed (seeking a job or on leave) reporting a greater negative impact of cancer than employed women. FOR scores were greater among White and Hispanic women, compared to Black women.

Table 5 contains the results of regression models using both socioeconomic indicators from Table 2 and potential mechanisms from Table 3 (hormonal and other symptoms, impact of cancer, and fear of recurrence) as correlates of physical and MH functioning scores. In the final model, where demographic and psychosocial variables were included together, race was significantly related to PF, with Black participants and participants in the "Other" ethnic category reporting poorer functioning compared to the White referent group (P < 0.01, 0.05). Not working outside the home, being retired or disabled and being unemployed (on leave, looking for work) were associated with poorer PF compared to currently working (P < 0.01, < 0.01). More severe urinary incontinence symptoms and greater fear of recurrence were both associated with lower PF scores (P = 0.04, 0.04, respectively). A less negative impact of cancer on the caregiver/financial domain was associated with an increase in PF (P = 0.01). However, a less negative impact of cancer on the social/emotional domain was related to a decrease in PF (P = 0.03). More positive impact of cancer on exercise/diet was related to an increase in PF (P < 0.01). In addition, current lymphedema and both

Table 1 Demographic and clinical characteristics of 804 HEAL participants who completed the quality of life follow-up survey,compared to 304 participants who did not

Characteristic	Complete	d ($n = 804$)	Not Con	P^{b}	
	n	%	n	%	
Baseline					
Age (yr)					
29–49	239	29.7	125	41.1	< 0.01
50-59	301	37.4	79	26.0	
60–69	178	22.1	45	14.8	
70+	86	10.7	55	18.1	
$(Mean \pm SD)$		(55.5 ± 10.4)		(55.3 ± 13.3)	0.81
Education		(
HS or less	205	25.5	126	41.4	< 0.01
Some college	293	36.5	117	38.5	
College grad	156	19.4	30	9.9	
Grad school (missing)	149 (1)	18.6	31	10.2	
Race/ethnicity	11) (1)	10.0	51	10.2	
Non-Hispanic White	486	60.4	121	39.8	< 0.01
Black	199	24.8	135	44.4	<0.01
Hispanic	95	11.8	48	15.8	
Other	24	3.0	40	0.0	
Registry	24	5.0	0	0.0	
	167	20.8	22	7.2	< 0.01
Western Washington New Mexico	167 439	20.8 54.6	22 147	7.2 48.4	<0.01
Los Angeles	198	24.6	135	44.4	
Stage at diagnosis	150		10	150	0.04
In situ	179	22.3	48	15.8	< 0.01
Localized	453	56.3	165	54.5	
Regional (unstaged)	172	21.4	90 (1)	29.7	
Breast cancer treatment type					
Surgery + chemotherapy	74	9.2	40	13.2	< 0.01
Surgery + chemotherapy + radiation	174	21.6	64	21.1	
Surgery + radiation	296	36.8	100	32.9	
Surgery only	260	32.3	95	31.3	
Other	0	0.0	5	1.6	
24-Month follow-up					
Marital status					
Married	450	58.1			
Widowed/divorced/separated	272	35.1			
Never married (missing) ^c	52 (30)	6.7			
Current employment					
Currently working	450	58.1			
Unemployed (on leave, looking for work)	26	3.4			
Not working outside the home/retired/disabled (missing) ^c	299 (29)	38.6			
Income (\$)	2)) (2))	50.0			
< = 10 K	54	7.4			
< = 10 K >10 K-20 K	54 86	11.9			
	80 93				
>20 K-30 K		12.8			
>30 K-50 K	168	23.2			
>50 K-70 K	211	29.1			
>70 K (missing) ^c	113 (79)	15.6			
Menopausal status					
Pre	143	18.4			
Post	589	75.8			
Unable to categorize (missing) ^c	45 (27)	5.8			
Tamoxifen					
Use between baseline & 24 mo	350	45.0			
Use at or before baseline only	69	8.9			
No use during study period (missing) ^c	358 (27)	46.1			
Antidepressants	. /				
Currently taking at 24 mo	119	15.3			
Not currently taking at 24 mo (missing) ^c	658 (27)	84.7			

Table 1 continued

Characteristic Complete $\frac{n}{n}$	Completed	(n = 804)	Not Complet	P^{b}	
	n	%	n	%	
Months from diagno	sis to QOL survey				
23-35	193	24.0			
36-41	274	34.1			
42-47	209	26.0			
48-63	128	15.9			
$(Mean \pm SD)$		(40.5 ± 6.5)			

Note: Table 2 reports on 1108 participants that were not diagnosed with a recurrent or new primary breast cancer by the time of the QOL survey date (out of the 1183 that completed a baseline survey)

^a Includes one additional woman that provided an incomplete QOL follow-up survey (insufficient to compute psychosocial scale scores)

^b P-values are either from Fisher's exact tests for categorical variables, or from a t-test for the difference in mean age

^c Includes women with baseline and QOL data who did not complete a 24-month assessment (n = 27)

short- and long-term fatigue were related to poorer PF (P < 0.01 for all three variables), in both the unadjusted and the adjusted models.

In the fully adjusted model, race/ethnicity was related to the MH component score. Black women

reported better MH than White women (P = 0.06), whereas Hispanic women reported poorer MH than White women (P = 0.05). The variables that were found to be significant in the unadjusted model were still significantly related to the MH component score

Table 2 Mean (SD) and least-squares mean values of functional status scores by race/ethnicity and socioeconomic level [n = 771]

Characteristic		SF-36 Physica	l componen	t score	SF-36 Mental component score			
		Mean (SD)	LSM ^a	Р	Mean (SD)	LSM ^a	Р	
Education								
HS or less	194	43.8 (11.6)	41.1	0.27	49.8 (11.4)	46.7	0.27	
Some college	280	44.9 (11.0)	40.9		49.4 (10.7)	46.4		
College grad	152	48.4 (9.7)	42.8		50.7 (8.1)	48.3		
Grad school	145	48.5 (9.9)	42.2		49.8 (9.4)	47.8		
Race/Ethnicity								
Non-Hispanic White	463	47.0 (10.5)	43.0	0.01	49.2 (9.7)	46.9	< 0.01	
Black	198	43.5 (11.6)	40.4		52.7 (10.6)	50.9		
Hispanic	86	46.8 (9.2)	44.0		47.2 (10.7)	44.9		
Other	24	43.4 (13.9)	39.4		46.9 (10.5)	46.5		
Current employment					· · · ·			
Currently working	447	48.8 (9.4)	45.6	< 0.01	49.8 (9.9)	48.3	0.38	
Unemployed (on leave, looking for work)	26	43.4 (10.5)	39.8		48.4 (12.1)	46.4		
Not working outside the home/retired/disabled	298	42.0 (11.7)	39.8		50.0 (10.5)	47.2		
Income (\$)								
< = 10 K	53	38.0 (12.6)			47.6 (12.8)			
>10 K-20 K	86	41.1 (11.8)			49.5 (10.9)			
>20 K-30 K	92	46.0 (10.7)			49.9 (10.7)			
>30 K-50 K	166	46.5 (10.8)			49.8 (9.5)			
>50 K-70 K	210	48.2 (9.4)			49.8 (10.1)			
>70 K (52 missing)	112	48.9 (9.1)			49.7 (10.1)			
Overall	771	46.0 (10.9)			49.8 (10.2)			

Note: SF-36 component scales have a mean of 50 and a standard deviation of 10, with increasing scores indicating better functioning ^a Least-squares means (LSM) adjust for baseline (age in years, education level, race/ethnicity, stage at diagnosis, breast cancer treatment type) and follow-up (marital status, current employment, menopausal status, tamoxifen use, antidepressant use, months from diagnosis to quality of life survey) characteristics. Follow-up income has been excluded as a model variable due to missing data, resulting in no corresponding LSM estimate. Overall $R^2 = 0.20$ for relating to the physical component score; $R^2 = 0.11$ for relating to the mental component score. *P*-values are computed based on LSM comparisons

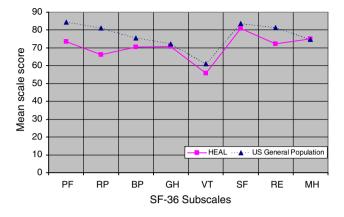


Fig. 1 Mean SF-36 subscale scores for HEAL participants [n = 771] compared with US population norms PF = Physical functioning; GH = General health; RE = Role-emotional; RP = Role-physical; VT = Vitality; MH = Mental health; BP = Bodily pain; SF = Social functioning; Note: SF-36 subscales ranged from 0–100 with increasing scores indicating better functioning

in the adjusted model. More severe cognitive/mood symptoms and greater fear of recurrence were associated with poorer MH (both P < 0.01). Less negative impact of cancer on the social/emotional domain was related to better MH (P < 0.01). Shortand long-term fatigue were significantly related to poorer MH in both unadjusted and adjusted analyses (both P < 0.01 for long-term fatigue; P = 0.01 and <0.01 for short-term fatigue). Self-reports of current lymphedema were positively and significantly related to MH summary score in the unadjusted analysis (P < 0.01), but were only borderline significantly related to MH summary scores in the adjusted analyses (P = 0.06).

Discussion

These data suggest that women who are surviving breast cancer for over two years are doing relatively well. The values for the eight scales of the SF-36 were somewhat lower than population norms, but not in all areas [24]. The clinical significance of this magnitude of decrease is debatable and is likely to represent meaningful problems for some women and insignificant changes for others, depending on resilience and other complicating factors in a given woman's life. In general, however, these results show that women without recurrent or second primary cancers are generally able to recover from the diagnosis and treatment experience and continue with their lives. These findings are supported by recent studies on long-term survivor functioning [1-3, 5]. In adjusted models, we see that the most consistent correlates of long-term MH and PF are fear of recurrence, the impact of cancer on social and emotional life, and fatigue; all symptoms that continue to be reported in long-term survivor groups.

The demographic associations identify demographic subgroups of women who report poorer physical and mental functioning. One possible explanation for the poorer PF in Black women might be that Black women are diagnosed at later stages, and later stage of diagnosis is related to different, more invasive treatment options and possibly more morbidity. In our data, Black women were more likely to be diagnosed at a later stage (data not shown) and were more likely to have lymphedema symptoms that would likely decrease their PF (data not shown). However, we controlled for disease stage and included lymphedema in the adjusted models. There could be an additional factor such as increased spirituality, social support, or better post-traumatic growth that may account for both fewer symptoms and higher MH scores in Black women.

It is interesting that current lymphedema was related to higher levels of MH summary scores. The literature (e.g., [1]) has shown the inverse relationship: persistent lymphedema is related to poorer MH outcomes. We conducted a post-hoc analysis to identify possible explanations for this unusual relationship. Black women had higher MH summary scores, as shown previously in Table 2. In our posthoc analyses, Black women accounted for almost half (46.7%) of the participants reporting current lymphedema. Because of the higher frequency of Black women in the current lymphedema group, combined with higher reported MH summary scores, the mean for the entire group may have been increased. However, the adjusted models should have taken this into account.

This study has several strengths. One is to include women from a multiethnic sample with a broad range of socioeconomic levels. Many survivorship studies have focused on small samples consisting primarily of White women. In these data we were able to compare women from different ethnic groups and women at differing levels of education and employment. Documenting demographic differences is important as we move from clinical to population-based approaches when studying cancer patients into survivorship. Another strength of this study is the use of previously developed and widely used measures, allowing for comparisons to other studies.

Characteristic			Urinary incontine	Urinary incontinence		Vasomotor		Weight/ appearance		Vaginal	
	Mean (LSM) ^a	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р	
Education											
High school or less	1.11 (1.46)	0.61	0.88 (1.19)	0.97	1.62 (1.52)	0.43	1.37 (1.76)	0.44	0.56 (0.62)	0.41	
Some college	1.04 (1.40)		0.89 (1.23)		1.60 (1.51)		1.38 (1.70)		0.55 (0.61)		
College graduate	1.04 (1.38)		0.89 (1.21)		1.52 (1.36)		1.40 (1.60)		0.47 (0.50)		
Graduate school	1.04 (1.34)		0.93 (1.24)		1.69 (1.41)		1.47 (1.58)		0.59 (0.61)		
Race/ethnicity	· /						. ,				
Non-Hispanic White	1.08 (1.39)	< 0.01	1.00 (1.30)	< 0.01	1.62 (1.54)	0.10	1.46 (1.70)	< 0.01	0.56 (0.61)	0.51	
Black	0.92 (1.16)		0.58 (0.87)		1.54 (1.30)		1.10 (1.22)		0.53 (0.53)		
Hispanic	1.17 (1.45)		0.94 (1.23)		1.63 (1.56)		1.58 (1.80)		0.50 (0.52)		
Other	1.47 (1.57)		1.21 (1.48)		1.79 (1.40)		2.06 (1.92)		0.63 (0.67)		
Current employment					. ,						
Currently working	1.05 (1.29)	0.04	0.79 (1.06)	0.08	1.72 (1.46)	0.97	1.57 (1.67)	0.41	0.53 (0.47)	0.10	
Unemployed (on leave, looking for work)	1.12 (1.42)		1.02 (1.34)		1.54 (1.46)		1.56 (1.77)		0.69 (0.71)		
Not working outside the home/ retired/disabled	1.07 (1.47)		1.05 (1.25)		1.44 (1.43)		1.14 (1.54)		0.55 (0.57)		
Income (\$)					. ,						
< = 10 K	1.28		0.94		1.36		1.19		0.48		
>10 K-20 K	1.02		0.97		1.26		1.15		0.60		
>20 K-30 K	1.08		0.98		1.48		1.34		0.47		
>30 K-50 K	1.03		0.83		1.66		1.39		0.60		
>50 K-70 K	1.08		0.98		1.81		1.60		0.53		
>70 K (52 missing)	1.00		0.73		1.60		1.50		0.55		
Overall sample mean $[\text{Overall } R^2]$	1.06	[0.122]	0.89	[0.088]	1.61	[0.179]	1.40	[0.164]	0.54	[0.098]	

Table 3 Mean and least-squares mean (LSM) values for symptoms scale scores, by race/ethnicity and socioeconomic level [n = 771]

Note: Hormone-related symptom scales were coded 0-4 with increasing scores indicating more severe symptoms

^a Least-squares means (LSM) adjust for baseline (age in years, education level, race/ethnicity, stage at diagnosis, breast cancer treatment type) and follow-up (marital status, current employment, menopausal status, tamoxifen use, antidepressant use, months from diagnosis to quality of life survey) characteristics. Follow-up income has been excluded as a model variable due to missing data, resulting in no corresponding LSM estimate. *P*-values are computed based on LSM comparisons

This study has several features that may limit the generalizability of the data. A higher proportion of women who completed the QOL follow-up assessments were White, more educated, and diagnosed at an earlier stage. However, participation was still relatively high due to the intensive follow-up procedures, and therefore we have confidence that the data from the follow-up do not show strong bias in this regard. Ethnic comparisons are not based on women equally recruited across sites, and therefore we cannot completely rule out the idea that race differences are due to center differences as much as differences among race or ethnic groups. Multiethnic samples recruited in the same ways from the same sites will address this question. Constant loss to the multiple procedures and follow-up efforts in this study resulted in a sample that is not fully generalizable to any population of cancer survivors. While this is somewhat less of a problem in the present sample, compared with other samples, one should keep this in mind when interpreting the data patterns. Finally, the study had measurement constraints of follow-up timing and survey length that resulted from the need for coordination across three distant sites.

Table 4 Mean and least-squares mean (LSM) values for BCIA and fear of recurrence scale scores, by race/ethnicity and socioeconomic level [n = 771]

Characteristic	Caregiving/ finances	Social/emo		ional Religiosity			Exercise/diet	Exercise/diet		
	Mean (LSM)	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р	Mean (LSM ^a)	Р
Education										
High school or less	0.03 (-0.00)	0.14	0.01 (-0.03)	0.18	0.54 (0.46)	0.89	0.22 (-0.00)	0.01	15.9 (16.8)	0.19
Some college	-0.07 (-0.10)		-0.06 (-0.10)		0.55 (0.49)		0.26 (0.03)		16.1 (16.9)	
College graduate	-0.06 (-0.10)		0.05 (-0.01)		0.58 (0.52)		0.53 (0.24)		15.5 (16.0)	
Graduate school	-0.07 (-0.11)		0.06(0.01)		0.60 (0.52)		0.54 (0.27)		15.8 (16.2)	
Race/Ethnicity	. ,								. ,	
Non-Hispanic	-0.07 (-0.19)	< 0.01	-0.01 (-0.15)	0.02	0.53 (0.44)	0.02	0.39 (0.09)	0.43	16.0 (16.1)	< 0.01
White					. 					
Black	-0.06 (-0.16)		-0.03 (-0.12)		0.57 (0.44)		0.27 (0.03)		14.9 (14.4)	
Hispanic	0.10 (-0.03)		0.09 (-0.04)		0.78 (0.68)		0.40 (0.13)		17.0 (16.9)	
Other	0.15 (0.07)		0.25 (0.18)		0.53 (0.43)		0.46 (0.30)		18.5 (18.4)	
Current employmen				~ ~ ~						
Currently	-0.01 (0.08)	< 0.01	0.03 (0.07)	0.05	0.62 (0.59)	0.12	0.40 (0.10)	0.34	16.0 (16.3)	0.84
working			0.40 (0.45)		0.51 (0.14)		0.50 (0.35)		160 (160)	
Unemployed (on	-0.35 (-0.25)		-0.19 (-0.15)		0.51 (0.44)		0.58 (0.27)		16.3 (16.8)	
leave, looking										
for work)					a .a (a .)					
Not working	-0.06 (-0.07)		-0.02 (-0.02)		0.48 (0.47)		0.27 (0.03)		15.6 (16.3)	
outside the										
home/retired/										
disabled										
Income (\$)	0.17		0.16		0.24		0.05		15.0	
< = 10 K	-0.17		-0.16		0.34		0.05		15.9	
>10 K - 20 K	-0.10		0.05		0.54		0.24		15.6	
>20 K - 30 K	-0.04		-0.08		0.45		0.32		15.8	
>30 K - 50 K	0.00		0.04		0.66		0.41		15.9	
>50 K - 70 K	-0.03		0.02		0.56		0.39		16.0	
> 70 K (52	-0.03		0.03		0.68		0.51		16.5	
missing)	0.04		0.00		0.57		0.26		15.0	
Overall sample	-0.04		0.00		0.57		0.36		15.9	
mean [Overall <i>R</i> ²]		[0.086]		[0.091]		[0.044]		[0.112]		[0.065]

Note: BCIA scores were centered at 0 (no impact), with values ranging from -2 (very negative impact) to +2 (very positive impact); Fear of recurrence was coded 5–25 with higher scores indicating higher fear of recurrence

^a Least-squares means (LSM) adjust for baseline (age in years, education level, race/ethnicity, stage at diagnosis, breast cancer treatment type) and follow-up (marital status, current employment, menopausal status, tamoxifen use, antidepressant use, months from diagnosis to quality of life survey) characteristics. Follow-up income has been excluded as a model variable due to missing data, resulting in no corresponding LSM estimate. *P*-values are computed based on LSM comparisons

Overall, these data indicate that race/ethnicity and socioeconomic factors are important determinants of QOL in long term survivors. The final regression models explained a large amount of variance in QOL, 38 and 41% of the variance in physical and mental scores, respectively. Racial/ethnic and socioeconomic variables remained significant in these models after adjustment. These data suggest that race/ethnicity and socioeconomic status represent health disparities that are important for breast cancer survivors. Given the relative importance of these demographic variables on functioning, future studies should address interventions to reduce negative functioning in these groups.

Acknowledgements This manuscript presents original data from our study. A portion of these data were presented at the Cancer Survivorship Pathways to Health meeting of the National Cancer Institute, June 2004.This research was supported by research contracts from the National Cancer Institute (N01-CN-75036-20, N01-CN-05228, N01-PC-67010) and by a training grant from the National Cancer Institute (R25 CA92408)

Characteristic	SF-36 Physic	cal comp	onent score		SF-36 mental component score				
	β (SE)	Р	β (SE) ^b	Р	β (SE)	Р	β (SE) ^b	Р	
Education									
High school or less			-0.25 (1.06)	0.82			-0.03 (0.98)	0.98	
Some college			-0.75 (0.95)	0.43			-0.52 (0.88)	0.55	
College graduate			0.36 (1.05)	0.73			0.05 (0.96)	0.96	
Graduate school [referent]			0.00 (-)	-			0.00 (-)	-	
Race/ethnicity									
Non-Hispanic White [referent]			0.00 (-)	-			0.00 (-)	-	
Black			-3.42 (0.99)	< 0.01			1.72 (0.91)	0.06	
Hispanic			0.27 (1.11)	0.81			-2.02 (1.02)	0.05	
Other			-3.75 (1.92)	0.05			0.54 (1.77)	0.76	
Current employment			. ,				. ,		
Currently working [referent]			0.00 (-)	-			- (-)	-	
Unemployed (on leave, looking for			-5.35 (1.86)	< 0.01			-1.12 (1.71)	0.51	
work)									
Not working outside the home/retired/			-4.80 (0.87)	<.01			-0.03 (0.80)	0.97	
disabled									
Physiological/psychosocial variables Sympt	oms								
Cognitive/mood	-1.16 (0.57)	0.04	-0.75 (0.54)	0.16	-4.22 (0.48)	< 0.01	-3.84 (0.50)	< 0.01	
Urinary incontinence	-1.29 (0.36)	< 0.01	-0.70 (0.34)	0.04	0.12 (0.30)	0.69	0.18 (0.31)	0.56	
Vasomotor	0.58 (0.36)	0.11	0.00 (0.35)	0.99	0.28 (0.30)	0.36	0.14 (0.33)	0.66	
Weight/appearance	0.67 (0.35)	0.06	-0.28 (0.35)	0.42	-0.12 (0.30)	0.68	0.14 (0.32)	0.66	
Vaginal	-0.28 (0.51)	0.58	-0.35 (0.49)	0.47	-0.07 (0.43)	0.87	-0.25 (0.45)	0.58	
Brief cancer impact assessment scales									
Caregiving/finances	2.26 (0.92)	0.01	2.45 (0.88)	0.01	0.68(0.78)	0.38	0.67 (0.81)	0.41	
Social/emotional	-1.17 (0.84)	0.16	-1.71 (0.79)	0.03	2.23 (0.71)	< 0.01	2.10 (0.73)	< 0.01	
Religiosity	0.66 (0.56)	0.24	0.32 (0.52)	0.54	-0.92 (0.47)	0.05	-0.90 (0.48)	0.06	
Exercise/diet	2.59 (0.50)	<.01	2.11 (0.48)	<.01	0.62 (0.42)	0.14	0.69 (0.44)	0.12	
Fear of recurrence	-0.12 (0.08)	0.16	-0.16 (0.08)	0.04	-0.43 (0.07)	< 0.01	-0.42 (0.07)	< 0.01	
Fatigue									
Long-term fatigued	-7.00 (0.98)	< 0.01	-6.99 (0.92)	<.01	-6.03 (0.83)	< 0.01	-6.00 (0.84)	< 0.01	
Short-term fatigued	-4.68(0.85)	< 0.01	-3.66(0.84)	<.01	-1.76(0.72)	0.01	-2.63 (0.77)	< 0.01	
Never fatigued [referent]	0.00 (-)	-	0.00 (-)	_	0.00 (-)	-	0.00 (-)	-	
Self-reported lymphedema									
Current lymphedema	-3.80 (1.04)	< 0.01	-3.14 (1.00)	< 0.01	2.50 (0.88)	< 0.01	1.76 (0.92)	0.06	
Past lymphedema	-1.66 (1.47)	0.26	-2.08 (1.39)	0.13	0.40 (1.24)	0.75	0.57 (1.27)	0.65	
Never lymphedema [referent]	0.00 (-)	_	0.00 (-)	_	0.00 (-)	-	0.00 (-)	-	
[Overall R^2]		[0.235]		[0.380]		[0.386]		[0.411]	

Table 5 Linear regression models relating functional status scores to physiological and psychosocial variables and background characteristics $[n = 767]^a$

Note: SF-36 component scales have a mean of 50 and a standard deviation of 10, with increasing scores indicating better functioning; Hormone-related symptom scales were coded 0-4 with increasing scores indicating more severe symptoms; BCIA scores were centered at 0 (no impact), with values ranging from -2 (very negative impact) to +2 (very positive impact); Fear of recurrence was coded 5–25 with higher scores indicating higher fear of recurrence

^a Excludes data from four additional women with unknown duration of fatigue

^b Multiple regression model includes baseline (age in years, education level, race/ethnicity, stage at diagnosis, breast cancer treatment type) and follow-up (marital status, current employment, menopausal status, tamoxifen use, antidepressant use, months from diagnosis to QOL survey) characteristics, and twelve physiological/psychosocial variables (symptoms, impact of breast cancer, fear of recurrence, fatigue, and lymphedema)

References

- Kornblith AB, Ligibel J (2003) Psychosocial and sexual functioning of survivors of breast cancer. Semin Oncol 30:799–813
- Ganz PA, Desmond KA, Leedham B et al (2002) Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. J Natl Cancer Inst 94:39–49
- Giedzinska AS, Meyerowitz BE, Ganz PA et al (2004) Health-related quality of life in a multiethnic sample of breast cancer survivors. Ann Behav Med 28:39–51

- Ganz PA, Rowland JH, Meyerowitz BE et al (1998) Impact of different adjuvant therapy strategies on quality of life in breast cancer survivors. Recent Results Cancer Res 152:396– 411
- Ganz PA, Rowland JH, Desmond K et al (1998) Life after breast cancer: understanding women's health-related quality of life and sexual functioning. J Clin Oncol 16:501–514
- Bower JE, Ganz PA, Desmond KA et al (2006) Fatigue in long-term breast carcinoma survivors: a longitudinal investigation. Cancer 106:751–758

- Adler NE, Newman K (2006) Socioeconomic disparities in health: pathways and policies. Inequality in education, income, and occupation exacerbates the gaps between the health "haves" and "have-nots." Health Aff (Millwood) 21:60–76
- Adler NE (2003) Community preventive services. Do we know what we need to know to improve health and reduce disparities? Am J Prev Med 24:10–11
- Rietman JS, Dijkstra PU, Hoekstra HJ et al (2003) Late morbidity after treatment of breast cancer in relation to daily activities and quality of life: a systematic review. Eur J Surg Oncol 29:229–238
- Bower JE, Ganz PA, Desmond KA et al (2000) Fatigue in breast cancer survivors: occurrence, correlates, and impact on quality of life. J Clin Oncol 18:743–753
- 11. Andersen MR, Peacock S, Nelson J et al (2002) Worry about ovarian cancer risk and use of ovarian cancer screening by women at risk for ovarian cancer. Gyn Oncol 85:3–8
- Irwin ML, Tworoger SS, Yasui Y et al (2004) Influence of demographic, physiologic, and psychosocial variables on adherence to a yearlong moderate-intensity exercise trial in postmenopausal women. Prev Med 39:1080–1086
- Patel AV, Press MF, Meeske K et al (2003) Lifetime recreational exercise activity and risk of breast carcinoma in situ. Cancer 98:2161–2169
- Meeske K, Press M, Patel A et al (2004) Impact of reproductive factors and lactation on breast carcinoma in situ risk. Int J Cancer 110:102–109
- 15. Marchbanks PA, McDonald JA, Wilson HG et al (2002) The NICHD women's contraceptive and reproductive experi-

ences study: methods and operational results. Ann Epidem-iol 12:213-221

- Marchbanks PA, McDonald JA, Wilson HG et al (2002) Oral contraceptives and the risk of breast cancer. N Engl J Med 346:2025–2032
- 17. Hays RD, Sherbourne CD, Mazel RM (1993) The RAND 36-item health survey 1.0. Health Econ 2:217–227
- Ware JE Jr (1996) The SF-36 health survey. In: Spilker B (ed) Quality of life and pharmacoeconomics in clinical trials. 2nd ed. Lippincott-Raven, Philadelphia, pp 337–345
- Alfano CM, McGregor BA, Kuniyuki A, Reeve BB, Bowen DJ, Baumgartner KB, Bernstein L, Ballard-Barbash R, Malone K, Ganz PA, McTiernan A (2006). Psychometric assessment of hormone-related symptoms among breast cancer survivors. PsychoOncology, 70:190–202
- 20. Alfano CM, McGregor BA, Kuniyuki A et al (In press b) Psychometric evaluation of the brief cancer impact scale among breast cancer survivors. Oncology
- 21. Northouse LL (1981) Mastectomy patients and the fear of cancer recurrence. Cancer Nurs 4:213–220
- 22. Muthen LK, Muthen BO (1998) Mplus user's guide. Muthen and Muthen, Los Angeles
- 23. Ware JE (1993) SF 36 health survey: manual and interpretation guide. The Health Institute New England Medical Center, Boston
- Yost KJ, Haan MN, Levine RA et al (2005) Comparing SF-36 scores across three groups of women with different health profiles. Qual Life Res 14:1251–1261