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Research

Quality of life of 5–10 year breast cancer survivors diagnosed between age 40 and 49

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Abstract

Background: The purpose of this report is to examine the correlates of quality of life (QOL) of a well-defined group of long-term breast cancer survivors diagnosed between the ages of 40 and 49.

Methods: Women were eligible if they were diagnosed with invasive breast cancer or ductal carcinoma *in situ* 5 to 10 years before June 30, 1998 and were enrolled at Group Health Cooperative, a health maintenance organization in western Washington State. A questionnaire was mailed to 290 women; 216 were included in this analysis. The questionnaire included standardized measures of QOL [e.g., the Cancer Rehabilitation Evaluation System (CARES-SF) and SF-36] as well as general demographic and medical information. ANOVA and logistic regression were used to estimate correlates of self-reported QOL.

Results: The mean age at diagnosis was 44.4 years, and the average time since diagnosis was 7.3 years. Women reported high levels of functioning across several standardized QOL scales; mild impairment was found on the CARES-SF Sexual Scale. The presence of breast-related symptoms at survey, use of adjuvant therapy, having lower income, and type of breast surgery were significantly associated with lower QOL 5 to 10 years post-diagnosis on one or more of the scales.

Conclusions: Our results emphasize that younger long-term survivors of breast cancer have a high QOL across several standardized measures. However, the long-term consequences of adjuvant therapy and the management of long-term breast-related symptoms are two areas that may be important for clinicians and women with breast cancer in understanding and optimizing long-term QOL.

Background

With an incidence rate of 135 women per 100,000 per year, breast cancer is the most common type of cancer affecting women [1]. Treatment for breast cancer usually involves the removal of all or part of one or both breasts. Women may also receive radiation therapy and/or chemotherapy plus systemic hormonal therapy for breast cancer treatment depending on stage and estrogen receptor status at diagnosis. Long-term consequences of therapy include painful and often debilitating lymphedema due

to surgery or radiation therapy, and reduced vaginal lubrication and hot flashes due to long-term hormonal therapy.

The five-year rate of survival from all invasive breast cancers is 86.6%, but can be as high as 97.0% in localized cases [1]. In the last decade, successes in breast cancer screening and treatment have led to an increase in the number of long-term survivors of breast cancer, now the largest group of female cancer survivors [2]. With this rise in survival, there has been increased interest in the quality of life (QOL) and consequences of therapy for breast cancer survivors. Though there has been a great deal of research aimed at understanding the quality of life of breast cancer patients, most of the research has focused on the early years of treatment (up to five years post-diagnosis) and older women with the disease [3-5]. Some studies have examined QOL up to 10 years post-diagnosis [6-9]. Studies have generally reported good or adequate global QOL with lingering sexual issues, psychosocial concerns, and physical symptoms such as pain.

The purpose of this report was to evaluate the QOL of a well-defined population-based group of younger long-term survivors of breast cancer who were diagnosed between 40 and 49 years of age. Several standardized measures of QOL were examined. Further, we sought to identify correlates of QOL among this group 5 to 10 years post-diagnosis in an effort to assist health care providers and survivors in assessing potentially important factors impacting the growing number of women living beyond a breast cancer diagnosis.

Methods

Study setting & sample selection

The study was conducted at Group Health Cooperative (GHC), a large non-profit group-model health maintenance organization (HMO) in Western Washington State, with the approval of the GHC Human Subjects Review Committee and informed consent of study participants. Eligible participants were all women with an initial diagnosis of ductal carcinoma *in situ* (DCIS) or invasive breast cancer 5 to 10 years before June 30, 1998. Women had to be between the ages of 40 and 49 years and still alive when they were recruited in January 1999. Study participants were identified using the western Washington Surveillance Epidemiology and End Results (SEER) cancer registry and through self-reported information on breast cancer diagnoses collected through the GHC Breast Cancer Screening Program (BCSP)[10]. The self-reported BCSP data were used to capture breast cancer diagnoses occurring before enrollment at GHC or outside the SEER catchment area.

Data collection procedures & instruments

Eligible women were mailed an invitation letter, a 22 paged self-administered questionnaire, and a postage paid return envelope in January 1999 (N = 290). In order to maximize response rates, questionnaires were mailed using a four-wave approach, based on methods described by Dillman [11] and Armstrong et al [12]. Of the 290 eligible participants, 217 women returned completed surveys. One woman was excluded due to a diagnosis of lobular carcinoma *in situ* that was identified after survey completion for a final sample size of 216; 74.5% of the initial sample.

QOL measures & depression

The questionnaire included several standardized measures of QOL, a depression scale, a demographic and medical history section, and a battery of questions pertaining to genetic testing that have been described elsewhere [13]. QOL was evaluated using two validated health-related QOL instruments, the Cancer Rehabilitation Evaluation System-Short Form (CARES-SF)[14] and the SF-36 Health Survey (SF-36)[15].

The CARES-SF was developed to assess rehabilitation and QOL among cancer patients and has been described in detail [14]. Briefly, the scale consists of 59 self-administered items. Together the items are used to generate a single global score as well as 5 sub-scores representing the following domains: physical, psychosocial, medical, marital and sexual functioning. The CARES-SF rates the degree to which a given problem applied during the 4 weeks before the survey. Scoring is based on a four point Likert scale from 0 (not at all) to 4 (very much), with higher scores indicating more difficulty or impairment.

The SF-36 is a generic health outcome measure that is designed for use across varied populations [15]. It is comprised of 36 items across eight scales: physical functioning, role function-physical, bodily pain, general health, vitality, social functioning, role function-emotional, and mental health. Each scale is scored from 0 to 100, with higher values indicating more favorable health status. Together these scales may be combined to form two summary measures, the Physical Health Summary (PCS) and the Mental Health Summary (MCS). The summary measures are computed as T-scores with a mean of 50 and a standard deviation of 10 in the general U.S. population [16]. A score of 40 represents one standard deviation below the mean for the general US population.

We included the Center for Epidemiologic Studies Depression Scale (CES-D) as a measure of the severity of depression [17]. The 20-point scale was designed to measure the severity of depressive symptoms in the general population the week before the survey. Individual items

are scored on a four-point scale and the overall score ranges from 0 to 60, with a higher score indicating more depressive symptoms. A score greater than or equal to 16 indicates potentially significant levels of depression [17].

Covariates

Covariates were collected through the self-administered questionnaire and GHC automated data. We used the extent of disease collected by SEER to calculate the American Joint Committee on Cancer's tumor-node-metastases (TNM) stage at diagnosis [18]. We combined automated GHC hospitalization and utilization data as well as self-reported data from women on their survey with SEER data to generate categories for surgical treatment (breast conserving therapy (BCT), mastectomy with and without reconstruction), systemic adjuvant therapy (chemotherapy, hormonal therapy), and radiation therapy. We used the most invasive surgical procedure to generate mutually exclusive categories for women who had more than one procedure. We combined self-reported data and SEER data to identify women who experienced a recurrence.

We ascertained demographic characteristics including race, income, education, marital status, age at diagnosis, and employment status by self-reported data at the time of the survey. The questionnaire included various health characteristics such as: smoking status, menopausal status, presence of breast-related symptoms at survey (e.g., pain, arm edema, localized numbness), and use of recent breast and cervical cancer screening (last mammogram 1, 2, 3, 5, or >5 years ago; Pap smear during the past 4 years). We used GHC's automated pharmacy data to compute the Chronic Disease Score (CDS), a marker variable used to assess the degree of comorbid conditions [19]. The CDS was computed for the year before diagnosis as well as the year before the survey date. The CDS ranges from 0 to 31 and is based on a weighted average of prescribed medications [19]. For all analyses, the CDS was categorized as low (0), medium (1–3) and high (4–31) based on prior work [20,21].

Statistical analysis

Our outcome variables included 5 summary scales, the CARES-SF Global Score, the CARES-SF Sexuality Score, the SF-36 PCS and MCS, and the CES-D. We looked at all of the CARES-SF subscales, the Sexuality Score was included because it was the only subscale where a difference was seen (markedly higher indicating more impairment). We dichotomized the outcome variables as high or normal QOL versus low QOL based on potentially clinically important cut points (PCS, MCS, CESD) [16,17] or tertiles where the two highest tertiles of QOL were compared to the lowest tertile of QOL (CARES-SF Global, CARES-SF Sexuality). Scales were categorized as high or normal QOL versus low QOL as follows: PCS and MCS, >40 or ≤ 40; CES-D, <16 or ≥ 16; CARES-SF Global, ≤ .70 or >.70, CARES-SF Sexuality, < 2.0 or ≥ 2.0. Dichotomizing each of the outcome variables, resulted in the following proportions of women with normal to high QOL versus low QOL: PCS: 79.6% normal to high, 20.4% low; MCS: 73.7% normal to high, 26.3% low; CARES-SF Global: 64.4% normal to high, 35.6% low; CARES-SF Sexuality 66.9% normal to high, 33.1% low; CESD 69.7% normal to high, 30.3% low.

We used analysis of variance to assess differences in the QOL scales by adjuvant therapy and the presence of symptoms at survey. We used logistic regression to examine QOL outcome variables in relation to groups of covariates. Covariates were divided into the three general groups of related variables for analytic purposes: tumor characteristics and treatment, demographic characteristics, and health characteristics in an approach similar to that of Ganz et al [6]. For each outcome variable, we completed individual forward stepwise regression family models to identify statistically significant correlates (p-value ≤ 0.10) within each group of covariates. For each outcome variable, we included the significant correlates (p-value ≤ 0.05) of QOL from each family model for the final stepwise model; resulting in 5 separate multivariate models. All analyses were completed using Stata statistical software, version 6 [22].

Results

There were no statistically significant differences in means between questionnaire respondents (n = 217) and non-respondents (n = 73) in age at diagnosis, years since initial diagnosis, health care utilization, and type of cancer. Among the 216 eligible respondents, the average age at initial diagnosis was 44.4 years of age (range, 40–49 years) (nonrespondent average, 44.2 years; range 40–49) and the average number of years between initial diagnosis and survey date was 7.2 years (range, 5–10 years) (nonrespondent average, 7.1 years; range 5–10 years).

Thirty-three women (15.3% of all respondents) experienced a second breast cancer or a recurrence between the initial diagnosis and the survey date; one woman had two recurrences or new breast cancers (Table 1). The average time between the second diagnosis or recurrence and survey was 2.5 years. Just under 70% of women had a diagnosis of invasive breast cancer, 13.0% had DCIS, and 17.6% were missing histology information. Study participants had been enrolled at GHC for an average of 16 years at the time of survey completion. All women reported some type of surgical treatment (BCT 45.8%; Mastectomy 54.2%) and 15.8% reported having no systemic adjuvant therapy (chemotherapy or hormonal therapy) or radiation therapy. One-third (33.7%) reported breast-related symptoms at survey. The presence of comorbidities was

Table 1: Selected demographic and health characteristics by QOL summary scores.*

Variable	N = 216 %	SF-36 Physical	SF-36 Mental	CARES-SF Global	CARES-SF Sexuality	CES-D
			Mean (Standard Deviation)			
Scale average		48.6 (11.5)	46.8 (11.3)	0.6 (0.5)	1.4 (1.2)	11.8 (10.6)
Tumor node and metastates stage						
0	13.0	52.2 (7.9)	48.1 (11.2)	0.4 (0.4)	0.9 (1.1)	10.3 (10.3)
I	29.2	48.1 (10.2)	46.3 (10.4)	0.6 (0.5)	1.5 (1.1)	12.5 (10.7)
IIA & IIB	29.6	48.2 (11.7)	46.29 (11.3)	0.7 (0.5)	1.8 (1.4)	12.2 (11.2)
III & IV	6.0	42.6 (15.0)	44.6 (11.3)	0.8 (0.6)	1.8 (1.2)	15.1 (11.9)
Missing	22.2	49.1 (13.3)	47.8 (12.8)	0.6 (0.4)	1.2 (1.1)	10.2 (9.6)
Age at survey						
45–49 yrs	26.1	49.7 (11.9)	44.9 (12.5)	0.7 (0.5)	1.5 (1.2)	13.6 (12.4)
50–54 yrs	51.2	48.0 (11.5)	47.5 (10.8)	0.6 (0.4)	1.3 (1.2)	10.9 (9.3)
55–60 yrs	22.8	48.7 (11.3)	47.2 (11.1)	0.6 (0.5)	1.6 (1.3)	11.8 (11.0)
Breast cancer recurrence since diagnosis						
No	84.7	48.7 (11.1)	46.9 (11.5)	0.6 (0.5)	1.4 (1.2)	11.6 (10.5)
Yes	15.3	48.5 (13.4)	46.3 (10.6)	0.7 (0.5)	1.6 (1.3)	12.7 (11.3)
Presence of breast-related symptoms at survey						
No	62.3	50.9 (9.4)	48.2 (11.0)	0.5 (0.4)	1.3 (1.2)	9.9 (9.1)
Yes	37.7	44.9 (13.5)	44.2 (11.3)	0.8 (0.6)	1.7 (1.3)	15.1 (12.1)
Type of breast symptom among women with symptoms at survey (not mutually exclusive)						
Pain	19.4	44.2 (12.6)	41.2 (10.4)	0.9 (0.6)	2.1 (1.3)	17.4 (12.2)
Swelling	10.3	44.8 (14.7)	47.0 (9.1)	0.7 (0.6)	1.7 (1.3)	12.4 (11.5)
Numbness	3.3	55.2 (7.2)	45.4 (13.7)	0.5 (0.3)	1.2 (0.8)	13.4 (17.0)
Other	8.4	43.0 (14.1)	45.4 (11.1)	0.6 (0.4)	1.1 (1.5)	14.2 (8.9)
Type of surgery (mutually exclusive)						
Breast conserving therapy	45.8	50.6 (10.0)	46.0 (12.1)	0.6 (0.5)	1.5 (1.3)	12.3 (11.9)
Mastectomy	54.2	47.0 (12.3)	47.4 (10.7)	0.6 (0.5)	1.4 (1.1)	11.3 (9.4)
Type of therapy (not mutually exclusive)						
None	15.8	51.2 (10.6)	46.6 (12.6)	0.4 (0.3)	0.7 (0.7)	11.7 (9.9)
Radiation	62.8	49.5 (10.8)	46.5 (11.4)	0.6 (0.5)	1.6 (1.3)	12.1 (11.3)
Chemotherapy	54.9	46.8 (12.6)	46.1 (11.3)	0.7 (0.5)	1.8 (1.2)	12.4 (10.7)
Hormonal therapy	37.2	46.9 (11.8)	45.5 (11.3)	0.6 (0.5)	1.7 (1.1)	12.8 (11.5)
Menopausal status						
Pre or peri-menopausal	16.4	49.8 (10.6)	50.6 (9.4)	0.6 (0.6)	1.0 (1.3)	9.1 (10.5)
Postmenopausal	83.6	48.3 (11.6)	46.1 (11.5)	0.6 (0.5)	1.5 (1.2)	12.3 (10.6)
Health behaviors						
Current smoker	9.3	43.8 (15.2)	45.3 (9.7)	0.8 (0.6)	1.8 (1.6)	15.2 (11.8)
Non-smoker	90.7	49.1 (11.0)	46.9 (11.5)	0.6 (0.5)	1.4 (1.2)	11.4 (10.4)
Last Pap smear < 4 years ago	90.0	49.3 (11.3)	47.2 (11.0)	0.6 (0.5)	1.4 (1.2)	11.3 (10.3)
Last Pap smear ≥4 years ago	10.0	44.0 (11.6)	45.6 (11.2)	0.7 (0.5)	1.7 (1.1)	13.8 (11.5)
Last mammogram <2 years ago	89.1	49.6 (10.5)	46.5 (11.0)	0.6 (0.5)	1.4 (1.2)	11.6 (10.2)
Last mammogram ≥2 years ago	10.9	40.8 (15.6)	49.8 (11.7)	0.8 (0.6)	1.6 (1.3)	13.0 (12.4)
Education						
≤ High school	21.7	46.6 (13.0)	47.0 (11.4)	0.7 (0.5)	1.6 (1.2)	12.0 (9.2)
Some college/technical school	36.8	47.3 (11.9)	45.5 (12.2)	0.7 (0.5)	1.5 (1.3)	14.6 (12.2)
≥ College graduate	41.5	51.1 (9.7)	48.1 (9.9)	0.5 (0.4)	1.2 (1.1)	8.9 (8.6)
Ethnicity						
Non-Caucasian	7.6	47.4 (13.6)	49.5 (13.2)	0.7 (0.8)	1.4 (1.4)	12.8 (15.5)
Caucasian	92.4	48.9 (11.3)	46.7 (11.0)	0.6 (0.5)	1.4 (1.2)	11.5 (10.0)
Employment status at survey (N = 189)						
Employed	76.2	49.7 (11.0)	46.9 (11.3)	0.6 (0.5)	1.5 (1.2)	11.2 (10.2)
Unemployed	23.8	46.3 (13.2)	46.7 (12.6)	0.7 (0.6)	1.5 (1.2)	13.1 (12.2)

Table 1: Selected demographic and health characteristics by QOL summary scores.* *(Continued)*

Income (N = 198)						
<$35,000	23.1	43.4 (14.4)	45.1 (11.7)	0.8 (0.6)	1.7 (1.2)	14.4 (11.2)
$35,001–75,000	43.1	49.9 (10.2)	45.8 (11.3)	0.6 (0.5)	1.4 (1.2)	11.6 (10.2)
>$75,000	33.9	51.6 (9.2)	49.3 (10.5)	0.5 (0.4)	1.3 (1.2)	9.8 (10.2)
Chronic disease score at survey						
0	53.2	50.3 (10.6)	47.5 (10.9)	0.5 (0.4)	1.4 (1.3)	11.2 (10.1)
1 to 3	25.9	50.3 (8.7)	47.0 (12.8)	0.6 (0.5)	1.5 (1.1)	11.3 (12.1)
≥4	20.8	42.2 (14.3)	44.8 (10.4)	0.7 (0.5)	1.5 (1.2)	13.9 (9.7)

*Scoring: SF-36 subscales 0 to 100 with higher scores indicating higher QOL; CESD 0 to 60 with higher score indicating more depressive symptoms; CARES-SF 0–4 with higher score indicating more difficulty or impairment.

low in this population; over half (53%) of the study participants had a comorbidity score of zero. In general, women with presence of breast-related symptoms at survey had lower QOL scores than women without breast-related symptoms across the outcome measures (Table 1). A weaker relationship was present for women with any type of therapy compared to those with no therapy. The SF-36 summary scores indicate that study participants were less than a quarter of a standard deviation below the US norm on the PCS and approximately a third of a standard deviation below the US norm on the MCS [17].

Analysis of variance results are presented for subscales of SF-36 and CARES-SF by systemic adjuvant therapy (Table 2) and presence of symptoms (Table 3). Women who did not receive systemic adjuvant therapy had higher QOL than women who received any systemic adjuvant therapy on several SF-26 subscales (physical role function, general health, social functioning, and the PCS summary scale) (Table 2). Similarly, scores indicating higher QOL were seen for the CARES-SF Global, Physical, Psychosocial, and Sexual subscales among women with no systemic adjuvant therapy compared to women who received any systemic adjuvant therapy. Women with breast-related symptoms at survey had lower QOL on all SF-36 subscales and all but one (CARES Medical) CARES-SF subscales (Table 3). Breast-related symptoms were reported in an open-ended format that was further categorized into pain, swelling, numbness, and miscellaneous symptoms. When examining the relationship of these specific symptoms to QOL, pain was by far the strongest correlate. When pain was substituted for the presence of breast-related symptoms in the multivariate logistic regression model, these associations were stronger, but became less stable (data not presented).

Table 4 shows five separate multivariate models resulting from forward stepwise regression. Each column represents a different model. We present the odds ratios for variables that were included in the model and represent multivariate odds ratios (e.g., adjusted for all variables in the model). For example, the components for the PCS model included breast-related symptoms at survey, annual income, chemotherapy, and type of surgery. In that example, the odds ratio for women with breast-related symptoms at survey were 3.7 times more likely to have lower QOL than women without breast-related symptoms at survey. In multivariate modeling, across all outcome variables, women who reported breast-related symptoms at the time of survey were significantly more likely to report lower QOL than women without breast-related symptoms even after an average of 7.2 years after initial diagnosis. Time since diagnosis was not associated with QOL outcomes in any of the models. Women with a combined family income over $75,000/year were less likely to report low QOL than women with income levels below $35,000/year, measured by the PCS, MCS and CARES-SF Global Scale. Women who underwent chemotherapy between their diagnosis and the time of the survey were significantly more likely to have lower QOL measured by the PCS, CARES-SF Global and CARES-SF Sexuality Scales than women who did not have chemotherapy (PCS odds ratio (OR) = 2.41; 95 % confidence interval (CI) 1.03–5.66. CARES-SF Global OR 3.14; 95% CI 1.59–6.21. CARES-SF Sexuality OR 3.38; 95% CI 1.64–6.98). Women who had a mastectomy were 2.60 times more likely to have a lower QOL on the PCS than women who had a BCT as treatment. Individuals having a mammogram within the two years before the survey were significantly less likely to have lower QOL on the CARES-SF than women who had not had a mammogram within the last two years.

Discussion

This report describes the QOL of an important yet understudied population of breast cancer survivors, namely women who are diagnosed with breast cancer at a young age and who become long-term survivors. The results of this study support prior findings that younger women are resilient following a diagnosis of breast cancer and have similar QOL in multiple areas to women who have not had breast cancer [4,6-8]. However, our results do suggest

Table 2: Mean values for quality of life sub-scales by systemic adjuvant treatment.*

	Chemotherapy + Hormonal Therapy N = 59	Chemotherapy N = 59	Hormonal Therapy N = 21	No Systemic Adjuvant Therapy N = 76	P-value†
SF-36 sub scales					
Physical Functioning	75.6	78.7	85.5	84.5	.08
Role Function-Physical	62.5	72.8	75.0	81.7	.02
Bodily Pain	67.7	69.6	72.6	75.4	.10
General Health	63.4	68.8	73.6	73.8	.05
Vitality	47.4	54.6	51.5	56.3	.12
Social Functioning	73.7	74.6	76.9	83.7	.01
Role Function-Emotional	69.1	66.7	60.0	76.8	.07
Mental Health	68.3	70.2	69.0	72.8	.16
SF-36 PCS	45.5	48.0	50.9	50.7	.05
SF-36 MCS	45.9	46.3	44.4	48.3	.14
CESD	13.1	11.7	12.0	10.8	.33
CARES-SF sub scales					
CARES Physical	0.6	0.6	0.5	0.3	<.01
CARES Medical	0.4	0.6	0.3	0.4	.29
CARES Psychosocial	0.7	0.8	0.7	0.6	.02
CARES Sexual	1.8	1.8	1.2	1.0	<.01
CARES Marital	0.7	0.8	0.4	0.4	.01
CARES Global	0.7	0.7	0.6	0.5	<.01

*Scoring: SF-36 subscales 0 to 100 with higher scores indicating higher QOL; CESD 0 to 60 with higher score indicating more depressive symptoms; CARES-SF 0–4 with higher score indicating more difficulty or impairment. † P value is for the comparison of women who received any adjuvant therapy to those who received no adjuvant therapy based on ANOVA.

Table 3: Mean values for quality of life sub-scales by presence of breast related symptoms at the time of survey.*

	Pain N = 42	Other symptoms N = 38	No symptoms N = 132	P-value†
SF-36 sub scales				
Physical functioning	70.2	74.9	85.7	<.01
Role function, physical	58.3	63.2	81.0	<.01
Bodily pain	57.0	68.9	77.0	<.01
General health	62.2	65.9	72.6	.01
Vitality	42.0	50.0	57.2	<.01
Social functioning	64.9	77.4	81.8	<.01
Role function, emotional	49.2	73.0	76.3	<.01
Mental health	62.1	70.2	73.0	<.01
SF-36 PCS	44.2	45.6	50.9	<.01
SF-36 MCS	41.2	47.6	48.2	.01
CESD	17.4	12.6	9.9	<.01
CARES-SF sub scales				
CARES Physical	0.8	0.6	0.3	<.01
CARES Medical	0.6	0.3	0.4	.47
CARES Psychosocial	1.1	0.7	0.6	<.01
CARES Sexual	2.1	1.4	1.3	.02
CARES Marital	1.0	0.5	0.5	.02
CARES Global	0.9	0.6	0.5	<.01

*Scoring: SF-36 subscales 0 to 100 with higher scores indicating higher QOL; CESD 0 to 60 with higher score indicating more depressive symptoms; CARES-SF 0–4 with higher score indicating more difficulty or impairment. † P value is for the comparison of women with presence of any symptoms at survey to those with no symptoms based on ANOVA.

Table 4: Odds ratios (OR)* and 95% confidence intervals (CI) of low QOL on SF-36 PCS and MCS, CARES-SF global score, CARES-SF sexuality scale, and CES-D in 217 women aged 40–49 at the time of their diagnosis of breast cancer, according to selected characteristics using forward stepwise logistic regression.

Characteristics	SF-36 PCS[A]	SF-36 MCS[B]	CARES-SF Global Scale[C]	CARES-SF Sexuality Scale[D]	CESD[E]
			Odds Ratio (95% CI)		
Breast-related symptoms at survey					
No	1.0	1.0	1.0	1.0	1.0
Yes	3.7 (1.6–8.2)	2.3 (1.2–4.6)	3.1 (1.6–6.1)	3.1 (1.5–6.3)	2.6 (1.4–4.9)
Annual income					
<$35,000	1.0	1.0	1.0		
$35,001–75,000	0.3 (0.1–0.8)	1.2 (0.5–2.8)	0.4 (0.2–0.9)		
>$75,000	0.2 (0.1–0.5)	0.4 (0.1–1.0)	0.3 (0.1–0.7)		
Chemotherapy (between diagnosis and survey)					
No	1.0		1.0	1.0	
Yes	2.4 (1.0–5.7)		3.1 (1.6–6.2)	3.4 (1.6–7.0)	
Type of surgery					
Breast Conserving Therapy	1.0				
Mastectomy	2.6 (1.1–6.1)				
Education					
≤ High school					1.0
Some college/technical school					2.4 (1.0–5.4)
≥ College graduate					0.7 (0.3–1.6)
Last mammogram					
≥2 years			1.0		
< 2 years			0.3 (0.1–0.9)		

A. OR represents the odds of having low QOL (≤ 40.0) compared to high QOL (>40.0) on the PCS. B. OR represents the odds of having low QOL (≤ 40.0) compared to high QOL (>40.0) on the MCS. C. OR represents the odds of having low QOL (>.70) compared to high QOL (≤ .70) on CARES-SF Global. D. OR represents the odds of having low QOL (≥ 2.0) compared to high QOL (<2.0) on CARES-SF Sexuality. E. OR represents the odds of having more depressive symptoms (≥ 16) compared to fewer depressive symptoms (<16) on CESD.

some impairment in the areas of emotional health and well being. Similar findings have been reported elsewhere [4,23]. The results presented indicate high functioning on cancer-specific factors as summarized by the CARES-SF Global Score. Women reported more difficulty with sexual issues than in the other CARES-SF sub-scales, a finding that is fairly consistent with other studies and expected given the age range of our population [8].

Unlike other studies [4,6], we found that the type of surgery significantly impacted long-term QOL as measured by the SF-36 PCS; this was the only QOL measure significantly impacted by type of surgery. In addition, we found the presence of symptoms at the time of survey and use of chemotherapy after diagnosis to be the strongest correlates of QOL for several standardized QOL summary scales. Somewhat surprisingly, stage at diagnosis, age at survey, recurrence since diagnosis, and number of years since diagnosis were not highly correlated with QOL in this population. We explored stage at diagnosis and comorbidity as potential confounders in the multivariate models. Our results are presented without adjustment for these covariates because of their lack impact on the estimates in the final models.

Late effects of treatment were determined by the relationship of adjuvant therapy to QOL in several QOL summary scales, most notably the CARES-SF Global and the SF-36 PCS. Women who did not receive chemotherapy or hormonal therapy had higher QOL than women who received either type of therapy. Long-term consequences of adjuvant therapy may be particularly pronounced in terms of sexual issues. Our results, and the findings from a large longitudinal study of QOL among long-term survivors across a broader age distribution, suggest that the effects of adjuvant therapy persist many years after the completion of chemotherapy [6].

The presence of breast related symptoms at the time of survey completion, and the presence of pain in particular, had a profound impact on QOL across all summary measures. There is a substantial body of literature documenting the under-treatment of cancer pain [24,25] with estimated pain prevalence rates of 33–52% in non-metastatic breast cancer [9]. Despite sample size limitations, our results suggest that the presence of inadequately managed breast cancer related pain, and other cancer-related symptoms, many years after diagnosis may have a significant impact on the day-to-day well-being of younger survivors. It is

worth noting that insufficient distribution of breast related symptoms prevented us from examining the effect of individual symptoms in multivariate modeling. We were therefore unable to control for the presence or absence of individual symptoms and cannot know the real extent of the effect attributable to pain. A greater understanding of the contribution of various breast related symptoms to QOL should be considered in future studies.

While the presence of breast related symptoms at survey was the only covariate to appear in the final logistic regression model for all QOL outcome measures, our results suggest that socio-economic status, as measured by annual family income, may also play an important role in determining QOL among younger long term survivors. While our study lacks substantial socio-economic diversity, these findings support the results of a previous study among an older and more ethnically diverse group of long-term breast cancer survivors [8]. These findings are difficult to interpret without a disease-free control group, given that socioeconomic status has been found to be an important correlate of QOL in the general population [26].

The limitations of this study include a sample size and the cross-sectional design. In the absence of a control group, we cannot be certain that any correlations between specific covariates and QOL are specific to breast cancer survivors. The cross-sectional design allows us to identify potential correlates of QOL but inferences about causality cannot be made based on this study. While small sample size resulted in instability in subgroup analyses, we chose to present these results because of the interesting trends; these results are by no means definitive and should be further explored. In addition, our results may be limited by the possibility that these women are not representative of all younger US long-term breast cancer survivors, due to the predominantly Caucasian sample, the relatively high level of education, access to comprehensive health care, and the absence of geographic diversity. It is also important to note that these findings may underestimate the impact of breast cancer in the general population. However, these women are likely to be representative of women with access to medical care and women with relatively high socioeconomic status; both of which are known correlates of breast cancer.

The strengths of the present study include the use of standardized QOL measures, a high response rate, a well-defined group of cases arising from the underlying population, and the focus on younger women who were more than five years post diagnosis. In addition, because all women received care in the same health system, this study lacks the variability in treatment patterns that exist in the general population, thus differences in quality of life are less likely to be attributed to treatment-specific differences.

Conclusion

Our results emphasize that younger women who are long-term survivors of breast cancer have a high QOL across several standardized measures. However, the long-term consequences of adjuvant therapy and the management of long-term breast related symptoms are two areas that may be important for clinicians and women with breast cancer to consider when attempting to understand and optimize long-term QOL.

Authors' contributions

DC participated in the design and coordination of the study; conducted study analyses; and drafted the manuscript. DB participated in the design, analyses, interpretation of results, and writing of the manuscript. ST conceived of the larger study from which the data are derived and participated in the study design and interpretation of results.

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