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Breast cancer survivors: psychosocial concerns and quality of life

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Abstract

Purpose: To describe the psychosocial concerns and quality of life of breast cancer survivors evaluated 2 and 3 years after primary treatment.
Methods: A sample of 139 breast cancer survivors who had been interviewed during the first year after primary treatment participated in a mailed survey at 2 years (N = 69) and 3 years (N = 70) after initial surgery. A random sample of these survivors were also interviewed in person. The mailed questionnaire included standardized instruments to assess quality of life (QL), rehabilitation needs, and psychological distress. Additional survey questions were developed to examine post-surgical recovery, employment and insurance problems, social support, and existential concerns. The in-person interviews expanded on these questions and systematically compared these patients' rehabilitation needs to those which existed at the time of an interview 1 year after surgery.
Results: The 2 and 3 year participants in this follow-up study did not differ from each other on their prior assessments with standardized QL instruments during the first year after surgery, nor did they differ from the full study sample of 227 women. The scores on the Profile of Mood States and the Functional Living Index-Cancer were the same for the 2 and 3 year survivor groups and did not differ from the previous assessments at 1 year after initial treatment. The scores on the Cancer Rehabilitation Evaluation System showed a significant decline in Global Quality of Life, Sexual Functioning and Marital Functioning between the 1 year and 3 year evaluations. For the 2 year sample only Sexual Functioning showed a deterioration between the 1 and 2 year evaluations. Using the RAND 36-Item Health Survey 1.0, the breast cancer survivors were compared with patients from the Medical Outcomes Study. The breast cancer survivors demonstrated higher levels of functioning in many dimensions (role functioning, social functioning, pain, and general health) than the patients with chronic medical conditions. In spite of relatively good physical and emotional functioning on this generic measure of health status and quality of life, these breast cancer survivors reported a number of important and severe rehabilitation problems that persisted beyond one year after primary treatment. Especially frequent were problems associated with physical and recreational activities, body image, sexual interest, sexual function, and problems with dating for those who were single.
Conclusions: Breast cancer survivors appear to attain maximum recovery from the physical and psychological trauma of cancer treatment by one year after surgery. A number of aspects of QL and rehabilitation problems worsen after that time. Nevertheless, breast cancer survivors rate their QL more favorably than outpatients with other common medical conditions, and they identify many positive aspects from the cancer experience.

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Introduction

Women who have had breast cancer are the largest constituency of cancer survivors. They enjoy high rates of cure for localized disease and long-term overall survival [1]. Increasingly, the issues and concerns of cancer survivors are being addressed, including issues related to employement and health insurance, as well as the long-term effects of therapy [2, 3]. Most physicians who treat patients with breast cancer are familiar with the acute effects of multi-modal treatment (surgery, radiation, chemotherapy, hormone therapy). However, relatively little information is available on the long-term adaptation of breast cancer patients beyond the first year after diagnosis [4–7]. Much of the available information is derived from older studies, which were primarily retrospective, cross-sectional interview studies that did not include standardized instruments.

In 1987 we began a longitudinal prospective study of newly diagnosed breast cancer patients with stage I or II disease, focusing on the rehabilitation and quality of life outcomes in this patient population [8]. A total of 227 patients were assessed at 4 points in time during the first year after surgery [9–11]. After recruitment of this cohort of women, we recognized the potential value of longer term follow-up, and obtained additional funding to study some of these women beyond the initially planned year.

In this paper we report our findings from a sample of breast cancer survivors who were members of the original study cohort. These women completed a mailed survey questionnaire at either two or three years after their initial study assessment (which was one month after breast cancer surgery). We collected data using several cancer-specific quality of life instruments used previously; however, we added a generic health-related quality of life instrument to this study, and are thus able to compare these women to patients with other chronic diseases. Finally, through other survey data and the in-person clinical interviews, we were able to examine other common physical and psychosocial sequelae of cancer treatment, and review how these problems evolved during the years following the initial study period of one year after surgery. We believe this is one of the first longitudinal and prospective studies of quality of life in breast cancer patients beyond the first year after diagnosis. Although descriptive in nature, our findings are an important first step in understanding the long-term effects of breast cancer treatment and should be useful to clinicians and researchers involved with breast cancer survivors.

Patients and methods

Original study cohort. The original study is described in detail in our earlier publications [10, 11]. In brief, the study subjects were recruited to participate in a randomized trial that tested two rehabilitation treatment interventions for newly diagnosed breast cancer patients. The intervention study did not show a significant benefit and thus all patients have been grouped together for the purposes of this analysis. Between July 1, 1987, and November 30, 1990, 253 newly diagnosed breast cancer patients consented to participate in the original research study. Of these subjects, 11 were considered ineligible after the initial interview and 15 dropped out or were lost to follow-up during the subsequent year. The final sample consisted of 227 subjects who completed the full year of assessments at four points in time.

Patients were recruited from the surgical practices of the full-time and voluntary faculty of the University of California at Los Angeles (UCLA) School of Medicine, as well as from community surgeons and surgeons at a major health maintenance organization (HMO). Permission to approach the patient was obtained from the physician, and then the research study was explained to the patient. Study eligibility criteria included the following: all patients were English-speaking, had stage I or II breast cancer, did not have a history of major psychiatric illness, did not have another disabling non-cancer illness, and lived within the geographic area (Los Angeles County, CA). The protocol for this study, and the subsequent follow-up study, were approved by the human studies institutional review board of each participating institution, and informed written consent was obtained from each pa-

tient. The age distribution and ethnicity of the final sample reflected the population of patients with early stage breast cancer in Los Angeles. The only potential bias in the sample was the lack of uninsured patients.

Design of the follow-up study and subject recruitment. Recruitment of subjects for the present study began April 1, 1990, and continued until March 31, 1992. Thus all subjects entered in the original study between July 1, 1987, and March 31, 1990, were potentially eligible for this study (N = 182 total). Subjects were partitioned into two independent subsamples based on the time since diagnosis: those entered during the first half of the original study were sampled 3 years after surgery; those from the second half of the original study were sampled 2 years after surgery (N = 94 from year 2 and N = 88 from year 3).

We attempted to locate all potentially eligible subjects from the original cohort at the predetermined assessment point (2 years or 3 years after the original 1 month assessment). To locate subjects we used information from physicians' offices, the department of Motor Vehicles, tumor registry information, and next of kin. We were able to obtain completed questionnaires on 139 (77%) of the eligible subjects. Only 18% of the eligible subjects refused to participate, and 5% were either dead or could not be located.

Procedures. We approached all eligible subjects for completion of a mailed comprehensive survey questionnaire booklet. The questionnaire booklet was 44 pages in length and contained the following sections: interval demographic information and medical history, social network information, quality of life assessments, assessments of mood, physical activity, physical consequences of breast surgery, relationships, work, and health insurance.

We conducted face-to-face interviews with a random sub-sample of the survey respondents. We prepared a list of all potentially eligible subjects from the 2 and 3 year group, and approached every third patient on the list. If a subject refused, then the next subject on the list was approached. Cost constraints and patient availability precluded interviewing all subjects in each survivor group. Interviews were conducted with 32 women from the two year group, and 27 women from the three year group. The in-person interview was conducted by an experienced oncology social worker who had conducted all of the initial interviews with the patients during the original research study. The women who participated in the follow-up study interviews completed their survey questionnaire prior to coming to the interview, and these responses were used to guide the interview [12]. The interview schedule for the follow-up interview was similar to the initial needs assessment interview of the original study [12]. At the end of each interview, a specific problem list was coded for each subject using an existing comprehensive list of rehabilitation problems. In addition, each problem was given a severity rating that was a composite of the patient's self-reported level of dysfunction or disability, modified by the social worker's clinical assessment. In conducting the 2 and 3 year follow-up interviews, the social worker had access to the problem list from the 1 year interview time point. Prior to the interview for the present study, she reviewed the problem list from one year after surgery, and in the course of the 2 or 3 year interview determined whether these persisted or had resolved. The interview lasted 60–90 minutes. Following the interview, the social worker used the same coding system that was developed as part of the original study to code the 2 or 3 year interviews. These paired problem lists that summarized the two interviews could then be compared.

Four new open-ended questions were also included in the interview to examine a variety of existential concerns that had been studied and found pertinent for cancer survivors [13, 14]. These questions were as follows: 'In what ways, if any, has having had breast cancer 1) changed your priorities or altered your daily activities, 2) changed your plans for the future, 3) changed your views of yourself, 4) changed your view of the world we live in.' Categories of response were developed subsequently to code these open-ended responses to summarize the interview data for analysis and presentation. Two of the authors reviewed the results from the open-ended questions and created a list of specific examples or description of changes for each category. Ini-

tially, each coder categorized the responses of each subject, which was then followed by a consensus process to ensure consistent interpretation. Final categorization was made through consensus of the two coders.

Specific instruments used in this study. Health related QL is defined by most investigators as a multidimensional concept which includes the subjective evaluation of the following aspects of the person's situation: disease symptoms and treatment side effects, functional status, psychological distress, social interaction, sexuality and body image, and satisfaction with medical treatment [15–17]. A 'gold standard' measure of QL has not as yet been developed. Some investigators have favored a single global rating of QL (e.g. 'How would you rate quality of life today?'), rather than a multi-item instrument [18]. As a consequence, there has been considerable debate in the literature about the amount of detail needed in QL assessments. We have favored a more detailed assessment of the various dimensions that affect patient ratings of QL, since an individual may make the same global rating of QL at different times, but in fact take different aspects of the situation into account in making the rating each time [8].

In this study, QL was evaluated using two cancer-specific, patient-rated, validated measures of QL, the Functional Living Index-Cancer (FLIC) [19] and the *CA*ncer *R*ehabilitation *E*valuation *S*ystem (CARES) [8, 20]. In addition, we used a generic measure of health-related quality of life, the RAND 36-Item Health Survey 1.0 (also known as the MOS SF-36) [21, 22], which has been used with other chronic disease patients. The FLIC has been serially validated and psychometrically evaluated [19] with published criteria for validity including stability of factor analysis, concurrent validation studies against scales of functional performance and activities of daily living, standardized measures of depression, pain and anxiety, as well as a scaled version of the General Health Questionnaire [19]. The authors of the FLIC have performed a systematic evaluation of the instrument to eliminate items that were contaminated by social desirability.

The FLIC is multidimensional and the specific questions are designed to assess the overall functional quality of a cancer patient's day-to-day life, including concerns related to pain, stress, and the ability to work and do household chores [19]. The instrument contains 22 questions rated on a visual analogue scale that is divided into seven equal intervals. The remarks at each end of the scale represent polar responses to each question. Patients are instructed to answer all questions by making a mark on the scoring line at the point that best represents their response. For scoring, each interval is divided in half and responses are scored to the nearest whole number. The scores for each question are summed to give an overall score, the minimum being 0 and the maximum being 154.

The second patient-rated measure of QL was the CARES, which is a standardized, comprehensive rehabilitation and QL questionnaire designed for use with cancer patients [8, 20]. It provides a very detailed assessment of a cancer patient's problems and needs. Its reliability, validity, factor structure, and other psychometric properties have been studied extensively [20]. (The early developmental versions of the CARES were named the Cancer Inventory of Problem Situations, CIPS). The CARES has been validated with standardized measures of psychological distress, physical function, marital adjustment, and QL.

Patients complete the CARES by rating problem statements on a 5 point scale ranging from 0 'Not at all' to 4 'Applies very much' during the last month. The instrument contains 139 items, although not all items are rated by every patient. Certain subsections apply to some patients and not others. For example, the 9 chemotherapy items are answered only by those patients who have had chemotherapy within the last month. Patients rate a minimum of 93 items and a maximum of 132 items. The CARES is scored into a Global Score, 5 higher order factors referred to as summary scales, or 31 more specific subscales. The 5 higher order summary scales represent the following domains: (a) Physical: the physical changes and disruption of daily activity caused by the disease, (b) Psychosocial: psychological issues, communication, relationship (other than partners) problems, (c) Medical Interaction: problems interacting and communicating with the medical team, (d) Marital: problems associated with any

marital or marital-type relationship, and (e) Sexual: problems related to interest and performance of sexual activity. The Global Score takes into consideration the varying number of possible problems for each patient and in addition has demonstrated its validity as a measure of QL [8, 20].

The RAND 36-item Health Survey 1.0 is a 36 item measure of health status that was adapted from longer questionnaires completed by patients participating in the Medical Outcomes Study [21, 22]. The RAND 36-item Health Survey measures physical health (physical functioning, bodily pain, role limitations due to physical health problems), mental health (emotional well-being, role limitations due to personal or emotional problems), social functioning, energy/fatigue, and general health perceptions and health change [21, 22]. This instrument has been extensively used with other non-cancer medical populations as well as in healthy individuals. We included this instrument in our survey to provide a comparison of breast cancer survivors with other chronically ill patients, and to allow some comparison of disease-specific measures (the FLIC and CARES) with a generic measure of health-related quality of life. Patients selected for the Medical Outcomes Study (MOS) were outpatients recruited from the offices of 298 clinicians who agreed to participate in the longitudinal, observational study. The demographic characteristics of the MOS baseline sample included a mean age of 54 years (range 18–98), 61% female, 79% white, with a mean of 13 years of education. Only 3% had no medical conditions, with 22% having diabetes, 58% hypertension, 6% congestive heart failure, and 13% major depression [23].

The Profile of Mood States (POMS) [24] is a standardized instrument that has been used to study the psychological aspects of cancer [25–27]. It is a 65 item adjective checklist that is rated on a five point Likert scale. The POMS has 6 subscales (tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, confusion-bewilderment) and an overall score representing Total Mood Disturbance (TMD), where a higher score indicates greater disturbance. The TMD score ranges from − 32 (best) to + 200 (worst). The authors of the instrument provide normative data for college students and psychiatric outpatients [24]. The scores of cancer patients are often lower than those of the normative samples and there are numerous published studies that have used the POMS with cancer patients [26, 27].

Statistical tests. Continuous variables were compared using t-tests. For the comparison of the FLIC and POMS scores, each survivor group was compared to its 1 month and 1, 2, or 3 year data using paired t-test. A Bonferroni correction is used to adjust for multiple comparisons, with a simultaneous confidence level set at 0.05. Under these conditions, only p values with a level of 0.005 or less are considered significant.

Results

Patient characteristics

We received completed questionnaires from 69 patients in the 2 year group and 70 patients in the 3 year group. In both groups, about 60% of the women had received a mastectomy as the initial surgical treatment. Sixty percent of the 2 year group were node negative at diagnosis, and 76% of the 3 year group were node negative at diagnosis. Table 1 shows the demographic characteristics of the survivors at the time of the mailed survey questionnaire. The majority were married, well-educated, and held professional or administrative occupations. In the 2 year group and 3 year groups respectively, 26% and 17% of the samples were non-White. These ethnic differences reflect differences in the recruitment sources of the original cohort. There was no significant difference in age between the 2 and 3 year groups. At the time of this survey, 2 women (3%) in the 2 year group and 10 women (14%) in the 3 year group had recurrent cancer ($p = 0.017$).

Quality of life and psychosocial concerns: trends over time

Neither the 2 nor 3 year samples differed from the entire cohort ($N = 227$) on any of the measures at 1

month or 1 year post surgery, nor did they differ from each other at the 1 month and 1 year assessments. Table 2 shows the POMS-TMD score over time for both the 2 and 3 year samples. A lower score indicates less distress. Consistent with our prior data on the large samples of women [9, 10], there is an improvement in the TMD score between 1 month and 1 year ($p = 0.03$ for the 2 year sample and $p = 0.007$ for the 3 year sample), but no significant difference between the 1 year assessment and the follow-up observations at 2 and 3 years. These mean scores on the POMS-TMD are within the normal range (i.e., lower than college students or outpatients with psychiatric illness), but it is important to note the extremely large standard deviations in these samples suggesting that a fair number of women exhibit significant mood disturbance. All of the 6 subscales of the POMS demonstrated a similar pattern longitudinally (data not shown).

Data from the FLIC are also shown in Table 2.

Table 1. Demographic characteristics at time of mailed survey

	2 Yr sample		3 Yr sample	
Mean age	57 yr (range 35–79)		59 yr (range 36–80)	
Marital status	(N = 69)	%	(N = 70)	%
Married	40	58	45	64.3
Divorced	15	21.7	7	10
Widowed	7	10	9	12.9
Single	5	7.2	8	11.4
Separated	2	2.9	1	1.4
Education				
High school or less	17	24.3	17	24.3
Full or partial college	39	56.7	32	45.7
Advanced degree	13	19	21	30
Occupation				
High level professional	4	5.8	7	10
Mid level professional	14	20.3	18	25.7
Administrative	15	21.7	13	18.6
Clerical/Sales	23	33.3	14	20.0
Skilled manual	1	1.4	3	4.3
Homemaker	12	17.4	15	21.4
Annual family income				
$ 0 to $ 15,000	5	7.4	9	13.2
15,001 to 30,000	10	14.7	9	13.2
30,001 to 45,000	17	25	13	19.1
45,001 to 60,000	11	16.2	6	8.8
60,001 to 75,000	7	10.3	9	13.2
Over 75,000	18	26.5	22	32.4
Didn't answer	1		2	
Ethnicity				
White	51	73.9	58	82.9
African American	13	18.8	6	8.6
Asian	4	5.8	4	5.7
Hispanic	1	1.4	2	2.9
Religious preference				
Protestant	31	44.9	25	35.7
Jewish	9	13	15	21.4
Catholic	11	15.9	11	15.7
None	9	13	13	18.6
Other	9	13	6	8.6

Consistent with our prior reports [9, 10], these samples show the same improvement in QL (a higher score indicates better QL) between 1 month and 1 year ($p = 0.0001$ for both the 2 and 3 year samples), but no further improvement during the second and third years of follow-up. The CARES provides a global quality of life score as well as five major summary scores that reflect important dimensions of quality of life. These scores are shown in Fig. 1. A lower score on the CARES indicates fewer problems and a better QL. Both samples had improvements in the CARES global, physical, medical interaction, and psychosocial scores during the first year after surgery; however, the CARES data from the 2 and 3 year assessments do not show any further improvement. In fact, the 2 year sample is significantly worse in the area of sexual functioning compared to year 1 data ($p = 0.0001$), and the 3 year sample has a worse global CARES score ($p = 0.0004$), Marital Interaction Score ($p = 0.0016$), Physical Functioning Score ($p = 0.03$), Psychosocial Functioning Score ($p = 0.009$), and Sexual Functioning Score ($p = 0.001$). As we have previously reported [9, 10], Sexual Functioning does not recover during the first year after breast cancer, and the data from our 2 and 3 year samples demonstrate significant further deterioration in this aspect of QL.

Health-related quality of life in comparison to non-cancer patients

The RAND 36-Item Health Survey was added to this study as a generic measure of QL. The value of this tool is that it allows comparison of these breast cancer survivors to samples of patients with other chronic illnesses (e.g., diabetes, hypertension, heart disease). A higher score on this instrument indicates a more favorable state of health or well-being. In Table 3 we compare the results from the breast cancer survivors with the Medical Outcomes Study outpatient reference sample of over 2,000 patients [21]. On average, the breast cancer survivors exhibit extremely high levels of role functioning, social functioning, and little physical pain, compared to the MOS reference sample norms. Scores for the other RAND scales were at or slightly above the mean of the reference sample, with the exception of health change in the 3 year sample. For example, the emotional well-being score mean for non-cancer patients is 70 and both the two and three year cancer groups have mean scores that are slightly higher. The two and three year cancer samples have similar mean scores, although there is a non-significant trend toward poorer scores on subscales for pain, physical limitations, and health change in the 3 year group. Examination of the MOS scores in patients

Table 2. POMS and FLIC scores for the survivor samples compared with first year data[1]

	1 Mo Post DX		1 Yr Post DX		2 Yrs Post DX		3 Yrs Post DX	
	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev	Mean	Std Dev
POMS-TMD								
2 Yr	13.42	32.06	5.94	31.37	11.15*	35.20		
3 Yr	15.77	32.25	6.30	31.93			7.88+	26.57
FLIC								
2 Yr	117.07	16.17	127.13	11.82	128.59 #	12.95		
3 Yr	116.85	14.85	126.91	13.43			127.35^	13.62

[1] Note, we have shown previously that comparisons between 1 month and 1 year are significantly different, showing improvement in scores on both instruments. A lower score on the POMS indicates less mood distress and a higher score on the FLIC indicates improved quality of life.

* NS difference between 1 yr and 2 yr ($p = 0.095$); 1 month and 2 yr, ($p = 0.55$)

+ NS difference between 1 yr and 3 yr ($p = 0.59$); significant difference between 1 month and 3 yr, ($p = 0.03$)

NS difference between 1 yr and 2 yr ($p = 0.28$); significant difference between 1 month and 2 yr, ($p = 0.0001$)

^ NS difference between 1 yr and 3 yr ($p = 0.81$); significant difference between 1 month and 3 yr, ($p = 0.0001$).

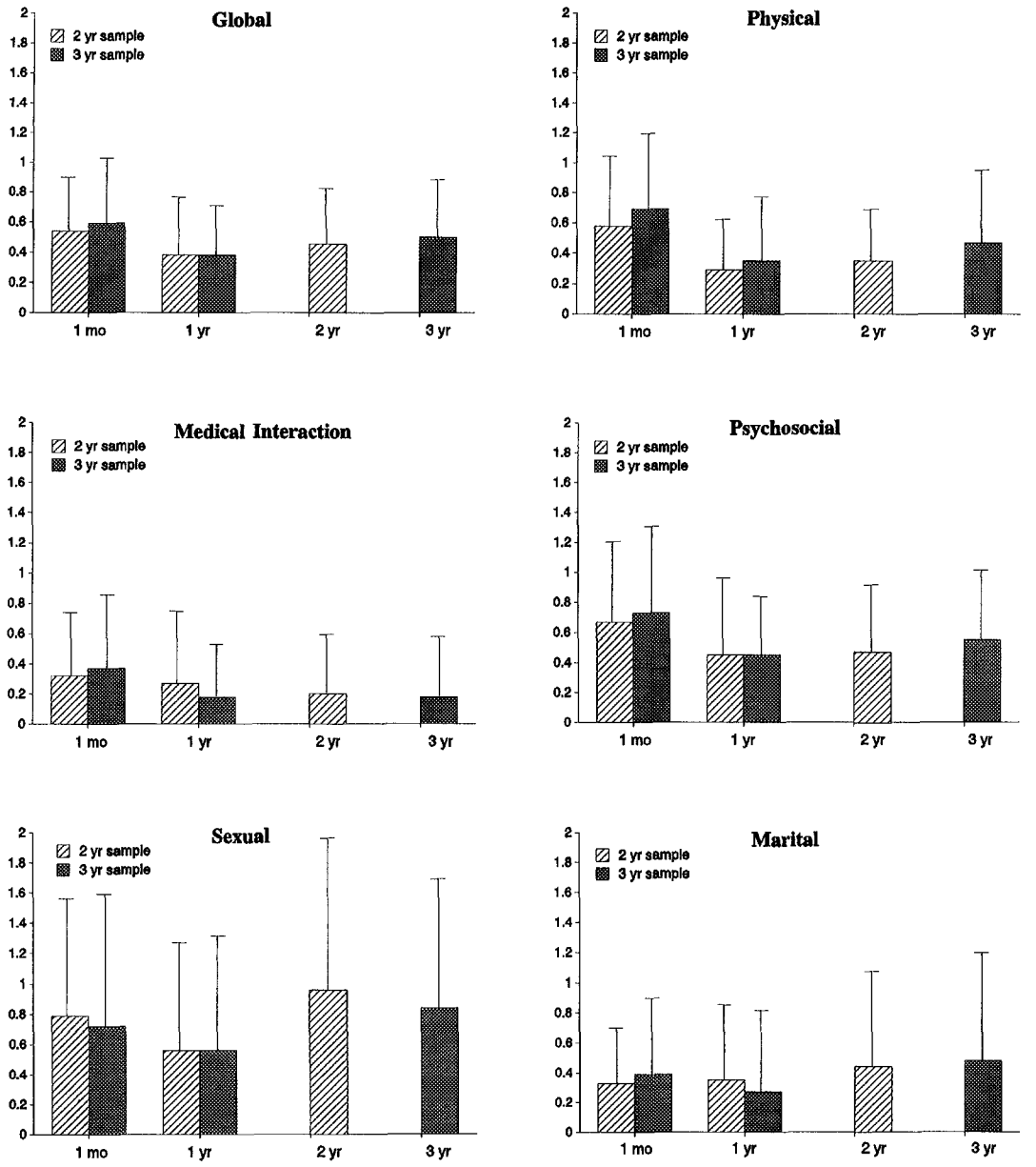

Fig. 1. Mean and standard deviation scores on the CARES Global Score and Summary Scale Scores for the 2 and 3 year samples at 1 month after surgery, 1 year after surgery, and at 2 and 3 years. Higher scores indicate more rehabilitation problems and poorer quality of life. Global quality of life declined significantly between 1 year and 3 years ($p = 0.0004$), as did Physical Functioning ($p = 0.03$), Psychosocial Functioning ($p = 0.009$), Sexual Functioning ($p = 0.001$), and Marital Functioning ($p = 0.002$). For comparison of the 1 year and 2 year data, the only significant change was a worsening of Sexual Functioning ($p = 0.0001$).

with and without recurrence showed no significant difference in any subscale score.

Specific concerns of breast cancer survivors

In addition to the global and dimension CARES scores shown in Fig. 1, the CARES permits a very detailed assessment of the rehabilitation problems confronting cancer patients [20]. In our previous paper on the entire sample (N = 227) we used a data reduction strategy to determine which CARES problems to present from the 1 month and 1 year data [10]. In the larger sample we examined a frequency distribution for each problem identified at 1 month after diagnosis and found that the median frequency with which each problem occurred was 25%. We then used this cut-off point, and presented only those problems that were endorsed by at least 25% of the patients. In some cases, we report problems that were less frequent, but when experienced they were of moderate severity. Table 4 provides detailed information about the most frequent and severe problems reported on the CARES in the two and three year groups. Those problems that were rated as severe in intensity are noted with an asterisk, indicating that the mean severity score was 2.0 or greater on a scale of 0 to 4. Although other general measures of health and well-being suggest that these survivors are functioning at a high level (see Table 3), they still report many important and severe problems. For example, many women still report a reduction in energy, a decrease in recreational activities, pain, and psychological distress. Anxiety in medical situations still occurs, in spite of the time that has elapsed since diagnosis. Nearly half the sample still report body image problems, and sexual problems are very frequent and severe in intensity. Communication and affection with partner are still concerns. At work concerns are problematic and severe for about 20% of those survivors who were working at the time they completed the questionnaire.

Physical effects of breast cancer surgery and other treatments

The following data were taken from the questionnaire battery items developed specifically for this study and are not derived from standardized instruments. Many breast cancer survivors reported persistent symptoms (Table 5) related directly to the breast cancer surgery, either from a modified radical mastectomy or segmental mastectomy, axillary node dissection, and radiation therapy. Paresthesia (numbness, pins and needles sensation), pain, and skin sensitivity are prevalent in both samples and were seen in women with both mastectomy and breast conservation surgery.

There were other sequelae from the primary treatment. These included chemotherapy-related problems (changes in hair, persistent nausea); changes in the irradiated breast (61–71% of breast conserved patients); concerns about sun exposure because of radiation; and endocrine problems (early menopause was reported by 21% of the 2 year group and 25% of the 3 year group). None of

Table 3. RAND 36-item health survey 1.0 results

Scale	2 Yrs post DX N = 69		3 Yrs post DX N = 69		MOS norms N = 2471	
	Mean	S.D.	Mean	S.D.	Mean	S.D.
Physical functioning	83.6	18.8	77.9	23.5	70.6	27.4
Role functioning/physical	79.3	32.6	76.4	37.1	53.0	40.8
Role functioning/emotional	84.5	31.6	83.6	30.6	65.8	40.7
Energy/fatigue	63.9	20.9	61.7	17.4	52.2	22.4
Emotional well-being	76.9	19.8	76.1	14.9	70.4	22.0
Social functioning	92.8	15.8	87.7	21.3	78.8	25.4
Pain	87.2	16.7	80.9	20.7	70.8	25.5
General health	70.9	15.9	69.2	17.9	57.0	21.1
Health change	67.4	23.6	55.4	18.6	59.1	23.1

Note: Data is from baseline of the Medical Outcomes Study, except for Health change, which was obtained one-year later (see ref. 19).

Table 4. CARES individual items

	2 Yr (N = 69) %	3 Yr (N = 70) %
Ambulation		
difficulty bending or lifting	39	50
difficulty doing physical activities	54*	69*
reduction in energy	68*	71*
Activities of daily living		
difficulty household chores	27	40
Recreational activities		
not interested recreational activities	42*	39
not engage recreational activities	46*	53*
not enough enjoyable activities	26	27
Pain		
frequently has pain	25	39
chronic pain from scars/surgery	22	37
pain controlled by medication	22	21
Clothing		
clothes do not look good	32	36
clothes do not fit	29	30
difficulty finding clothes	26	30
Psychological distress		
frequently anxious	43	51
frequently depressed	43	50
frequently angry	29	36
frequently upset	45	57
frequently overwhelmed feelings about CA	33	27
difficulty sleeping	42	47
Cognitive problems		
difficulty concentrating	33	36
difficulty remembering	51	49
difficulty thinking clearly	32	24
Difficulty communicating with friends/relatives		
difficulty asking friend/relatives for help	33	41
difficulty telling friend/relative about CA	23	21
Friends/relatives difficulty interacting		
friends/relatives avoid talk about CA	23	27
friends/relatives uncomfort. talk about CA	25	21
Anxiety in medical situations		
uncomfortable seeing patients get treatments	45	39
nervous going to hospital	46	50
nervous waiting to see doctor	48	56
nervous waiting for test results	66	81
nervous having diagnostic tests	66	71
nervous getting blood drawn	52	50
Worry		
worry whether treatments worked	35	37
worry whether cancer progressing	54	66
worry not able to care for self	38*	56
worry how family will manage if die	43	46
Body image		
embarrassed to show body	48	49*
uncomfortable showing scars	49	51*
uncomfortable with body changes	42	43*

the patients in this study had immediate reconstruction with a flap; however, a few had initial placement of a tissue expander. Of the mastectomy patients, only 13% of the 2 year group and 21% of the 3 year group had undergone reconstructive surgery at the time this follow-up questionnaire was completed, and most were very satisfied with the results of the surgery.

Table 4. Continued

	2 Yr (N = 69) %	3 Yr (N = 70) %
At work concerns[1]	(N = 41)	(N = 41)
difficulty to talk to boss about CA	24	12
difficulty talk to people at work about CA	22	27*
difficulty telling employer can't do work	17*	12*
Sex interest		
not feel sexually attractive	49*	49
thinks not sexually attractive to partner	27*	27
not interested in having sex	38*	47*
not think partner(s) interested in sex	19	23*
Sexual dysfunction[1]	(N = 49)	(N = 42)
frequency of intercourse decreased	63*	48*
difficulty become sexually aroused	61*	48
difficulty getting lubricated	57*	64*
difficulty reaching orgasm	55*	52*
Communication with partner[1]	(N = 46)	(N = 51)
difficulty talking about feelings	41	47
difficulty talking about fears	39	39
difficulty talking what happens after death	50	51
difficulty talking about future	26	37
difficulty talking about the CA	39	37
difficulty talking will/financial	35	37
Affection with partner[1]	(N = 46)	(N = 51)
no feel like kiss, embrace, touch	26*	23*
partner no feel kiss, embrace, touch	20	21*
no interest in touching partner	30	21*
partner no interest touching me	24	20*
Interaction with partner[1]	(N = 46)	(N = 51)
not get along as well as usual	15*	14*
upset with each other more often	26	22
Neglect of care by partner[1]	(N = 46)	(N = 51)
partner not take care	10*	20*
diff ask partner for care	20*	20*
Dating[1]	(N = 22)	(N = 18)
difficulty initiating contact	64*	44*
difficulty meeting dates	68*	56*
afraid to get to meet dates	54*	17*
difficulty telling date about CA	68*	22
afraid initiate sex relation	50*	39*

* Indicates that the average severity rating for the item was 2.0 or higher, therefore more severe.

[1] Some questions do not apply to all patients and, therefore, the total number of patients responding to an item or subset of items will be less as presented below. Note that when the N is small, the percentage of people endorsing an item may appear artificially high, e.g. chemotherapy, radiation, & seeking employment.

Satisfaction with treatment

Most of the women in our 2 and 3 year samples were very satisfied with their initial treatment and follow-up care for breast cancer. A few expressed regrets about their primary treatment (usually choice of surgery), but roughly three-quarters had no regrets. When asked how often they worried about their breast cancer, the 2 year sample reported more frequent worry than the 3 year sample (58% vs. 43%).

Among the patients who had a mastectomy, 75% of the 2 year and 60% of the 3 year samples were using a breast prosthesis. Most of those who used a breast prosthesis were satisfied with it. A small but not insignificant number of women with mastectomy reported difficulties obtaining a prosthesis, including not being able to afford it or having troubles finding one to fit.

Insurance and work related issues

Of the women recruited for the original study, al-

Table 5. Percent of patients with physical sensations at local surgical site

	2 Yrs post DX (N = 69) %	3 Yrs post DX (N = 70) %
Chest wall (mastectomy only)		
Pain	56	59
Pins & needles	53	45
Numbness	74	73
Skin sensitivity	51	52
Swelling	21	23
Breast (segmental only)		
Pain	58	65
Pins & needles	35	38
Numbness	35	50
Skin sensitivity	54	46
Swelling	50	30
Arm		
Pain	51	44
Pins & needles	51	50
Numbness	72	77
Skin sensitivity	51	44
Swelling	43	40
Underarm		
Pain	48	51
Pins & needles	43	37
Numbness	85	87
Skin sensitivity	52	43
Swelling	33	33
Area of scar		
Pain	43	47
Pins & needles	33	33
Numbness	49	61
Skin sensitivity	46	50
Swelling	17	23
Other changes		
Tight/tender/discomfort (chest wall)	78	67
Tight/pull/stretch (arm/underarm)	68	71
Heaviness (arm)	41	40
Weakness (arm/hand)	49	41

most all had health insurance at the time of diagnosis. In the follow-up questionnaires we sought to explore the impact of the breast cancer diagnosis and treatment on subsequent health insurance coverage. At the 2 and 3 year assessments, the vast majority (about 90%) of the women described their health insurance coverage as adequate. Although still covered by insurance, some women had lost their own insurance and were dependent on the coverage of their spouses. A few were covered by COBRA at the time of our assessment. Eighty percent of the 2 year sample had no change in their coverage while only 60% of the 3 year sample reported no changes. Some of the changes that occurred included increased premiums, loss of insurance, or reduced benefits. Importantly, 35% of the 2 year group and 50% of the 3 year group were worried about their health insurance coverage in the future.

At the time of our evaluation, 65% of each group were working for pay or doing volunteer work. The mean number of hours worked per week was 34.4 for the two year group and 33.2 for the 3 year group; however, there was a substantial range of hours reported. These survivors reported relatively few difficulties with time off for medical appointments, or difficulty communicating with employers or coworkers, and we found minimal evidence of overt discrimination.

Social support network

We were also interested in learning about how these breast cancer survivors managed their worries and with whom they shared their concerns. The overwhelming majority of survivors reported that they had someone to talk with about their feelings or concerns (96% year 2 and 82% year 3). The persons with whom they most often talked were their spouses and close friends. For those who reported that they did not often share their worries or concerns, the main reasons were that they did not want to worry others, they did not have a need to discuss them, that they were afraid of other's reactions, and they did not want to appear self-centered or complaining.

Results from the interview study

The patients who participated in the interviews were similar in medical and demographic characteristics to the larger group of 2 and 3 year survivors. Several had had a breast cancer recurrence. These interviews confirmed the high frequency of physical problems related to the breast cancer surgery (see Table 5). Although the common problems associated with treatment for breast cancer, such as fatigue, nausea, and hair loss, resolved over time, many women continued to experience problems because of endocrine treatment. The interview-derived coded problem list revealed that one fourth of the survivors reported hot flashes secondary to treatment with tamoxifen or chemotherapy. Ten percent experienced hot flashes after the cancer diagnosis because they were no longer able to take estrogen replacement therapy. Of those who received tamoxifen or chemotherapy, 16% reported menstrual changes or amenorrhea as a result of treatment. One third of those on tamoxifen had vaginal problems such as dryness, itching, and discharge.

Everyone was asked whether they had experienced a change in their interest in sexual activity since their cancer, and 40% reported a decrease in interest. Many related this to not feeling as sexually attractive as before. Of those who were sexually active, one third reported problems with lubrication and several (13%) had a decrease in frequency of sexual intercourse.

Many women reported increased communication problems with their partner due to the cancer. Often these problems pre-existed the cancer diagnosis but became worse over time. About one fourth had interaction problems with their partner such as the partner being overprotective. On the positive side, one third felt that their relationship with their partner improved. For the single women in the sample, the cancer diagnosis posed different concerns. One half reported they would have difficulty telling a date about the cancer. About one third felt afraid to initiate a sexual relationship.

Overall, 15% experienced weight gain while 21% had concerns regarding weight maintenance. Sixty-five percent had concerns related to diet, diet

changes, or possible relationship of diet and cancer. For some women, concerns regarding nutrition, diet, and weight gain existed before the cancer diagnosis and then were heightened as a result of the diagnosis and treatment.

About one fourth had communication problems with their doctors such as insufficient explanations. Some survivors felt reluctant to ask questions or express feelings to their doctor. The most common problem for patients was their anxiety about diagnostic tests and awaiting the results. On the positive side, most felt they received adequate support from family and friends.

The most frequent concern was worry about recurrence, reported by 82%. Although for most women the severity of this worry was not great, recurrence fears persisted and were typically exacerbated during medical follow-up visits. Anxiety and depression were experienced by 38%. About one fourth still felt overwhelmed at times by their emotions about the cancer. Those who had daughters expressed concern about the hereditary risk of breast cancer.

Almost half of the women felt uncomfortable with the changes in their body. This included those who had breast conservation as well as those who had mastectomy. Difficulty with clothing was more of a problem for those who had mastectomy, as we had previously reported [9]. Overall, this detailed review of problems previously identified in the first year after breast cancer showed relatively little change, confirming the plateau in recovery of quality of life observed in the response to the standardized instruments (CARES, FLIC, POMS).

Open-ended questions

In this section of the interview we were able to explore a range of issues from the perspective of a longer time after diagnosis and treatment. The survivors were asked about changes in day-to-day activities and priorities, plans for the future, view of self, view of the world, and relationship with others. For example, in the section about changes in day-to-day activities and priorities, we identified the following categories of response: doing more now versus postponing, putting self first, greater appreciation of life, making life style changes, and able to dismiss trivia. The majority of these responses were positive and life affirming. Many women reported improved self-image, feeling more self-assured, having survived the adversities of their cancer experience. Another common theme was the experience of vulnerability and mortality, after being face to face with a life threatening disease.

It is known that a cancer diagnosis often alters the patients' perception of time. Some women began to think in shorter increments of time – 'I only plan a year ahead, I don't think about 10 years from now.' Many women reported a desire to travel, or to consider possible early retirement, and no longer wanted to postpone long range plans for the future. While one woman reported the future as threatening, the rest were able to adjust and cope adequately with the uncertainty created by the cancer diagnosis.

When asked if having cancer changed their views about the world, the most frequent response was increased concern about carcinogens and other environmental issues such as pollution of air, water, and food stuffs. Many women felt that the government should reorder priorities related to health care issues and wanted increased funding for cancer research. There were many who felt increased concern for the homeless, poor, and those lacking the basic elements of a decent life.

In terms of relationships with other people, several common themes emerged. A high percentage felt more sympathetic and compassionate towards others. Many expressed feeling more tolerant towards others who had differing points of view or different lifestyles. Many women felt more emotionally open, with enriched relationships with their family and friends.

Additionally, women were asked to evaluate how they felt their life had changed because of the cancer. About 80% felt that some good things had happened in their lives as a result of the cancer. Many women cited examples such as closer family relationships, a new appreciation and a positive outlook on life, and perhaps for the first time *felt entitled to put their own needs first.* When this question was put in the negative, that the cancer had brought nothing

but pain and hardship, again 80% reported that this did not apply to them at all.

Two questions were posed about the effect cancer had on the good things in their lives. Specifically, they were asked whether the cancer had eliminated the positive things or if the positive aspects continued after the cancer. Less than 10% felt that the cancer had created pain and hardship, whereas the majority (97%) expressed that good things continued to exist despite their cancer.

Practically all patients felt that they could exercise some degree of personal control over their cancer. On a scale of 1 to 4, about half rated a 1 or 2 (a little to some), while the other half rated 3 or 4 (much to very much). Typically, the control included having a positive attitude, becoming more assertive, making dietary or lifestyle changes, and complying with their medical care.

Discussion

This follow-up study of breast cancer survivors who were 2 and 3 years after their primary surgical treatment suggests that recovery from the physical and psychological effects of breast cancer treatment plateaus at one year and declines in some areas in the following two years. Overall, women who survive breast cancer function at a fairly high level compared to patients with other chronic diseases (see Table 3). They continue to work and perform their useful social roles. However, it should be noted that these women were in professional and white collar occupations in which there is considerably more flexibility and control around employement and work-related issues. Nevertheless, our data are consistent with other studies of breast cancer survivors [28].

In spite of these generally positive findings, the results from the more detailed information provided by the CARES, the survey questions, and our interviews, confirmed that many physical, psychosomal, and sexual functioning problems affecting breast cancer survivors persist or even worsen over time. Most of the interviewed survivors continued to experience the same problems that were present during their exit interview from the original study 2 or 3 years earlier. We found nearly identical rates of arm problems related to the initial surgical procedure (numbness, tightness and pulling in the arm, and intermittent mild pain). While these were not serious or disabling problems, many women wished they had received more detailed information about the physical recovery after breast cancer, and the persistence of many of these problems. There were similar findings in other common problem areas such as decreased interest in sexual activity and feelings of sexual attractiveness, body image concerns, fear of recurrence, and communication with doctors. Interventions to address these common problems in breast cancer survivors could be developed and might lead to further improvement in quality of life beyond the first year after treatment. There are certain problems that occur infrequently but have severe consequences, such as poor results of breast reconstruction, loss of medical insurance, or fertility. These concerns require more intensive intervention.

This longer follow-up study also provides important information about sexual functioning after breast cancer. In one of our earlier reports we noted that sexual functioning was the only major dimension of quality of life that did not seem to recover during the first year after surgery, and that the persistence of difficulties was independent of whether the woman had breast conservation treatment or mastectomy [9]. In a more recent set of analyses, we identified a group of women at increased risk of psychosocial distress in the year after breast cancer, and this at risk group has significantly higher rates of sexual dysfunction [10]. We hypothesized that a major reason for the lack of recovery of sexual functioning during the first year after surgery was the sensitivity of this complex function to the physical and psychological trauma of breast cancer treatment. Therefore, in examining the sexual functioning data from the 2 to 3 year samples, we expected to see some evidence of recovery. Unfortunately, there was no further improvement in sexual functioning in these survivors at the follow-up assessments and there is significant worsening (see Fig. 1).

Our interview derived data suggest several potential reasons for the lack of improvement in sexual functioning in these breast cancer survivors. Al-

though we did not collect systematic data on the menopausal status of these women at the inception of our original study, we noted that many pre- and perimenopausal women were abruptly pushed into menopause as a result of adjuvant chemotherapy. They reported profound symptomatology (hot flashes, sleep disturbance, vaginal dryness, emotional lability) that seemed more intense than experienced in women with a natural menopausal transition that usually occurs over many years [29, 30]. Some of the postmenopausal breast cancer patients had been on hormone replacement therapy at the time of their diagnosis and this therapy was then withdrawn. These women often experienced a recurrence of menopausal symptoms as a result of the cessation of hormone replacement therapy. And finally, while tamoxifen is generally well-tolerated compared to chemotherapy, it often causes hot flashes, vaginal dryness or discharge, and menstrual irregularities [31]. Therefore, there are many hormone related reasons that explain why breast cancer survivors might experience symptoms that affect their sexual interest and functioning.

As a result of these findings on sexual functioning, we have begun a large study funded by the National Cancer Institute to examine the sexuality and intimacy concerns of breast cancer survivors. In the first phase of the study we will survey 1000 breast cancer survivors in two large metropolitan areas, as well as conduct detailed face-to-face interviews with a 15% sample. In the second phase of the research, we will test the efficacy of a 6 week group psychoeducational intervention program in a randomized trial to determine whether the persistent sexual dysfunction we have identified can be addressed with a targeted intervention program. Through this research we hope to develop a better understanding of the relationship between breast cancer treatment, menopause, and sexual functioning, as well as to evaluate the efficacy of a psychoeducational program in improving sexual functioning.

Before concluding, we would like to comment on some of the attitudinal changes these breast cancer survivors reported on their outlook on life. The cancer experience changed them in many ways. However, despite the many hardships they endured, the majority of women came away from the experience with a positive and optimistic outlook. Their experiences enriched them and deepened the compassion that they felt for others. Much like the old saying that 'even in the darkest clouds, there are silver linings,' these women seem to have found the positive in a difficult experience. They found life richer in many ways and were energized to look for changes in our environment and the future. It is important not to ignore these effects of cancer when we talk about quality of life issues. The ability to move forward with compassion may be the most important aspect of survival. It may be the issue that we need to share with patients as they struggle through the most difficult treatments.

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References

1. Boring CC, Squires TS, Tong T, Montgomery S: Cancer Statistics, 1994. CA-Cancer Journal for Clinicians 44: 7–26, 1994
2. Ganz PA for the ASCO Committee on Patient Advocacy: The physician as the patient's advocate. J Clin Oncol 11: 1011–1013, 1993
3. Leventhal BG, Shearer PD: Recognizing and managing the late effects of cancer treatment. Oncology 3(5): 73–84, 1989
4. Morris T, Greer HS, White P: Psychological and social adjustment to mastectomy: A two year follow-up study. Cancer 40: 2381–2387, 1977
5. Taylor SE, Lichtman RR, Wood JV, Bluming AZ, Dosik GM, Leibowitz RL: Illness-related and treatment-related factors in psychological adjustment to breast cancer. Cancer 55: 2506–2513, 1985
6. Jamison K, Wellisch DK, Pasnau RO: Psychosocial aspects

of mastectomy: I. The woman's perspective. Am J Psychiatry 135: 432–436, 1978
7. Knobf MT: Physical and psychologic distress associated with adjuvant chemotherapy in women with breast cancer. J Clin Oncol 4: 678–684, 1986
8. Ganz PA, Schag CC, Cheng H: Assessing the quality of life – A study in newly-diagnosed breast cancer patients. J Clin Epidemiol 43: 75–86, 1990
9. Ganz PA, Schag CAC, Lee JJ, Polinsky ML, Tan S-J: Breast conservation versus mastectomy: Is there a difference in psychological adjustment or quality of life in the year after surgery? Cancer 68: 1729–1738, 1992
10. Schag CAC, Ganz PA, Polinsky ML, Fred C, Hirji K, Petersen L: Characteristics of women at risk for psychosocial distress in the year after breast cancer. J Clin Oncol 11: 783–793, 1993
11. Ganz PA, Hirji K, Sim M-S, Schag CAC, Fred C, Polinsky ML: Predicting psychosocial risk in patients with breast cancer. Medical Care 31(5): 419–431, 1993
12. Ganz PA, Rofessart J, Polinsky ML, Schag CC, Heinrich RL: A comprehensive approach to the assessment of cancer patients' rehabilitation needs: The cancer inventory of problem situations and a companion interview. J Psychosocial Oncol 4: 27–42, 1986
13. Collins MS: Distinguishing among the attributions of causality, responsibility, and blame, including the effects of each on adjustment to a victimizing event. Doctoral Dissertation, University of California, Los Angeles, 1990
14. Taylor SE, Wayment H, Collins MS: Positive illusions and affect regulation. In: Wegner DM, Oennebaker JW (eds) Handbook of Mental Control, Prentice Hall, Englewood Cliffs, NJ, 1993, pp 325–343
15. Aaronson NK: Quality of life: What is it? How should it be measured? Oncology 2: 69–74, 1988
16. Schipper H, Levitt M: Measuring quality of life: Risks and benefits. Cancer Treatment Reports 69: 1115–1123, 1985
17. Ware JE Jr.: Conceptualizing disease impact and treatment outcomes. Cancer 53 (Supplement): 2316–2323, 1984
18. Gough IR, Furnival CM, Schilder L, Grove W: Assessment of the quality of life of patients with advanced cancer. Eur J Cancer Clin Oncol 19: 1161–1165, 1983
19. Schipper H, Clinch J, McMurray A, Levitt M: Measuring the quality of life of cancer patients: The functional living index-cancer: Development and validation. J Clin Oncol 2: 472–483, 1984
20. Schag CC, Heinrich RL, Aadland R, Ganz PA: Assessing problems of cancer patients: Psychometric properties of the cancer inventory of problem situations. Health Psychology 9: 83–102, 1990
21. Hays RD, Sherbourne CD, Mazel RM: The RAND 36-item health survey 1.0. Health Economics 2: 217–227, 1993
22. Ware JE, Sherbourne CD: The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. Medical Care 30: 473–483, 1992
23. Stewart AL, Ware JE (eds): Measuring function and well-being. The Medical Outcomes Study Approach. Duke University Press, Durham, 1992
24. McNair PM, Lorr M, Droppelman L: EITS manual for the profile of mood states. Educational and Industrial Testing Service, San Diego, CA, 1971/1981
25. Cassileth BR, Lusk EJ, Brown LL, Cross P: Psychosocial status of cancer patients and next of kin: Normative data from the profile of mood states. J Psychosoc Oncol 3: 99–105, 1985
26. Cella DF, Tross S, Orav EJ, Holland JC, Silberfarb PM, Ralfa S: Mood states of patients after the diagnosis of cancer. J Psychosoc Oncol 7: 45–54, 1989
27. Wolberg WH, Romsaas EP, Tanner MA, Malec JF: Psychosexual adaptation to breast cancer surgery. Cancer 63: 1645–1655, 1989
28. Polinsky ML: Functional status of long-term breast cancer survivors: Demonstrating chronicity. Health and Social Work 19: 165–173, 1994
29. Schover LR: The impact of breast cancer on sexuality, body image, and intimate relationships. CA-A Journal for Clinicians 41(2): 112–120, 1991
30. Kaplan HS: A neglected issue: The sexual side effects of current treatment for breast cancer. J Sex and Marital Therapy 18: 3–19, 1992
31. Fisher B, Constantino J, Redmond C *et al.*: A randomized clinical trial evaluating tamoxifen in the treatment of patients with node-negative breast cancer who have estrogen-receptor-positive tumors. N Engl J Med 320: 479–484, 1989