

INVOLVEMENT IN DECISION-MAKING AND BREAST CANCER SURVIVOR QUALITY OF LIFE^{1,2}

M. Robyn Andersen

Fred Hutchinson Cancer Research Center

Nicole Urban

Fred Hutchinson Cancer Research Center,
University of Washington, and
Marsha Rivkin Ovarian Cancer Research Center

ABSTRACT

Advances in treatment for breast cancer have improved women's chances of surviving this disease, while giving patients more treatment options than in the past. This study examined the influence of patient involvement in decision-making on survivor quality of life. A prevalence sample of breast cancer survivors were interviewed about their involvement in decision-making about their cancer treatment and follow-up care. A series of multivariate regression analyses were then conducted to examine how involvement in decision-making about cancer treatment and follow-up care contributed to survivor quality of life. Analyses revealed involvement in decision-making about the use of testing for recurrent disease (TFR) as part of follow-up care is associated with improved quality of life in several domains ($p < 0.05$). This association of improved quality of life with involvement in decision-making about follow-up TFR was independent of associations of quality of life with surgical treatment received, involvement in decision-making about surgical treatment, frequency of TFR, use of mammography, age, income, education, and years since diagnosis. This suggests that efforts to increase patient involvement in decision-making about follow-up care may improve quality of life for breast cancer survivors.

(*Ann Behav Med* 1999, 21(3):201-209)

INTRODUCTION

Advances in treatment for breast cancer have improved women's chances of surviving this disease, while making treatment for breast cancer more varied than in the past. In many cases, more than one treatment option is available to a woman. The aim of treatment and care for breast cancer, beyond prolonging life, is to ensure a high quality of life (QOL) for patients. When treatment options offer similar chances of survival, physicians of patients with breast cancer have to decide how to care for patients so as to

maximize quality of life. When this happens, patients are sometimes invited to participate in decisions about the use of treatments which have not been shown to affect survival. Medical treatment options thought to have no effect on breast cancer survival but potentially important effects on survivor quality of life include breast-conserving surgery and some tests for recurrent disease (TFR) commonly included in follow-up care.

There is evidence that for some women with breast cancer both mastectomy and breast-conserving surgeries with adjuvant radiation treatment have similar survival rates (1,2). Breast-conserving surgery with adjuvant radiation is thought by some to be the better treatment of the two because it is less disfiguring. Women who undergo breast-conserving surgery have also been found to have better body image after their treatment and may experience less frequent depression (3). There is, however, little evidence that breast-conserving treatments improve breast cancer survivors' overall quality of life (3,4-7), and mastectomy continues to be a common method of treatment for breast cancer (8). With more than one treatment available, many women are offered choices regarding the surgical treatment they receive for breast cancer. Involvement in decision-making about cancer surgery allows women to select the treatment they feel would best address their needs and concerns, appears to improve survivor quality of life (4,9,10), and may give women a sense of control over their treatment.

Follow-up care for breast cancer survivors commonly includes both tests for recurrent disease and for new tumors. Screening mammography and clinical breast examination are important parts of follow-up care, as they can detect new tumors of the breast and find local recurrences. Other procedures designed to detect recurrent disease after metastasis are more controversial. Studies have found no evidence to indicate that the use of blood tests, bone scans, or chest x-rays in asymptomatic patients increase a woman's chances of survival after cancer (11,12). Current recommendations from both the American Society of Clinical Oncology and the National Cancer Institute do not encourage the use of TFR, though the use of mammography and clinical breast examination is encouraged (13,14). Some clinicians feel that although TFR does not improve medical outcomes, failure to provide TFR as a part of follow-up care would be negligent because TFR reassures patients and reduces anxiety (12,15-20).

Opportunities to make choices about breast cancer treatment may reduce survivors' distress due to cancer and improve survivors' quality of life. Studies of breast cancer survivors have examined the effect of offering patients a choice of surgical treatment. These studies have found patients offered a choice of

¹ Preparation of this manuscript was supported in part by grant 3 R01 CA 60131-03S1 from U.S. Public Health Service, Office of Women's Health as part of the National Action Plan on Breast Cancer initiative and by grant CA 63146 from the National Cancer Institute.

² The authors would like to thank Dr. Erin Ellis, Dr. Ben Anderson, Dr. Julie Gralow, and Susan Wilson, M.P.H., for their comments on earlier drafts of this manuscript.

Reprint Address: M. R. Andersen, Cancer Prevention Research Project, Fred Hutchinson Cancer Research Center, 1100 Fairview Avenue, North, MP-804, Seattle, WA 98109-1024.

© 1999 by The Society of Behavioral Medicine.

treatment were less anxious and depressed than those not offered a choice (9,10). To our knowledge, no prior studies have examined involvement in decision-making about TFR. There are a number of possible mechanisms by which involvement in decision-making about treatment or follow-up may improve survivor quality of life. Involved women may choose to receive different treatments than are chosen for women who are less involved. Alternatively, involvement itself may have beneficial effects because it gives women a feeling of control over their treatment. While it is not clear that control over treatment for severe illnesses is generally helpful to patients (9,21–23), patients with good prognoses generally benefit from increased control (22,24,25). Early stage breast cancer patients, because of their good prognosis for cancer-free survival, are one group for whom increased control could have beneficial effects.

In this study, we chose to use multiple measures of quality of life to assure a comprehensive assessment. Domains of QOL assessed included both a comprehensive assessment of general physical and mental health but also additional measures of issues thought to be particularly important for survivor adjustment. Our assessment of QOL included measures of perceived risk of breast cancer and cancer worry. Studies of breast cancer survivors have repeatedly suggested that perceived risk of recurrence and worry about cancer recurrence are important issues for cancer survivors (16,26,27). Studies of the effects of perceived risk of breast cancer on women at elevated risk for breast cancer due to family history have found unrealistically high levels of perceived risk, anxiety, depression, and worry about cancer risk (28). High levels of perceived risk and worry are also associated with failure to use mammography for breast cancer screening (28). It is reasonable to assume that high levels of perceived risk and worry about cancer risk may have similar effects on breast cancer survivors.

Although there have been studies of breast cancer survivorship that have examined the effects of choice (4,9,10), breast conservation (3,4), and follow-up TFR (11,12,16–18), few studies have examined the long-term effects of these treatments. As survivors of cancer may live many years after their cancer experience, it is important to examine the long-term effects of medical procedures used in the care of cancer patients on their quality of life.

METHODS

This project investigated the effects of involvement in decision-making on survivor quality of life in a population sample of women who were not in treatment for breast cancer at the time of the interview and who had survived breast cancer by at least 3 years. Questions relating to the care of breast cancer survivors and to their QOL were asked of a previously identified representative population sample of breast cancer survivors during a telephone interview. All participants gave informed consent to participate according to procedures approved by the institutional review board of the Fred Hutchinson Cancer Research Center.

Study Participants

Cancer survivors interviewed were between the ages of 50 and 85 years and living in 40 rural and suburban communities in Washington State. Cancer survivors were identified during their participation in a representative population survey of the 40 communities conducted in 1994 as the baseline survey for the Community Trial Mammography Promotion (CTMP), a randomized community trial examining the effectiveness of two mammog-

raphy promotion interventions (29). The 1994 survey was conducted using a sampling frame of all 44,503 women aged 50–80 living in the 40 communities. Of the 14,080 women randomly sampled for inclusion in the survey, 11,596 women were eligible and 9,484 were interviewed, for a completion rate of 81.8% of the eligible sample.

Four hundred and eighty-five breast cancer survivors were identified during the initial survey based on their self-report of malignant breast conditions. Because the survey identified all women reporting a history of breast cancer in a representative community sample, the breast cancer survivors identified are a representative prevalence sample of rural community-living breast cancer survivors. The 485 survivors identified in the 1994 survey were interviewed again in 1996. Thirteen percent were considered ineligible for the interview in 1996 because they were deceased, institutionalized, or had moved from the community. Of the remaining 423 women, 344 participated in the interview, representing 83% of the eligible sample. Eligible women who did not participate in the interview included 9 (2%) women who were too ill to be interviewed or otherwise unable to participate, 24 (6%) women who refused to complete the interview, and 39 (9%) who could not be contacted.

Two hundred and ninety-two breast cancer survivors were included in the analyses presented here. As we wished to examine the effect of decision-making in cancer treatment on women who were free of recurrent disease, women were excluded from this analysis if they reported being in treatment for cancer at the time of the second interview ($n = 36$) or had been diagnosed with cancer a second time within 2 years of the interview ($n = 16$). The final sample of women included in analyses consisted therefore of women who were doing relatively well and excluded women with severe chronic illnesses, recurrent disease, and those who needed ongoing treatment for active cancer.

Measures

Survivors participating in the interview were asked about their treatment for breast cancer, including the type of surgery they received, whether or not they received chemotherapy or radiation, and the degree to which they felt they participated in making decisions about their surgical treatment.³ Survivors were also asked about their use of TFR, the frequency with which they received such testing immediately after their initial treatment for cancer, whether they were getting testing regularly at the time of the interview, and the degree to which they felt they participated in making decisions about TFR. Survivors were also asked standard demographic questions and questions about their quality of life, including assessments of perceived risk and worry about a recurrence of breast cancer.

Treatment for Initial Breast Cancer and Current Treatment

Survivors were asked about the year and month of their diagnosis of breast cancer and how their cancer was first found. Women were also asked whether or not they had received a mastectomy and/or lumpectomy as a result of breast cancer. Women's responses to this question were coded into three catego-

³ Survivors were asked about their involvement in decision-making regarding their use of radiation and chemotherapy, but their responses to these questions are not included in this paper and were not used in analyses because decisions to use radiation are often part of the surgical treatment decisions and use of chemotherapy is generally determined by the stage at which a woman's cancer is diagnosed.

ries: lumpectomy only, mastectomy only, and both surgeries performed. If women reported that they had received a mastectomy at any point during their treatment, they were asked if they had received a double mastectomy. Women were also asked about nonsurgical treatments for breast cancer including radiation and chemotherapy. Answers to these questions were coded separately such that any woman reporting radiation treatment was coded 1 for radiation while women reporting no radiation treatment were coded 0. Similarly, any woman reporting chemotherapy was coded 1 for chemotherapy while women reporting no chemotherapy as part of their treatment for cancer were coded 0. Because we used telephone interviews for the collection of data on the participating breast cancer survivors, medical records were not available for the collection of data on participants' stage of cancer at diagnosis, making information on cancer stage at diagnosis unavailable for analysis. As cancer stage is an important predictor of cancer survival and might be a confounder of associations between TFR or involvement in decision-making and subsequent survivors' quality of life, we were interested in controlling for cancer stage at diagnosis to the maximum degree possible in analyses examining participants' quality of life. As cancer stage at diagnosis is often used to determine whether women need treatment with radiation or chemotherapy agents, these variables were included in analysis not only as indicators of treatment but also in an effort to control for stage of cancer at diagnosis.

Use of Follow-Up Testing for Cancer Recurrence

Survivors of breast cancer were asked about the frequency with which they initially visited their doctor and how often they were scheduled for TFR after they completed their initial treatment for cancer. Survivors indicated whether they visited their physician regularly for blood tests, chest x-rays, or bone scans performed to make sure the cancer had not spread immediately after their initial treatment. Women who indicated that they received one or more of the three tests were asked about the frequency with which they routinely received this testing during the period immediately following their initial treatment for breast cancer, how long testing continued, and whether they were getting such testing regularly at the time of the interview. Women who were still getting TFR at the time of the interview were asked how frequently they had testing. In all cases, mammography and clinical breast examination (CBE) were excluded from the list of tests included as TFR to distinguish between women's use of recommended breast cancer screenings and use of the more controversial TFR. The frequency with which women reported getting TFR after their initial cancer treatment was coded into one of four categories: those getting one or more of the tests more than twice a year, those getting testing twice a year, those getting testing annually, and those getting no testing or testing less than once a year. Copies of all questions on survivor's cancer treatment and follow-up TFR are included in Appendix A. Women were also asked a series of questions about their use of mammography and CBE at the time of the interview. Women were asked if they had received a mammogram within 1 year of the interview and if they had received CBE within 2 years.

Involvement in Treatment Decision-Making

Questions about women's participation in treatment decision-making were also asked. These questions were based on comments from breast cancer survivors who participated in focus groups. We composed questions that were perceived to be nonthreatening and

nonjudgmental by survey participants, by making the questions about participation or nonparticipation in treatment decision-making similar to comments spontaneously used by breast cancer survivors to describe themselves. Women were told, "Some women prefer to make decisions about their medical treatment themselves, others prefer to have their physician or someone else make decisions for them. I want to know how involved you feel you were in making decisions about your care." After this women were asked to rate their involvement in decision-making at different points in their breast cancer treatment on a 3-point scale from 1 (*you were not at all involved*) to 3 (*you were extremely involved and made all the decisions yourself*). In asking about involvement in decision-making regarding surgical treatment or TFR, women were told, "In some cases there are choices to be made about the type of surgery used for treatment of breast cancer," and "In some cases there are choices to be made about follow-up tests done after the initial treatment for breast cancer." Women were asked to use the 3-point scale to judge how involved they feel they were in making decisions about either the type of surgery they received or the TFR they received after their initial breast cancer treatment. As medical community standards regarding patient involvement in decision-making about cancer treatment for breast cancer have changed dramatically during the period in which women participating in this study received their treatment, women indicating that these questions were not applicable in their case because their treatment required few or no decisions to be made by them or their doctor were coded 1 (*not at all involved in decision-making*).

Women were also asked whether they would have preferred to be more or less involved in making decisions about their treatment for breast cancer using a 5-point scale from 1 (*I would have preferred to be much less involved*) to 5 (*I would have preferred to be much more involved*). Copies of the questions about involvement in decision-making are included in Appendix B.

Survivor Quality of Life

Quality of life for breast cancer survivors was assessed using multiple measures. We included a general measure of overall quality of life suitable for the assessment of quality of life across a broad range of health states and additional measures of quality of life that assess perceived breast cancer risk and worry due to breast cancer. General quality of life was assessed using the SF-36 (30). Additional measures included a modified version of the Lerman Cancer Worry Scale (31) and a question designed to assess perceived risk of getting breast cancer again (32).

General Quality of Life: General quality of life was assessed using the SF-36, a well-validated, widely-used instrument that assesses several aspects of quality of life including physical, social, and psychological functioning (30). It consists of 36 items designed to measure a number of different dimensions of quality of life. These dimensions include physical functioning, problems with work or other daily activities due to health problems, bodily pain, self-assessed general health status, feelings of vitality, social functioning, problems with work or other daily activities due to emotional problems, and mental health. The SF-36 has been used in intervention studies and longitudinal studies, has been found to measure quality of life across a broad range of levels of general functioning, and is sensitive to changes in general life functioning common in relatively healthy populations.

TABLE 1

Characteristics of a Prevalence Sample of Breast Cancer Survivors

Years Since Diagnosis	
3–5 years	12.3%
5–9 years	31.5%
10–19 years	33.2%
20–30 years	22.9%
Surgical Treatment	
Breast-conserving surgery only	18.5%
Mastectomy only	70.5%
Both breast-conserving surgery and mastectomy	12.0%
Radiation Treatment	
Yes	30.9%
No	69.1%
Chemotherapy	
Yes	17.3%
No	82.7%
Follow-Up Appointments for CBE	
Less than annually	10.0%
Annually or more often	90.0%
Frequency of Testing for Recurrence	
More than twice a year	21.8%
Twice a year	19.5%
Annually	30.2%
Less than annually	29.0%
Testing for Recurrence Received	
Chest x-rays	
Yes	70.5%
No	29.5%
Blood tests	
Yes	64.9%
No	35.1%
Bone scans	
Yes	23.7%
No	76.3%
Involvement in Decision-Making about Surgical Treatment	
Very involved	52.2%
Somewhat involved	18.4%
Not at all involved	29.4%
Involvement in Decision-Making about TRF	
Very involved	48.3%
Somewhat involved	24.7%
Not at all involved	27.0%
Satisfaction with Level of Involvement in Decision-Making	
Wished they had been more involved	19.2%
Level of involvement about right	80.4%
Wished they had been less involved	0.4%

Perceived Risk of Breast Cancer: Perceived risk of breast cancer was assessed using a question that has been used in prior studies of perceived breast cancer risk (32). This question was modified for use with women who have had breast cancer in the past. Women were asked “What do you think the chances are that you will have breast cancer again some day? By again I mean either developing a new breast cancer tumor in your previously unaffected breast or suffering a recurrence of your prior cancer. Please answer using a percentage scale where 100 means you will definitely get cancer again, and 0 means there is no chance you will get it again.” Responses were categorized as “more than 50%,” “less than 50% but more than 25%,” “less than 25% but more than 10%,” “less than 10% but still some chance,” and “no chance” or “0%.”

Worry About Breast Cancer: Worry about breast cancer was assessed using the 3-item Lerman Cancer Worry Scale (31).

Women rate the frequency with which they worry about getting breast cancer and the frequency with which worry about breast cancer affects their mood and their ability to carry out daily activities on a 5-point scale from 1 (*rarely or not at all*) to 5 (*almost all the time*). This scale has been used in prior research on women at high risk for breast cancer and found to demonstrate adequate reliability (31).

Statistical Analysis

Analyses began with descriptive analyses describing the characteristics of the population studied, the degree to which survivors reported being involved in decision-making about their treatment and follow-up care, and survivor quality of life.

A series of multivariate regression analyses were then conducted to examine the study’s main hypothesis that the involvement in decision-making about treatment and TFR predicted quality of life. Other potential predictors of survivor quality of life were included in the analyses both for reasons of interest and to assure adjustment of the association between decision-making and quality of life for potential confounding influences associated with women’s disease. These predictors were chosen on an a priori basis and included in all analyses of quality of life domains. These predictors included demographics commonly associated with QOL (age, income, education), years since breast cancer diagnosis, and cancer treatment variables frequently associated with stage of disease including surgery type and the use of chemotherapy or radiation. Use of TFR after initial treatment for breast cancer and current use of TFR were also included.

Bivariate analyses examining the association of involvement in decision-making with other study variables were also conducted, as were analyses examining the associations of involvement in decision-making with surgery type and TFR. These analyses were conducted both to help clarify the degree to which involvement in decision-making is associated with demographic characteristics and to examine the possibility that differences in the treatment received by women who were and were not involved in making decisions about their care might be the means by which decision-making affects QOL.

RESULTS

Characteristics of a Population Sample of Breast Cancer Survivors

Characteristics of the sample of cancer survivors interviewed are reported in Table 1. The survivor sample reflected the general population of women living in the CTMP communities, in that they were predominantly White and generally well-educated. Ninety percent of the women in this sample reported visiting their physician at least annually for a clinical breast examination after their initial treatment for breast cancer. Seventy-one percent of the sample reported TFR (blood tests, x-rays, or bone scans) at least annually after their initial treatment for breast cancer. Over half of the survivors surveyed ($n = 163$; 56%) reported that they were still getting TFR at the time of the interview.

Survivors’ Reported Involvement in Treatment Decision-Making

More than half of the survivors interviewed (52.2%) felt that they had been very involved in making decisions about their surgical treatment for breast cancer. A similar proportion of women reported involvement in decision-making about TFR. When asked if they would have preferred to be more or less involved in making

TABLE 2
Predictors of Quality of Life: Subscales of the SF-36, Worry about Cancer and Perceived Risk

	SF-36 Subscale								Worry About Cancer Affecting Mood B
	General Health B	Mental Health B	Physical Functioning B	Role- Emotional Functioning B	Social Functioning B	Role- Physical Functioning B	Pain B	Vitality B	
Age	-1.07**	-1.10**	0.43	-0.19	-0.22	-0.30	0.14	0.26	-0.00
Income	4.20**	5.02*	1.67	2.68*	3.04*	2.60*	2.49	-0.10	-0.02
Education	-0.25	-2.11	-1.78	-1.77	-3.62	-4.33	-3.42	-2.02	0.05
Years since diagnosis	-0.07	0.11	-0.45	0.29	0.36	0.16	0.69	0.34	-0.01
Radiation	7.90	8.44	6.02	4.92	0.61	2.26	4.54	1.82	0.04
Chemotherapy	-0.08	9.34	6.10	0.92	6.63	10.84*	4.55	3.97	-0.04
Involvement in decision- making about surgery	-5.65*	-8.16	-6.11*	-2.65	-3.18	-2.92	2.86	3.25	-0.04
Surgery type									
Mastectomy	ref	ref	ref	ref	ref	ref	ref	ref	ref
Lumpectomy	-7.76	-5.90	-12.05	0.72	-0.20	-1.59	1.33	-1.50	-0.09
Both surgeries	-11.94*	-6.09	-9.82*	-11.23*	-7.68	-2.92	7.93	-2.23	0.25*
Involvement in decision- making about TFR	5.63*	5.36	5.77*	5.82**	7.31**	4.80*	4.68	3.23	-0.01
Frequency of TFR	-2.93	-5.11	-3.39	-4.56**	-4.01*	-3.51*	-3.54	-3.96**	-0.01
Currently getting TFR	-0.86	-0.64	1.46	4.05	0.54	3.44	1.66	3.07	-0.25
Model F	4.58**	2.44*	1.56	2.76**	2.59**	1.12*	1.12*	2.52**	1.68
Model R ²	0.27	0.17	0.11	0.19	0.18	0.15	0.08	0.17	0.12
Model N	158	158	158	158	158	158	158	158	158

* = $p < .05$.

** = $p < .01$.

decisions about their treatment for breast cancer, most of these survivors (80.4%) reported their level of involvement to be about right for them.

Survivors' Quality of Life

Although risk for recurrence varies according to stage of cancer at diagnosis and the effectiveness of breast cancer treatments, in general, survivors of early stage breast cancer have a risk of ipsilateral recurrence within 10 years of treatment of between 10% and 18% (33). Risks for recurrence in patients with Stage 2 or 3 disease can be higher (34). However, as the hazard rate for recurrence peaks at 18 months after surgery and generally tapers off slowly after 5 years survival (34) and all the survivors interviewed for this study were not in treatment and at least 3 years postdiagnosis, a 25% risk of recurrence estimate is likely an overestimate of the risk of cancer faced by study participants, with an estimate of 10% or less likely more accurate for most of our study participants. Based on this estimate, about 38% of the survivors interviewed appeared to have exaggerated perceptions of their chances of having breast cancer again. Seventeen percent thought the chance that they would get breast cancer again was more than 50%, while an additional 21% thought the chance was less than 50% but more than 25%. Another 8% reported the chance was less than 25% but more than 10%. Only 14% of the breast cancer survivors reported thinking the chance that they would have breast cancer again was between 10% and 1%. Forty percent of the cancer survivors interviewed believed that there was absolutely no chance that they would ever have breast cancer again.

In spite of these high levels of perceived risk, the overall quality of life reported by this sample of breast cancer survivors was quite high. On average, survivors of breast cancer scored within the range expected for women of their age on the eight

subscales of the SF-36 measuring quality of life. Survivors also reported infrequent worry about breast cancer. Eighty percent (80.2%) of the women reported thinking about their chances of developing breast cancer again rarely or not at all, 12.0% reported that they thought about it sometimes, while 7.8% reported thinking about it often or almost all the time. Seven percent (7.1%) of the cancer survivors reported that thoughts about their chances of having breast cancer again affected their mood at least sometimes, while 1.8% reported that thoughts about breast cancer affected their ability to perform daily activities. These low rates of worry in spite of high levels of perceived risk are consistent with past studies of perceived risk and worry that have found the association between these variables to be small (35).

Multivariate Analyses Examining Survivor Quality of Life

Multivariate regression modeling was used to examine the influence of involvement in decision-making on survivor quality of life independent of treatment and testing use. Age, income, education, years since diagnosis, and use of radiation and chemotherapy were included in all analyses examining survivor quality of life. Separate analysis runs were conducted for the eight subscales of the SF-36, survivors' perceived risk of breast cancer, and survivors' reported worries about breast cancer affecting their mood. The results of these analyses are shown in Table 2.

Involvement in decision-making about the use of TFR was a significant predictor of survivor quality of life on six dimensions including pain, general health, vitality, physical functioning, emotional functioning, and mental health. Involvement in decision-making about surgery was not a statistically significant contributor to survivor quality of life on any of the SF-36 scales. Survivors' age, education, income, and years since diagnosis also contributed

to survivor quality of life, as did type of surgery and frequency of TFR.⁴

Predictors of Involvement in Treatment Decision-Making, Surgery Type, and Use of TFR

Breast cancer survivors reporting little or no involvement in decision-making about their surgical treatment for breast cancer or their follow-up testing for recurrent disease did not differ from survivors reporting being very involved in decision-making in age, income, or education ($p > .05$ in all comparisons). As would be expected based on the history of breast cancer treatment, there were, however, differences between these two groups in time since diagnosis. Survivors who were diagnosed more recently were more likely to report involvement in decisions about surgery than those diagnosed many years prior to the interview, $\chi^2(6) = 27.73$; $p < 0.01$. Forty-one percent (41.3%) of women diagnosed 20 years or more prior to the interview reported no involvement in decision-making about their surgical treatment. This percentage fell to 31.3%, 20.0%, and 7.5% for women diagnosed 10 to 19 years prior, 5 to 9 years prior, and 3 to 5 years prior, respectively. There were no significant differences in women's reports of involvement in decision-making about their use of TFR by year of diagnosis ($p > 0.05$).

Women who did or did not get mastectomies were not significantly different in the extent to which they reported having been involved in making decisions about their surgical treatment ($p > 0.05$). Similarly, women who did or did not get TFR did not differ in the extent to which they reported having been involved in making decisions about their use of TFR ($p < 0.05$).

DISCUSSION

Involvement in Decision-Making and QOL

The results of this study suggest that breast cancer patients who report more involvement in decision-making about their use of some tests for recurrent disease report better quality of life as long-term survivors than those who report less involvement in decision-making about TFR. Involvement in decision-making about TFR does not appear to be related to perceived risk for breast cancer or to worry about cancer risk affecting mood. Although other studies of involvement in decision-making about cancer care have found effects of involvement in decision-making about surgical treatment, in this study the effects of involvement in decision-making about use of TFR during follow-up appear to be stronger than the effects of involvement in surgical decision-making, which did not reach conventional levels of statistical significance.

To our knowledge, this is the first study to find that involvement in decision-making about TFR affects breast cancer survivors' quality of life. Although these findings are interesting, the cross-sectional survey methodology employed, the use of multiple comparisons in study analysis, and the use of retrospective self-report measures of involvement in decision-making should be considered in evaluation of these findings. Women were asked to report their level of involvement in decision-making at the time of their initial treatment for breast cancer and their subsequent follow-up, but they may have misremembered the details of their involvement in decision-making, as this involvement had occurred many years in the past. Dispositional characteristics may even have influenced women's recollections of their involvement in decision-making about surgical treatment and TFR. That the effects found in this study arise purely from errors in women's retrospective reporting of involvement seems unlikely; however, because reporting errors and dispositional influences would likely affect reporting of involvement in decision-making about surgery and TFR equally, and in this study only involvement in decision-making about TFR was associated with later QOL. Prospective randomized studies will be needed to definitively determine whether patient involvement in decision-making about TFR improves women's quality of life after cancer.

Because the survivors studied here were not randomly assigned to participate in decision-making, the reason for the association found is unclear. It is possible that characteristics of women who were doing poorly at the time of the interview affected women's reports of their history of involvement in decision-making. Indeed, what women mean when they report that they were involved in making decisions about their use of TFR is unclear. While these women did, of course, have final decision-making power regarding their use of TFR (that is to say they could choose not to comply with their scheduled appointments), it is unclear how involved physicians encouraged them to be. Women's reports of involvement may reflect differing levels of control over appointment scheduling or differing education about their TFR, rather than decision-making control over testing use.

As to why involvement in decision-making about TFR should influence cancer survivor's quality of life years after treatment ends, we can only speculate. Some influence might be expected because cancer diagnosis and treatment are traumatic and important life events in the lives of many cancer survivors. As traumatic life events have effects that may persist for years after the event, if involvement in decision-making helps women to deal with the traumas associated with cancer diagnosis, treatment, and survivorship, involvement in decision-making would be expected to influence women's QOL many years after cancer treatment was completed.

Use of TFR and QOL

This study also found little evidence to suggest that TFR serves to reassure breast cancer survivors or that it reduces survivors' worries about their risk for recurrent breast cancer. Indeed, in this sample, reports of frequent use of TFR by breast cancer survivors immediately after cancer treatment are associated with reduced quality of life on the general health, vitality, social functioning, and mental health subscales of the SF-36.

The findings of this study with respect to the hypothesis that frequent TFR is reassuring to survivors appear to be inconsistent with the findings of prior studies of follow-up care for breast

⁴ A second series of multivariate analyses was conducted which included mammography use in the past 2 years as a predictor of survivor quality of life. The results of this analysis differed only slightly from those shown in Table 2. Mammography use was not significantly associated with any of the subscales of quality of life and its addition to the model did not significantly change the results of analyses examining quality of life ratings on the SF-36 significantly. The addition of mammography use to the models predicting survivors' worry about cancer affecting their mood and survivors' perceived risk of breast cancer revealed that women using mammography after breast cancer perceived their risk of breast cancer recurrence to be lower than those who do not. The inclusion of mammography use in the multivariate equation also changed the parameter estimate of the association of current TFR with worry about cancer affecting mood by slightly more than 10% (to -0.135). When adjusted for survivors' use of mammography, current use of TFR was associated with a statistically significant reduction of survivor worry affecting mood at the ($p < 0.05$) level.

cancer survivors, that have generally found women to report that they find testing to be reassuring (12,16,18). Differences in the design of this and past studies may explain the inconsistent results. Studies examining the effect of testing on survivors have often failed to include women who either get a limited amount of testing or do not get testing at all. Many studies have thus had to rely on women's introspective self-reports of the effects of testing instead of comparing tested and untested women. Studies using introspective self-reports have generally found women to report that they find testing to be reassuring, suggesting that when women introspect about the effects of that testing, they often report feeling reassured by testing.

When we compared women with different histories of TFR use on their responses to standardized scales assessing worry about cancer and quality of life, a different picture emerged. This analysis revealed little evidence that frequent TFR serves to reassure breast cancer survivors or that it reduces survivors' worries about their risk for recurrent breast cancer. Indeed, frequent TFR after cancer treatment was associated with reduced quality of life that does not appear to improve even after several years time.

Levethal's theory of self-regulation suggests that the provision of health care interventions can have negative psychological side effects if they label people as ill or at high risk of illness or serve as reminders of a health problem that is thought by the person with it to be a serious threat to their health (36). Labeling is hypothesized to affect how a woman feels about her health and how healthy she believes herself to be. The finding that initial testing appears to adversely affect self-assessed general health status, feelings of vitality, social function, and mental health, is consistent with the labeling hypothesis.

As this study used only cross-sectional methods and could not get information on women's stage at diagnosis, other interpretations are also consistent with these findings. If physicians consistently encourage women with poor prognoses, advanced disease, or who are anxious or depressed at the time of their cancer treatment to get testing but do not encourage testing for those women with less advanced disease, those who are less anxious, and those who they feel are doing well, the women getting testing after cancer treatment would be expected to demonstrate higher levels of anxiety, depression, and reduced quality of life as was found in this study. This selection effect could persist years later, even if TFR is reassuring and helpful to those women who receive it. As this study did not review women's medical records created at the time of their diagnosis of breast cancer, it is possible that physicians recommended TFR more frequently to women with more advanced stage disease. If this occurred, this study's findings that TFR use is associated with reduced QOL could arise purely from the association of stage with more frequent TFR. Future studies of the effect of TFR of cancer survivors' QOL should include cancer stage at diagnosis to better examine this possible alternative explanation for associations between TFR use and QOL.

As this study was cross-sectional, it is possible that the association between QOL and TFR occurs because women with reduced QOL choose to pursue TFR more frequently than those whose QOL is higher. This possibility can not be ruled out, however; when we asked women about their use of TFR, we did ask them to report the frequency with which they got TFR immediately after their initial treatment for breast cancer. We did this to help reduce reporting error due to women changing the

frequency with which they got TFR later into their recovery from breast cancer.

Directions for Future Research

The relevance of this study's findings to women currently in treatment for breast cancer is not completely clear. Because the women who participated in this study were generally long-term survivors of breast cancer who were treated for cancer more than 5 years earlier, the testing many of these women received immediately after they completed their treatment for breast cancer may be different from the testing a woman would receive today. Similarly, the degree to which these women may have been invited to be involved in treatment decision-making or may have expected to be involved in treatment decision-making may also be different from the degree to which women are currently invited to take control over their treatment and their use of TFR.

With evidence now available from randomized controlled trials finding that TFR does not reduce mortality or morbidity in survivors of breast cancer (11), there is considerable controversy about the use of TFR. As the tests included in TFR have not been shown to offer women a clear QOL benefit overall, their benefit, if any, to patients may arise from the opportunity they offer patients to be involved in decision-making about cancer treatment. If this finding that patient involvement in decision-making about TFR is associated with higher quality of life were to be replicated in a randomized trial, it would suggest that physicians might improve their patients' QOL by offering their patients the opportunity to make their own informed decisions about the value of TFR. Even if TFR were not available, physicians might offer their patients increased opportunities to become involved in decision-making about their follow-up care, perhaps through increased efforts to inform patients about the value of mammography and CBE as part of follow-up and to involve patients in follow-up appointment scheduling. Further research on the effects of involvement in decision-making about testing, especially a randomized trial examining the effects of involving patients in decision-making about their follow-up care, seems warranted.

APPENDIX A

Questions About Cancer Treatment

- As a result of breast cancer, have you had a mastectomy, lumpectomy, both, or neither? PROBE: Did you have the breast removed?

<input type="checkbox"/> 1 Mastectomy (breast removed)	<input type="checkbox"/> 2 Lumpectomy (tumor/lump removed)
<input type="checkbox"/> 3 Both	<input type="checkbox"/> 4 Neither
<input type="checkbox"/> 8 Don't know	<input type="checkbox"/> 9 Refused
- Are you still receiving treatment for breast cancer?

<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
<input type="checkbox"/> 8 Don't know	<input type="checkbox"/> 9 Refused
- Did you ever receive radiation therapy during your treatment for breast cancer?

<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
<input type="checkbox"/> 8 Don't know	<input type="checkbox"/> 9 Refused
- Did you ever receive chemotherapy during your treatment for breast cancer?

<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
<input type="checkbox"/> 8 Don't know	<input type="checkbox"/> 9 Refused
- Blood tests are sometimes used to check to make sure that the cancer has not spread. Following your initial breast cancer diagnosis and treatment, did you have regular blood tests?

<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 0 No
<input type="checkbox"/> 8 Don't know	<input type="checkbox"/> 9 Refused

6. How often did you have regular blood tests? Would you say . . .
- 1 More than twice a year, 2 Twice a year,
3 Once a year, or 4 Less often than every year?
8 Don't know 9 Refused
7. A chest X-ray is an X-ray of your heart and lungs sometimes used to check to make sure your lungs are free of cancer. Following your initial breast cancer diagnosis and treatment, did you have regular chest X-rays?
- 1 Yes 0 No
8 Don't know 9 Refused
8. How often did you have chest x-rays? Would you say . . .
- 1 More than twice a year, 2 Twice a year,
3 Once a year, or 4 Less often than every year?
8 Don't know 9 Refused
9. A bone scan is sometimes used to check that the cancer has not spread to your bones. Following your initial breast cancer diagnosis and treatment, did you have regular bone scans?
- 1 Yes 0 No
8 Don't know 9 Refused
10. How often did you have bone scans? Would you say . . .
- 1 More than twice a year, 2 Twice a year,
3 Once a year, or 4 Less often than every year?
8 Don't know 9 Refused
11. Do you still go regularly for (blood tests, chest X-rays, or bone scans)?
- 1 Yes 0 No
8 Don't know 9 Refused
3. In some cases there are choices to be made about chemotherapeutic and radiation treatments for breast cancer. Again using a three-point scale, how involved do you feel you were in making decisions about chemo and radiation treatments? Would you say (READ 1-3)
- 1 Not at all involved—others made decisions for me
2 A fair bit
3 Very involved—I made all the decisions myself
N/A Not Applicable—In my case there were few or no decisions to be made by me or my doctor regarding chemotherapy.
8 Refused
9 Don't know
4. In some cases there are choices to be made about follow-up tests done after the initial treatment for breast cancer. These tests may include blood tests, chest x-rays, or other procedures. Again using a three-point scale, how involved do you feel you were in making decisions about tests after treatment? Would you say (READ 1-3)
- 1 Not at all involved—others made decisions for me
2 A fair bit
3 Very involved—I made all the decisions myself
N/A Not Applicable—In my case there were few or no decisions to be made by me or my doctor.
8 Refused
9 Don't know
5. Would you have preferred to be more or less involved in making decisions about your treatment for breast cancer? Would you say (READ 1-5)
- 1 Much less involved
2 A little less involved
3 My involvement was about right
4 A little more involved
5 Much more involved
8 Refused
9 Don't know

APPENDIX B

Involvement in Treatment Decisions Scale

These next questions ask about your involvement in making decisions regarding your treatment for breast cancer. Before I ask you these questions, I want to emphasize that there are not right or wrong answers. Every case of breast cancer is different, as is every patient with breast cancer. Some women prefer to make decisions about their medical treatment themselves, others prefer to have their physician or someone else make decisions for them. I want to know how involved you feel you were in making decisions about your care.

1. On a three-point scale from 1 meaning you were not at all involved to 3 meaning you were extremely involved and made all the decisions yourself, how involved do you feel you were in making decisions about your treatment for breast cancer overall? Would you say (READ 1-3)
- 1 Not at all involved—others made decisions for me
2 A fair bit
3 Very involved—I made all the decisions myself
N/A Not Applicable—In my case there were few or not decisions to be made by me or my doctor.
8 Refused
9 Don't know
2. In some cases there are choices to be made about the type of surgery used for treatment of breast cancer. Again using a three-point scale, how involved do you feel you were in making decisions about the type of surgery you received? Would you say (READ 1-3)
- 1 Not at all involved—others made decisions for me
2 A fair bit
3 Very involved—I made all the decisions myself
N/A Not Applicable—In my case there were few or no decisions to be made by me or my doctor about the type of surgery I should have. There was only one type of surgery appropriate.
8 Refused
9 Don't know
- (1) Serrazin D, Dewar JA, Arrigada R: Conservative management of breast cancer. *British Journal of Surgery*. 1986, 73:604-606.
- (2) Veronesi U, Zucall R, Luini A: Local control and survival in early breast cancer: The Milan Trial. *International Journal of Radiation Oncology Biology Physics*. 1986, 12:717-720.
- (3) Kiebert GM, de-Haes JC, van-de-Velde CJ: The impact of breast-conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: A review. *Journal of Clinical Oncology*. 1991, 9:1059-1070.
- (4) Fallowfield LJ, Hall A, Maguire GP, Baum M: Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *British Medical Journal*. 1990, 301:575-580.
- (5) Ganz PA, Schag AC, Lee JJ, Polinsky ML, Tan SJ: Breast conservation versus mastectomy. Is there a difference in psychological adjustment or quality of life in the year after surgery? *Cancer*. 1992, 69:1729-1738.
- (6) Hall A, Fallowfield L: Psychological outcome of treatment for early breast cancer: A review. *Stress Medicine*. 1989, 5:167-175.
- (7) Levy SM, Haynes LT, Herberman RB, et al: Mastectomy versus breast conservation surgery: Mental health effects at long-term follow-up. *Health Psychology*. 1992, 11:349-354.
- (8) Ganz PA: Treatment options for breast cancer—Beyond survival [editorial; comment]. *New England Journal of Medicine*. 1992, 326:1147-1149.
- (9) Morris J, Royle GT: Offering patients a choice of surgery for early breast cancer: A reduction in anxiety and depression in patients and their husbands. *Social Science and Medicine*. 1988, 26:583-585.
- (10) Pozo C, Carver CS, Noriega V, et al: Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: A prospective

- study of the first year postsurgery. *Journal of Clinical Oncology*. 1992, 10:1292-1298.
- (11) The GIVIO Investigators: Impact of follow-up testing on survival and health-related quality of life in breast cancer patients. A multicenter randomized controlled trial. *Journal of the American Medical Association*. 1994, 271:1587-1592.
- (12) Morris S, Corder AP, Taylor I: What are the benefits of routine breast cancer follow-up? *Postgraduate Medicine*. 1992, 68:904-907.
- (13) National Cancer Institute: Breast Cancer. PDQ (Physician Data Query) [database online]. Bethesda, MD: National Cancer Institute, 1995.
- (14) American Society of Clinical Oncology: Recommended breast cancer surveillance guidelines. *Journal of Clinical Oncology*. 1997, 15:2149-2156.
- (15) Cocconi G: Follow-up of patients with breast cancer [letter; comment]. *Journal of the American Medical Association*. 1994, 272:1657.
- (16) Kiebert GM, Welvaart K, Kievit J: Psychological effects of routine follow-up on cancer patients after surgery. *European Journal of Surgery*. 1993, 159:601-607.
- (17) Klaff RA: Follow-up of patients with breast cancer [letter; comment]. *Journal of the American Medical Association*. 1994, 272:1658.
- (18) Muss HB, Tell GS, Case LD, Robertson P, Attwell BM: Perceptions of follow-up care in women with breast cancer. *American Journal of Clinical Oncology*. 1991, 14:55-59.
- (19) Ryo UY: Follow-up of patients with breast cancer [letter; comment]. *Journal of the American Medical Association*. 1994, 272:1658-1659.
- (20) Wertheimer MD: Against minimalism in breast cancer follow-up. *Journal of the American Medical Association*. 1991, 265:396-397.
- (21) Andersen BL: Surviving cancer. *Cancer*. 1994, 74:1484-1495.
- (22) Taylor SE, Helgeson VS, Reed GM, Skokan LA: Self-generated feeling of control and adjustment to physical illness. *Journal of Social Issues*. 1991, 47:91-109.
- (23) Taylor SE, Lichtman RR, Wood VJ: Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology*. 1984, 46:489-502.
- (24) Thompson SC: Will it hurt less if I can control it? A complex answer to a simple question. *Psychological Bulletin*. 1981, 90:89-101.
- (25) Thompson SC, Cheek PR, Graham MA: The other side of perceived control: Disadvantages and negative effects. In Spaceapan S, Os-kamp S (eds), *The Social Psychology of Health (Claremont Symposium on Applied Social Psychology, 1987)*. Newbury Park, CA: Sage Publications, 1988, 69-93.
- (26) Fredette SL: Breast cancer survivors: Concerns and coping. *Cancer Nursing*. 1995, 18(1):35-46.
- (27) Lasry JM, Margolese RG: Fear of recurrence, breast conserving surgery, and the trade-off hypothesis. *Cancer*. 1991, 69:2111-2115.
- (28) Kash KM, Holland JC, Halper MS, Miller DG: Psychological distress and surveillance behaviors of women with a family history of breast cancer. *Journal of the National Cancer Institute*. 1992, 84:24-30.
- (29) Stoddard AM, Lipkus I, Lane D, et al., for the National Cancer Institute Breast Cancer Screening Consortium: Characteristics of under-users of mammogram screening aged 50 to 80. *Preventative Medicine*. 1998, 27:478-487.
- (30) Ware JE, Snow KK, Kosinski M, Gandek B: *SF-36 Health Survey: Manual and Interpretation Guide*. Boston, MA: The Health Institute, New England Medical Center, 1993.
- (31) Lerman C, Trock B, Rimer B, et al: Psychological and behavioral implications of abnormal mammograms. *Annals of Internal Medicine*. 1991, 114:657-661.
- (32) Lerman C, Lustbader E, Rimer B, et al: Effects of individualized breast cancer risk counseling: A randomized trial. *Journal of the National Cancer Institute*. 1995, 87:286-292.
- (33) Dalberg K, Mattsson A, Rutqvist LE, et al: Breast-conserving surgery for invasive breast cancer: Risk factors for ipsilateral breast tumor recurrences. *Breast Cancer Research and Treatment*. 1997, 43:73-86.
- (34) Demicheli R, Abbattista A, Miceli R, Valagussa P, Bonadonna G: Time distribution of the recurrence risk for breast cancer patients undergoing mastectomy: Further support about the concept of tumor dormancy. *Breast Cancer Research and Treatment*. 1996, 41:177-185.
- (35) McCaul KD, Branstetter AD, Schroeder DM, Glasgow RE: What is the relationship between breast cancer risk and mammography screening? A meta-analytic review. *Health Psychology*. 1996, 15:423-429.
- (36) Leventhal H, Cameron L: Behavioral theories and the problem of compliance. *Patient Education and Counseling*. 1987, 10:117-138.