Quality of Life, Survivorship, and Psychosocial Adjustment of Young Women With Breast Cancer After Breast-Conserving Surgery and Radiation Therapy

Karen Hassey Dow, PhD, RN, FAAN, and Patricia Lafferty, RN, MSN

Purpose/Objectives: To examine changes in quality of life (QOL), psychosocial adjustment, and survivorship issues over time of women younger than 45 years who underwent breast-conserving surgery and radiation therapy (RT) for breast cancer.

Design: Repeated measures, longitudinal design.

Methods: Data were collected at four time points: start of RT, midpoint of RT, end of RT, and six months after RT. Three instruments were used to collect data: Quality-of-Life Index, Psychosocial Adjustment to Illness Scale, and the newly developed Adaptation to Survivorship Experience. Subjects also participated in an in-depth interview at the start of RT.

Setting: A large radiation oncology department located in an urban teaching hospital in the Northeast United States.

Sample: 23 women with newly diagnosed stage I or II breast cancer who were starting RT following breast-conserving surgery, with a mean age of 37.8 years (range = 25–45 years).

Main Research Variables: QOL, psychosocial adjustment, and adaptation to survivorship experience.

Findings: Although subjects adjusted their lives to accommodate RT, QOL declined from the start of RT to midpoint, with gradual improvement reported six months later. Social and sexual adjustment declined from start of RT to six months later. Negative perceptions of the survivorship experience and worry about cancer increased from the start of RT to six months later.

Conclusions: Young women with breast cancer experience changes in QOL, psychosocial adjustment, and adaptation to survivorship issues during RT. Changes may not reflect what is observed in clinical practice.

Implications for Nursing Practice: Nurses need to be aware of changes in QOL, psychosocial adjustment, and survivorship to better understand and support young women during RT.

Key Points . . .

- The overall incidence of breast cancer in younger women is low.
- Young age is a prognostic but not predictive factor in survival.
- Varying definitions of 'younger women' are used in research.
- Quality of life and psychosocial adjustment decline during radiation therapy.
- Age-related differences in quality of life and survivorship exist with breast cancer.

Breast cancer is a relatively uncommon cancer among women younger than 30 years. The incidence of breast cancer among American women ages 30–34 is about 25 per 100,000 compared with women ages 45–49, in whom the incidence is 200 per 100,000 (Greenlee, Murray, Bolden, & Wingo, 2000). Surveillance, Epidemiology, and End Results Program (SEER) data from the National Cancer Institute (NCI) indicate that breast cancer incidence rates are decreasing among younger women (Greenlee et al.). However, breast cancer occuring in young women has been associated with high-risk disease, poorer survival, decreased psychosocial adjustment, and loss of productive years (Swanson & Lin, 1994). The purpose of this article is to report on the results of a descriptive study that examined changes in quality of life (QOL), psychosocial adjustment, and survivorship issues over time in women younger than 45 years who underwent breast-conserving surgery (BCS) and radiation therapy (RT) for breast cancer and to discuss implications for practice when caring for young women with the disease.

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Background and Literature Review

Approaches to breast cancer screening, early detection, and treatment for young women are changing based on new and emerging evidence (Hankey, Miller, Curtis, & Kosary, 1994; National Institutes of Health, 1997; Swanson & Lin, 1994; Velentgas & Daling, 1994; Winchester, 1996). The American Cancer Society (ACS) guidelines for screening and early detection of breast cancer were revised in 1997 based on increasing evidence that the detectable, preclinical phase of breast cancer was shorter in premenopausal women than in postmenopausal women (Smith, Mettlin, Davis, & Eyre, 2000). Evidence from two Swedish clinical trials (Tabar, Chen, Fagerberg, Duffy, & Smith, 1997) and a meta-analysis of eight randomized clinical trials with an average follow-up of 12.7 years showed a statistically significant reduction in mortality (18%) among younger women as a result of mammography screening (Hendrick, Smith, Rutledge, & Smart, 1997). ACS and NCI changed their recommendations for mammography screening. They now suggest that women in the general population begin having mammographies at age 40 and high-risk women begin at an earlier age.

Women younger than 35 years are believed to have poor prognostic features, including positive lymph nodes, larger tumors, negative steroid hormone receptors, high S-phase fractions, and abnormal expression of p53, more often than women ages 35–50 years (Albain, Allred, & Clark, 1994; Swanson & Lin, 1994). Bertheau, Steinberg, Cowan, and Merino (1999) reviewed clinicopathologic characteristics (i.e., clinical history, staging, and treatment) of 191 patients younger than 40 years who were diagnosed with breast cancer. They found that breast cancer in young women was associated with high-risk features and suggested that breast cancers occurring in young women are different from those occurring in older women. Other investigators found no differences in the biologic behavior of tumors diagnosed in the same stage between younger and older women (Gillett, Kennedy, & Carmalt, 1997).

Treatment outcomes based on age are mixed (Chabner et al., 1998; Malone et al., 1996). Young age has been associated with an increased risk of local recurrence after BCS and RT (Morrow & Harris, 2000). An increased frequency of adverse pathologic features such as lymphatic vessel invasion, absence of estrogen receptors, and presence of extensive intraductal component has been observed. Young age also has been associated with a higher likelihood of recurrence and decreased survival (Nixon et al., 1994).

Using a retrospective cohort study of more than 10,000 women with primary breast cancer who were younger than 50 years at diagnosis, Kroman et al. (2000) investigated young age at diagnosis as a negative prognostic factor. They examined the relative risk of dying within the first 10 years after diagnosis according to age at diagnosis. Overall, young women with low-risk disease who did not undergo adjuvant treatment had a significantly increased risk of dying. This trend was not seen in patients who underwent adjuvant chemotherapy. Kroman et al. concluded that the negative prognostic effect of young age was seen in women diagnosed with low-risk disease who did not undergo adjuvant chemotherapy and that these women, on the basis of age alone, should be regarded as high-risk patients and undergo adjuvant chemotherapy. Overall, available data suggest that young age is a prognostic but not predictive factor.

Differences in incidence and mortality patterns between young African Americans and Caucasians have been observed (Brinton et al., 1997; Dignan, 2000; Swanson & Lin, 1994). Using SEER data on survival patterns, Swanson and Lin found that African American women who were diagnosed at a younger age had a higher probability of dying of breast cancer than Caucasian women.

Psychosocial Factors

Psychosocial research suggests that younger women may be at greater risk of emotional distress at diagnosis compared with their older counterparts (Jamison, Wellisch, & Pasnau, 1978; Mor, Malin, & Allen, 1994; Schover, 1994; Vinokur, Threatt, Vinokur-Kaplan, & Satariano, 1990). However, few studies focus specifically on younger women (Dow, 1994; Ferrell & Dow, 1998; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Northouse, 1994). Definitions of "young women with breast cancer" differ from one investigation to the next.

Chu et al. (1996) examined mortality data from the National Center for Health Statistics and incidence and survival data by extent of disease and stratified by patient age from SEER. The age-adjusted breast cancer mortality rate for white U.S. females dropped 6.8% from 1989 through 1993. Mortality trends significantly decreased (2% per year) in every decade for women ages 40–79 years. Despite the epidemiologic evidence to the contrary, Lerman, Kash, and Stefanek (1994) reported that more than 75% of women younger than 50 years with a family history of breast cancer believe that they are likely to develop breast cancer. The perception of psychological risk differs from epidemiologic risk in young women.

Several comparative studies of younger and older women provide descriptive data on age differences. Vinokur et al. (1990) conducted a longitudinal investigation using a representative community sample of 274 patients with breast cancer who were within the first year of diagnosis. They examined adjustment to disease based on changes in physical and mental health functioning and factors (e.g., age) that predict or facilitate the recovery process. Comparison of the outcomes at 4 and 10 months after diagnosis showed age differences in adjustment to mental health and well-being. Younger patients with advanced disease experienced significantly greater deterioration in their mental health and well-being compared with older patients who were more vulnerable to a decline in physical functioning. Mor et al. (1994) also found similar age-related differences in adjustment between younger and older women. Their study indicated that although younger women have greater economic and social resources, they experience more negative QOL effects of the disease than older women.

Numerous studies have reported outcomes in survivorship issues and QOL of long-term breast cancer survivors (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Ferrell et al., 1998; Fredette, 1995; Mast, 1998; Wyatt & Friedman, 1996, 1998; Wyatt, Kurtz, & Liken, 1993). Although each of these studies included a subset of younger women, the average age of the survivors was 50 years or older. Wyatt and Friedman (1996) sought to identify concerns and issues related to QOL

in long-term female cancer survivors who were recruited through a Michigan tumor registry. They collected QOL data from mailed questionnaires from 188 long-term female cancer survivors with a mean age of 61 years. They found that the lowest levels of QOL were in spiritual/philosophic views, diet and exercise habits, and social/emotional support; the highest area of QOL was in physical well-being (defined as absence of somatic concerns).

Mast (1998) found that fear of recurrence was associated with emotional distress and uncertainty was related to physical symptoms in a sample of 91 women who completed treatment for breast cancer ($\overline{X}$ = 60 years of age). She found that younger women had a higher fear of recurrence than older women and suggested that older women who have faced many losses have dealt with mortality issues and were less likely than younger women to fear an uncertain prognosis. In a related qualitative investigation, Fredette (1995) conducted a descriptive study using semistructured interviews to delineate concerns and coping as perceived by 14 women who had lived at least five years after a breast cancer diagnosis. The majority indicated that awareness of vulnerability had affected their view of life. Their major concern was fear of recurrence.

Hoskins (1997) examined variations in side effects of treatment, psychological distress, and health status over time in a sample of 93 women with breast cancer ($\overline{X}$ = 51.4 years of age) who underwent either mastectomy or BCS. Subjects reported minimal physical side effects, with the exception of fatigue and emotional distress, which persisted up to a year after treatment. Psychological distress and perceptions about health status improved over time, but no overall differences existed between the two treatment groups. Hoskins concluded that adjustment to diagnosis and treatment is a process that occurs over time.

Northouse (1994) pointed out that an inverse relationship between emotional distress and age is not consistent across the few available studies examining these factors. Age alone is rarely the most significant indicator of women's psychosocial adjustment to breast cancer.

Purpose

The purpose of this descriptive study was to examine changes in QOL, psychosocial adjustment, and survivorship in young women after BCS and RT for breast cancer.

The specific aim of this study was to examine patterns of change in QOL, survivorship, and psychosocial outcomes over time in women younger than 45 years with early stage breast cancer who were undergoing BCS and RT as well as to examine changes in QOL, survivorship, and psychosocial outcomes between the start of RT and six months after completing BCS and RT for breast cancer.

Framework

This study was grounded in a multidimensional QOL framework in which QOL refers to a sense of general well-being and satisfaction with life (Dow et al., 1996; Ferrans, 1990; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995). The major domains influencing QOL include physical health and functioning, socioeconomic status, psychological well-being, spiritual well-being, and family functioning. Perceptions of QOL are assumed to change over time during the cancer survivorship experience (Dow et al.; Ferrell et al., 1995). The variable of time influences the process of adaptation to the survivorship experience (Boston-Based Adaptation Research in Nursing Society, 1999).

Methods

A longitudinal repeated measures design was used to answer the main research questions.

Setting and Sample

During a six-month period, all young women with breast cancer who were beginning a course of BCS and RT at a major urban teaching hospital in the Northeast and who met the inclusion criteria were invited to participate in this research study. The following inclusion criteria were used: 21–45 years of age, newly diagnosed with stage I or II breast cancer, not undergoing concurrent chemotherapy or hormonal therapy at the time of entry into the study, and willing and able to participate in the study. The exclusion criterion was no previous diagnosis or treatment for any cancer.

Procedure

After receiving approval from the institutional review board, the researchers identified potential subjects by reviewing a list of patients scheduled for RT and worked with the radiation oncology staff to ascertain whether subjects met the eligibility criteria. The researchers approached eligible patients before the start of RT to elicit their interest in participating in the study. They provided written information about the study protocol, purpose, length of time to participate and complete the study questionnaires, and risks and benefits. They also answered questions and addressed concerns. Interested subjects gave written informed consent to participate.

Data were collected at three time points during RT (weeks 1, 3, and 5) and at one time point six months after beginning RT. Weeks 1, 3, and 5 were chosen to correspond to specific time points in the RT regimen. RT for breast cancer follows a general protocol that consists of a total of 46 Gy: 180 cGy/day, five days a week, for four and a half weeks to the entire breast (Morrow & Harris, 2000). At the completion of RT, patients receive an additional boost of radiation, usually via electrons, for an additional 2 Gy to the primary tumor bed or 200 cGy per day over a five-day period. Time 1 (week 1) served as baseline data; time 2 (week 3) was the midpoint in RT, when acute treatment side effects such as skin reactions and fatigue occur; and time 3 (week 5) was at the completion of RT, when acute treatment side effects are most troublesome. Time 4 was six months after entry into the study and was used as the endpoint in evaluating acute RT side effects. The subjects also met with the researchers during RT for an in-depth interview. The subjects received and returned time 4 study questionnaires via the mail.

Instruments

Three research instruments, a demographic data form, and an in-depth interview were used to gather the data. This article reports only on the quantitative results from the study questionnaires.

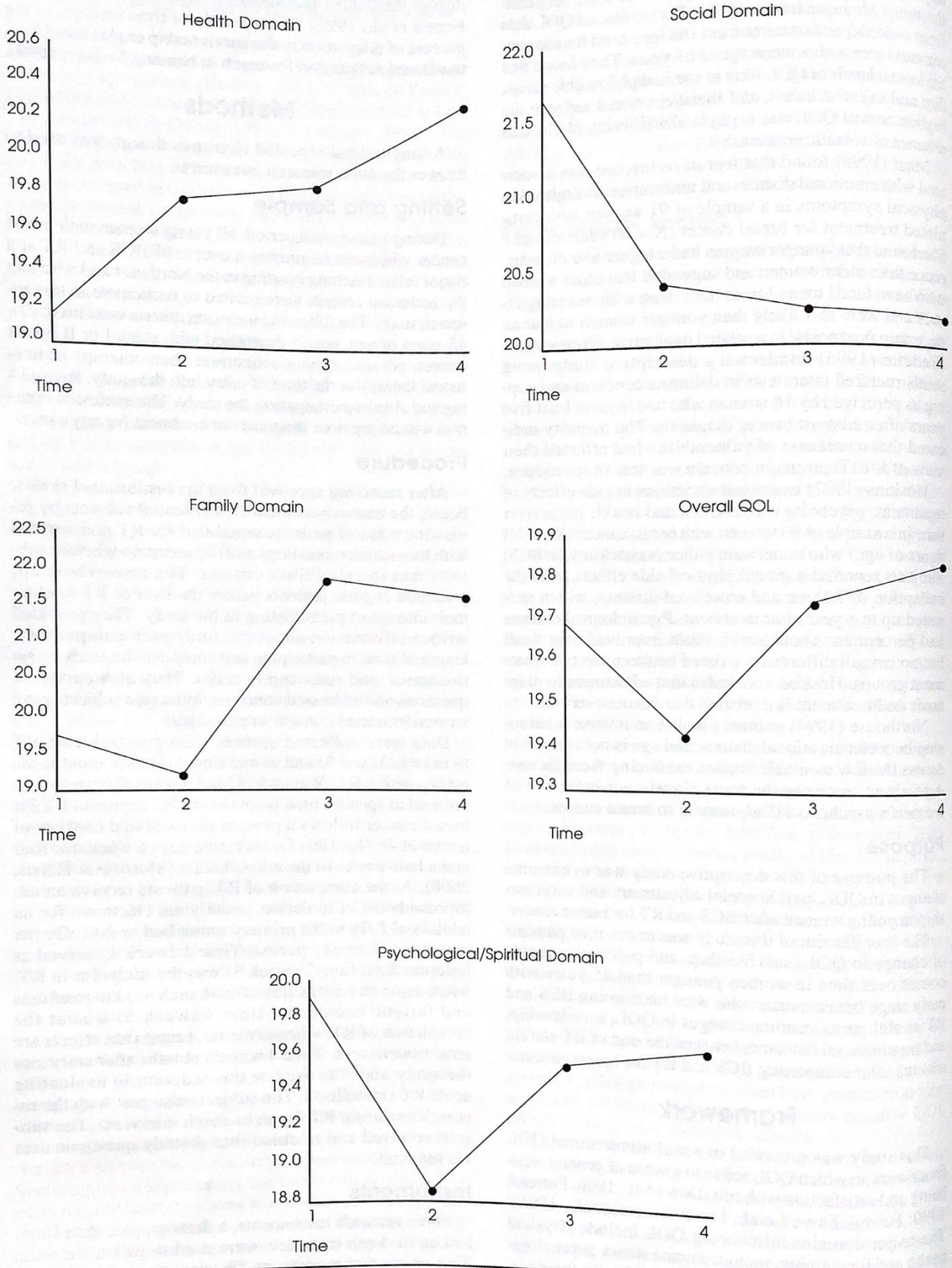

Figure 1. Changes in Quality-of-Life (QOL) Domains Over Time as Measured by the QOL Index

Table 1. Quality of Life (QOL) Satisfaction Over Time[a]

QOL Domains	Time 1		Time 2		Time 3		Time 4			
	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	F	p
Health	19.14	3.70	19.81	4.75	19.93	4.11	20.36	3.31	0.69	0.57
Social	21.70	4.47	20.39	4.68	20.28	4.86	20.22	4.31	1.52	0.26
Psychological/spiritual	19.90	5.39	18.87	5.86	19.54	6.65	19.65	6.72	0.46	0.72
Family	19.66	8.16	19.23	8.41	21.98	5.17	21.58	6.88	1.68	0.22
Total QOL	19.68	3.08	19.42	4.04	19.72	3.89	19.84	3.34	0.19	0.90

[a] Higher scores reflect higher satisfaction with QOL.

The **Ferrans Quality-of-Life Index—Cancer Version (QLI)** is a 34-item, multidimensional, weighted QOL scale that consists of two parts: the first half measures satisfaction with various domains of QOL, and the second half measures the importance of these domains to the subject (Ferrans, 1990). The domains include physical health and functioning, socioeconomic, psychological/spiritual, and family. Respondents are asked to reply to items using a six-point Likert-type scale ranging from 1 (very satisfied) to 6 (very dissatisfied) for items on Part I and from 1 (very important) to 6 (very unimportant) for items on Part II. The QLI was norm-referenced using 111 subjects with breast cancer. The range of weighted satisfaction/importance scores for the entire QLI and for each of the subscale scores is 0–30. Cronbach's alpha ranged from 0.73–0.93 for the QLI subscales in this study.

The **Psychosocial Adjustment to Illness Scale (PAIS)** is a 46-item scale that measures overall adjustment to illness and includes a subscale on healthcare perceptions, work/vocational adjustment, family adjustment, sexual functioning, social relationships, and psychological distress (Derogatis, 1986). Respondents select statements that are consistent with a Likert-type response. For example, responses to questions on sexual functioning range from "no change" to "complete change." The entire PAIS and two selected subscales (sexual functioning and social relationships) were used in this study. The range of scores for the PAIS in this study was 264–393, with *lower* scores indicating *higher* psychosocial adjustment. Cronbach's alpha for the PAIS was 0.76 in this study.

The **Adaptation to the Survivorship Experience (ASE)** is a newly developed cancer survivorship questionnaire that consists of 12 items and four subscales measuring adaptation to the meaning of cancer, worry about the future, connection with others, and changes in personal relationships. The ASE was norm-referenced using 291 subjects with various cancer diagnoses, the majority of whom had breast cancer. The original ASE contained 30 items that were derived from a qualitative study of cancer survivors. The ASE was factor-analyzed using principal-components analysis and varimax rotation. Items with a low inter-item correlation of less than 0.2 were deleted. The resulting ASE scale consisted of four factors with eigenvalues greater than 1 that accounted for 76% of the variance. Subjects were asked to respond to a five-point Likert-type scale ranging from 1 (no changes) to 5 (the most change). The range of responses for the entire ASE was 0–60. Cronbach's alpha for the ASE and subscales ranged from 0.71–0.81 in this study.

Data Analysis

The Statistical Package for the Social Sciences (SPSS), version 8.0 (SPSS, 1998), was used to analyze date. Descriptive statistics were used to analyze the demographic data and changes in QOL, psychosocial adjustment, and adaptation to cancer survivorship. Repeated measures analysis of variance (ANOVA) and paired t-tests also were used to answer the research questions. An alpha of 0.05 was used as the level of significance.

Results

Sample

Of 28 eligible subjects who agreed to participate, 5 withdrew for personal reasons and time constraints, leaving a total of 23 subjects. The mean age was 37.8 years (SD = 5.1), with a range of 25–45 years. Of the subjects, 40% (n = 11) were single, 32% (n = 9) were married, and 11% (n = 3) were divorced; 43% (n = 12) worked either full-time or part-time, 11% (n = 3) were homemakers, and 7% (n = 2) were either planning to return to work after staying at home for child care reasons or were reentering the work force at the time of their breast cancer diagnosis; 91% (n = 21) were Caucasian, 4% (n = 2) had ethnically diverse backgrounds (one was Puerto Rican, another recently immigrated from Russia); and 14% (n = 4) had a first-degree relative with breast cancer.

Changes in Quality of Life Over Time

Figure 1 shows descriptive changes occurring in QOL. Social, family, psychological/spiritual, and overall QOL decreased from the start of RT to the midpoint of treatment. Scores on the family, psychological/spiritual, and total QOL scales returned to near baseline levels from the midpoint of RT to six months later. The only difference occurred with the social subscale of the QLI, which showed that social QOL scores declined from baseline and remained low six months later. A different pattern of scores was seen with the health QOL subscale. The initial mean health QOL subscale scores were lower at the start of RT and rose consistently to remain slightly higher than at baseline after completion of RT.

A one-way repeated measures ANOVA was conducted to determine whether a statistically significant difference

existed in QOL scores between the start of RT and six months later. Table 1 shows the mean and standard deviation scores for the QLI total and subscale scores. The results of the ANOVA indicated no significant time effect in QOL.

Psychosocial Adjustment to Illness Over Time

Figure 2 shows descriptive changes in psychosocial adjustment over time. Improved psychosocial adjustment (demonstrated by a decline of scores) was reported from the start of RT to six months later. Increased difficulties with sexual adjustment were reported from the start to the end of RT. Six months later, difficulties with sexual adjustment improved to near baseline levels.

A one-way repeated measures ANOVA was conducted to determine whether a statistically significant difference existed in psychosocial adjustment over time. Table 2 shows the mean and standard deviation scores for the PAIS total and selected subscale scores. The results indicated a significant time effect on social and overall psychosocial adjustment. Follow-up paired-samples t-tests showed a statistically significant difference between the start of RT and at six months with regard to improved level of overall psychosocial ($p = 0.011$) and social adjustment ($p = 0.002$). When Holm's sequential method was used to control for type I error across the paired-samples t-tests, a statistically significant difference remained for social adjustment.

Adaptation to Survivorship Issues Over Time

Figure 3 shows descriptive changes in adaptation to survivorship issues. The ASE showed changes from the start of RT to six months later. Scores increased from the beginning through the end of RT and remained consistent from the end of RT to six months later. The ASE contains a worry subscale that showed an inverse, curvilinear pattern in which subjects reported higher levels of worry at the start of RT. These levels consistently decreased to the end of RT and then rose to near baseline levels six months later.

A one-way repeated measures ANOVA was conducted to examine whether a statistically significant difference existed in survivorship issues from baseline to six months later. Table 3 shows the mean and standard deviation scores for the ASE. The results show no significant changes in adaptation to cancer survivorship experiences between the start of RT and six months later.

Differences in Quality of Life, Psychosocial Adjustment, and Adaptation to Survivorship

Paired-samples t-tests were used to test whether a significant difference existed in QOL, psychosocial adjustment, and adaptation to cancer survivorship between the start of RT and six months later. Table 4 shows the results, which showed no significant difference in the overall mean QLI, PAIS, and ASE scores from the start of RT to six months later. A statistically significant difference in mean social adjustment scores on the PAIS was seen between the start of RT ($\overline{X} = 49.38$, $SD = 11.49$) and six months later ($\overline{X} = 42.94$, $SD = 11.13$), ($t[15] = 3.67$, $p = 0.002$). The magnitude of the difference in the mean scores for the two time periods was large. Cohen's measure of effect size (d) was 0.94, representing a large effect of time. The mean difference from the start of RT to six months later was 6.44 points, representing an improvement in adjustment. With the exception of changes in social adjustment, the results do not support a significant difference in

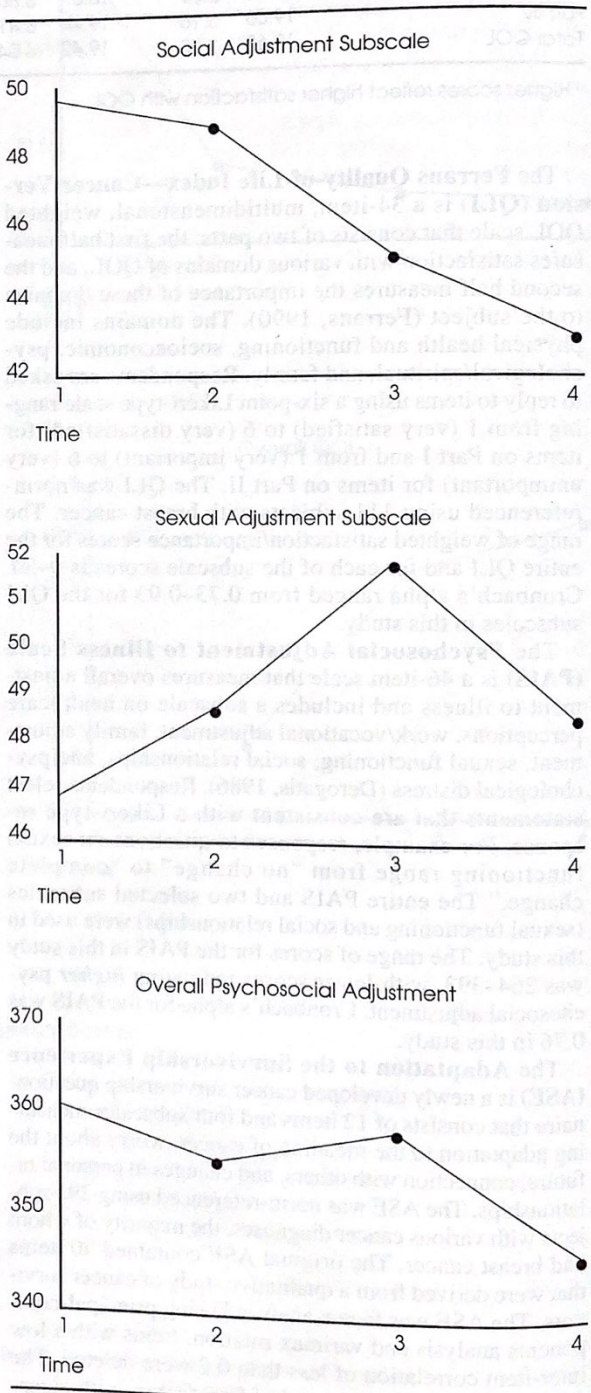

Figure 2. Changes in Psychosocial Adjustment Over Time as Measured by the Psychosocial Adjustment to Illness Scale

Table 2. Psychosocial Adjustment Over Time[a]

Psychosocial Adjustment to Illness Scale Subscales	Time 1		Time 2		Time 3		Time 4			
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	F	p
Social	49.38	11.49	48.75	13.08	44.94	12.76	42.94	11.13	7.61	0.003
Sexual	46.87	6.49	48.38	8.26	51.44	9.87	48.25	9.57	2.67	0.09
Total adjustment	360.69	38.95	354.502	38.72	357.06	39.64	346.44	39.64	4.31	0.03

[a] Higher scores reflect greater difficulty in adjustment.

QOL, psychosocial adjustment, and adaptation to survivorship from the start of RT to six months after RT.

Discussion

The results of this study showed some descriptive changes in QOL, psychosocial adjustment, and adaptation to survivorship experiences over time in a sample of young women undergoing RT following BCS. The decline in family and psychological/spiritual domains and overall QOL from the first to the third week of RT is of clinical interest. In clinical practice, patients generally are cautioned that the start and end of RT, not the midpoint of treatment, present the most difficulties in adjusting treatment to work, family, and social routines (O'Rourke & Robinson, 1996). Radiation oncology nurses tend to see increased activity and scheduling changes among patients within the first week of treatment. By the third week of RT, patients settle into a routine of activities and care. The changes in adjustment seen in this study do not reflect general clinical observations. Perhaps observable behavior patterns are not consistent with changes in QOL. Although young women may need to make necessary adjustments to their family routines and work patterns during RT, they may not be satisfied with the adjustments. Once they make the needed adjustments, a corresponding change in satisfaction with the new routine may occur.

The decline in satisfaction with and adjustment to the social domain of QOL, with no reports of recovery up to six months later, is consistent with observations in clinical practice and empirical studies of breast cancer (Dow, 1994; Dow et al., 1996). Young women undergoing RT continue to work, maintain an active family schedule, and rarely relinquish social responsibilities during the course of breast cancer treatment. They tend to add to the burden of cancer treatment with additional routines as another means of coping with a life-threatening situation. They may put on a façade of being able to deftly handle responsibilities and adversity with relative ease. Thus, maintaining the semblance of a normal routine is a short-term solution to a long-term concern. Over time, a decline in satisfaction with social QOL, with little recovery in adjustment, compared with other areas of QOL and psychosocial adjustment supports clinical observations.

A different pattern was seen in satisfaction with the health domain of QOL compared with other QOL domains. The mean health QOL scores were lower at the start of RT and rose consistently after treatment. Undergoing cancer treatment is associated with taking an active stance against the disease. A period of uncertainty surrounding diagnosis and workup is followed by an active period in which treatment schedules are outlined, expected symptoms are managed, and the oncology team is available. Thus, subject reports of improvement in satisfaction with health QOL are consistent with observations in clinical practice.

The descriptive changes in sexual adjustment reported in this sample of young women were consistent with published reports that show an increase in sexual difficulties over the course of breast cancer treatment (Schover, 1994; Schover et al., 1995). RT to the breast is associated with an increase in skin color, nipple discomfort, and transient shooting pains in the breast (O'Rourke & Robinson, 1996). Other treatment-related side effects such as tiredness, sleep problems, and emotional discomfort may add to difficulties in sexual adjustment. An improvement in sexual adjustment was noted between the end of RT and six months later, suggesting a treatment-related pattern of sexual adjustment.

Adaptation in cancer survivorship is consistent with reports in the literature (Dow et al., 1996; Ferrell et al., 1995; Mast, 1998). Survivors describe an initial increase in changes occurring immediately during treatment. This pattern generally levels off until after treatment is finished and then returns to a high level within the first year after the end of treatment. In this study, subjects reported a decrease in worry during treatment that is consistent with taking an active stand against the disease. They had access to their radiation oncology team on a day-to-day basis and likely had their questions and concerns addressed and resolved as they arose. Daily visible presence and support from the oncology team marked a decline in worry during RT. Worrying about the future (whether it is about cancer treatment, second cancers, or recurrence or metastasis), which increased six months after RT, is also consistent with literature showing that cancer survivors commonly express uncertainty about the future and fear of recurrence after treatment ends (Mahon, Cella, & Donovan, 1990; Mast; Northouse, 1981).

Changes in adaptation to survivorship are consistent with findings from several qualitative studies (Ferrell & Dow, 1998; Wyatt et al., 1993). Subjects reported increased changes in adaptation during RT that remained at the same level six months later. General observations in clinical practice indicate that young women experience changes in family relationships that are qualitatively different compared with older women. Single young women may have to return home during the time of treatment for family support and even financial assistance. Young women with young children may carry an added burden of juggling family responsibilities and care during the course

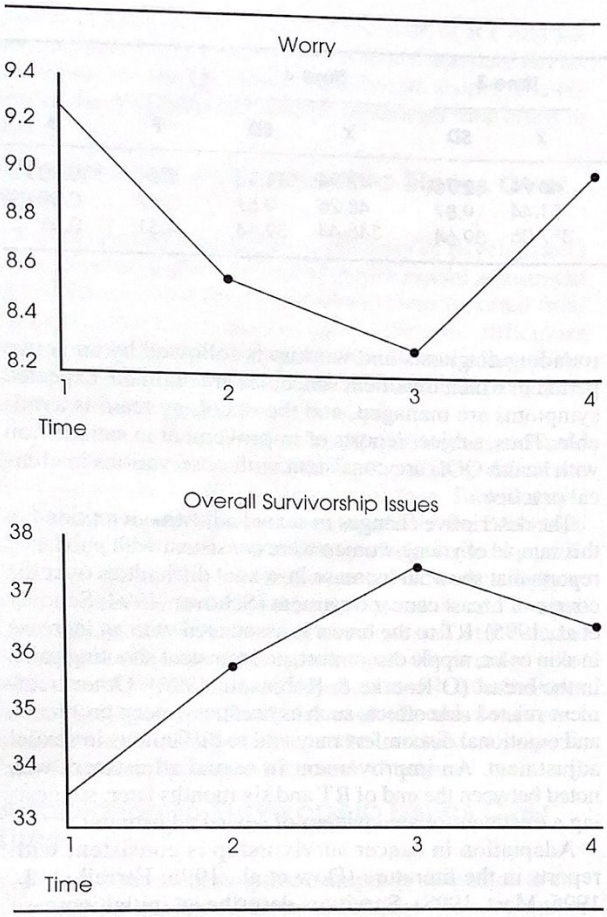

Figure 3. Changes in Survivorship Issues as Measured by the Adaptation to the Survivorship Experience Questionnaire

of their treatment. Both represent a change in the nature and character of family life that is different than before the breast cancer diagnosis.

Implications for Practice

This study provides additional understanding of observations in clinical practice.

- Patients may experience a decline in satisfaction with QOL up to the third week of RT for breast cancer. Although patients may outwardly demonstrate an adjustment to the required change in daily routines imposed by RT, their satisfaction with these changes may be low. Radiation oncology nurses can help these young women by exploring areas of patient satisfaction. Assessment of and preparatory education about changes in routine and satisfaction with these changes may be warranted.
- Although "getting-back-to-normal" routines may be important (Hilton, 1996), clinicians may consider telling their patients that maintaining a busy routine and lifestyle and keeping up with social responsibilities may not be conducive to coping and adjusting in the long run. Helping young women to reassess their desire to maintain social and work priorities balanced against the time and energy required while receiving RT may be necessary. Having patients keep a calendar of events that visually depicts the time requirements and their availability may help them balance their desire to maintain routines and temporarily halt or eliminate routines or responsibilities of low priority.
- Reinforcing the positive benefits of undergoing RT, such as having daily access to the oncology team, may be helpful. Oncology nurses may need to reinforce to young women that they are taking an active role in their care simply by "showing up" for treatment each day. Daily contact with their care providers can be a positive experience during which time these young women can have questions and concerns addressed and receive support and care.
- The decline in sexual adjustment during RT is a reminder that sexual concerns during treatment warrant assessment and sensitive discussion with young patients.
- Oncology nurses should ask young women about their worries (e.g., cancer treatment, second cancers, recurrence, metastasis) during discussions about adapting to the survivorship experience. The optimal time to introduce this issue is unknown, but it usually occurs toward the end of RT.
- Changes in family relationships are expected, and young women need to be provided with preparatory information about these changes. "Family" takes on a new meaning as these young women depend on their family members for support (which also may include financial support) during the cancer diagnosis. Young women with children may need to rely on their extended family to help with child care during their treatment. Change in the nature and character of family life continues after treatment ends.

Implications for Research

Despite inherent difficulties in conducting a longitudinal study with young women, this study's descriptive findings offer several directions for research.

Table 3. Adaptation in Survivorship Over Time[a]

Adaptation to the Survivorship Experience (ASE) Subscales	Time 1		Time 2		Time 3		Time 4			
	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	F	p
Worry	9.08	2.96	9.10	2.88	8.47	3.63	9.00	3.06	0.65	0.56
Total ASE	32.83	9.12	35.52	8.33	36.68	8.74	36.81	8.78	1.83	0.19

[a] Higher scores reflect greater adaptation in survivorship.

Table 4. Comparison Among Quality of Life (QOL), Psychosocial Adjustment, and Adaptation in Survivorship at Start of Radiation Therapy and at Six Months

Instruments	Changes in Mean Scores	SD	95% Confidence Interval		t	Sig (2-tailed)
			Lower	Upper		
QOL Domains						
Health	−1.22	3.19	−2.92	0.49	−1.52	0.15
Social	1.48	3.37	−0.31	3.28	1.76	0.09
Psychological/spiritual	0.24	4.79	−2.31	2.80	0.20	0.84
Family	−1.92	3.73	−3.91	0.066	−2.06	0.05
Total QOL	−0.16	1.79	−1.11	0.79	−3.59	0.72
Psychosocial Adjustment to Illness Scale (PAIS) Subscales						
Sexual	−1.38	6.99	−5.10	2.35	−0.79	0.44
Social	6.44	7.01	2.70	10.17	3.67	0.002
Total PAIS	14.25	19.66	3.77	24.73	2.90	0.011
Adaptation to the Survivorship Experience (ASE) Subscales						
Worry	0.25	2.32	−0.99	1.49	0.43	0.67
Total ASE	−3.44	7.25	−7.30	0.42	−1.90	0.07

- Because the overall incidence of breast cancer in young women is comparatively low, accrual into studies likely will be slow. Thus, investigators who have access to or are particularly interested in the needs of young women should consider collaborative, multisite endeavors.
- Comparison studies with a middle-age or older group of women are needed. Changes in patterns of QOL, psychosocial adjustment, and survivorship issues may be compared with older age groups to help identify whether any age differences are lasting. Data are sparse with regard to interventions that focus specifically on younger women and their needs.
- Further psychometric testing of the ASE, particularly the worry subscale, also is warranted with different groups of cancer survivors.

Limitations

Despite the consistency of findings with previous reports in the literature and clinical practice, caution must be taken in the interpretation of findings. However, descriptive trends identified in this study are useful in serving as the basis for future larger scale studies of young women. Reliability issues with newly developed instruments such as the ASE support the need for larger sample sizes. Wider scale studies need to be conducted across institutions that serve larger cohorts of young women with breast cancer. The ability to determine meaningful age-based differences in survivorship issues and psychosocial adjustment of young women is in the very early phases. Cultural diversity continues to pose challenges in subject accrual. Data that show racial and ethnic differences in morbidity and mortality lend further support for wider racial and ethnic diversity. The interaction of subject and setting may have threatened external validity. The clinical setting where the study was conducted has a vital nursing presence in the interdisciplinary care of patients with cancer. Finally, the definition of "young" women needs further refinement. Some investigators use age 35 or younger, 40 or younger, 45 or younger, or younger than 49 as the definition of "young women." This study used the definition of 45 years or younger. Thus, cross-study comparisons make accumulating information on larger numbers of younger women with breast cancer difficult.

Conclusion

This study of QOL, psychosocial adjustment, and adaptation to survivorship issues in young women with breast cancer found descriptive changes occurring from the start of RT to six months later. Study findings are consistent with other studies of QOL and psychosocial adjustment of women with breast cancer. Study findings are also consistent with other studies suggesting that changes in QOL and psychosocial adjustment may decline during cancer treatment. These findings highlight the need to continue the evaluation of potential age-related differences and similarities in QOL, psychosocial adjustment, and survivorship of women with breast cancer and, when differences exist, to explore value of age-related interventions.

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