# Comparison of Health-Related Quality of Life Between Adjuvant Breast Cancer Treatment Groups

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**OBJECTIVES:** To compare the health-related quality of life (HRQOL) of women who did (receivers, n = 372) and did not (intentional nonreceivers, n = 46) receive all recommended adjuvant treatments for breast cancer.

**SAMPLE & SETTING:** Women were recruited through integrative oncology clinics and the Cancer Surveillance System registry in western Washington.

**METHODS & VARIABLES:** A cross-sectional and correlational study using secondary data was conducted. Self-reported data included involvement in treatment decision making (TDM) and HRQOL. Registry data included demographics, disease characteristics, and records on recommended treatments as well as receiving/not receiving them. Descriptive statistics, t tests, chi-square tests, correlations, and analysis of variance were used to compare receivers and intentional nonreceivers.

**RESULTS:** Among women who were "very involved" in TDM and those who reported their involvement as "just right," intentional nonreceivers scored higher in role-physical, general health, and vitality than receivers after controlling for demographic and disease characteristics.

**IMPLICATIONS FOR NURSING:** Nurses need to be aware that intentional nonreceivers of adjuvant therapy, particularly if assessed as "very involved" and "just right" involvement in deciding to refuse treatment, may report better HRQOL than receivers, which could be attributed to lack of common side effects from adjuvant treatment.

**KEYWORDS** breast cancer; adjuvant treatment; health-related quality of life; decision making
***ONF, 46*(1), 59–70.**
**DOI** 10.1188/19.ONF.59-70

Studies have shown that some women with breast cancer do not receive all conventional treatments recommended by their doctors. For example, a study by Kim, Andersen, and Standish (2018) found that about 11% of women did not receive at least one adjuvant treatment recommended by their doctors after surgery and were very involved in their treatment decision making (TDM). Studies have also found that involvement in TDM among women with breast cancer is an essential factor for better health-related quality of life (HRQOL), which is related to improved prognosis (Andersen, Bowen, Morea, Stein, & Baker, 2009; Montazeri, 2008). However, no information is available on how HRQOL differs between women who receive all recommended treatments and those who do not, and whether involvement in TDM is related to HRQOL in these two groups. In the current article, "receivers" indicates women who received all physician-recommended conventional breast cancer treatments, including surgery, chemotherapy, radiation therapy, and endocrine-manipulation therapy. "Intentional nonreceivers" refers to those who voluntarily did not receive all or part of the physician recommended adjuvant therapy (i.e., chemotherapy, radiation therapy, and endocrine-manipulation therapy) after surgery. Figure 1 depicts the conceptual framework for this study.

The overall aim of this study was to compare relationships between HRQOL in receivers and intentional nonreceivers in relation to involvement in TDM. An additional aim was to compare HRQOL between receivers and intentional nonreceivers in relation to the participation congruence between preferred and actual involvement in TDM.

## Background

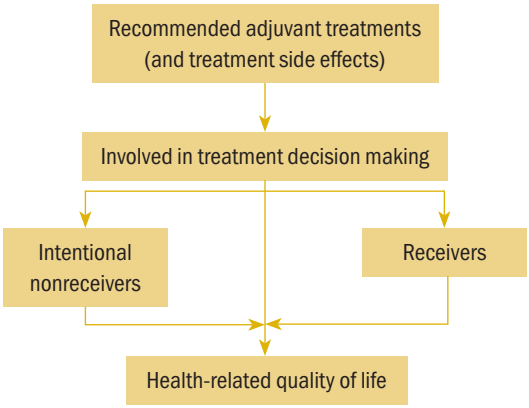
An estimated 330,080 new cases of breast cancer were diagnosed in the United States in 2018, and this number has been increasing each year (American Cancer Society, 2018). Breast cancer is a highly

curable disease, with a five-year survival rate of about 90% when using evidence-based conventional cancer treatments (National Cancer Institute, 2017a, 2017b; Taghian, El-Ghamry, & Merajver, 2016). However, studies found that about 6%–13% of women with breast cancer, among whom chemotherapy was clinically recommended, did not receive the treatment (Greenlee et al., 2016; Neugut et al., 2012; Saquib et al., 2012). However, no information is available about HRQOL among women who choose not to receive all recommended treatment.

### Health-Related Quality of Life

Women with breast cancer report deterioration in their physical and mental health during diagnosis, treatment, and survivorship, which alters their HRQOL (Boini, Briancon, Guillemin, Galan, & Hercberg, 2004; Montazeri, 2008; Morrow et al., 2014). In this article, HRQOL is defined as the general well-being of women with breast cancer; dimensions include physical, social, and mental well-being, as well as functioning in usual roles, general health, and vitality (Ferrell, Dow, & Grant, 1995; Ware, Snow, Klosinski, & Gendek, 1993). When newly diagnosed individuals with cancer, including those with breast cancer, are compared with an age- and sex-matched cancer-free control group, individuals with cancer experience a significantly lower HRQOL than the control group (Boini et al., 2004). Specifically, a cancer survivor group, compared with a cancer-free control group, reported significantly more limitations in daily activities related to lower physical functioning, more bodily pain, less vitality, and lower general health. No difference was found in mental health, role-emotional, and social functioning (Boini et al., 2004). In a systematic review of 28 studies, the main HRQOL issues among young women with breast cancer (aged 50 years or younger) included psychosocial concerns such as depression, anxiety, and menopausal symptoms (weight gain, hot flashes, and vaginal dryness) (Howard-Anderson, Ganz, Bower, & Stanton, 2012). The current study sought to understand the degree to which challenges in HRQOL in the first two years after diagnosis are associated with receiving or choosing not to receive some adjuvant treatments.

**FIGURE 1. Conceptual Framework**




**Note.** Treatment side effects are not assessed in this article.

### Involvement in Treatment Decision Making

Involvement in TDM among receivers and intentional nonreceivers is not well studied. What is known is that individuals seem to have their preferred role in TDM. Hamelinck et al. (2018) found that both younger (aged 40–64 years) and older (aged 65 years or older) women with breast cancer living in the Netherlands most frequently perceived that they had an active role (49% and 56%, respectively), followed by shared (37% and 32%) and passive (14% and 12%) roles; 32% of the younger and 36% of the older women reported participation congruence (Hamelinck et al., 2018). A meta-analysis of six studies (N = 3,491) conducted in North America found that 36% of the participants had a passive role, followed by 34% with a shared role and 30% with an active role, in their TDM for their cancer (Singh et al., 2010). Singh et al. (2010) and a meta-analysis with 44 studies by Brom et al. (2014) found that about 60%–61% of participants reported participation congruence, defined as correspondence between preferred and actual involvement in TDM. This rate is lower than the 80% of participation congruence found among Chinese women with breast cancer living in Hong Kong: 59% of these women wanted a shared role, 33% wanted an active role, and 8% wanted a passive role (Lam, Fielding, Chan, Chow, & Ho, 2003). Shared decision making was related to greater satisfaction with information provided, more trust and confidence in physicians, and improved decision satisfaction (Lam et al., 2014).

### Involvement in Treatment Decision Making and Health-Related Quality of Life

Although there is general agreement that involvement in TDM is valuable and may improve HRQOL among cancer survivors, studies provide mixed results. Among women with breast cancer, higher levels of involvement in TDM for overall treatments,

including surgery, chemotherapy, and follow-up care, were linked to improved HRQOL (physical functioning, role-physical, general health, vitality, social functioning, and mental health) after controlling for demographic and disease characteristics (Andersen et al., 2009; Hack, Degner, Watson, & Sinha, 2006). The participation congruence was related to physical functioning, role-physical, bodily pain, general health, vitality, and mental health among women with breast cancer (Andersen et al., 2009). Among Chinese women with breast cancer living in Hong Kong, however, participation congruence was unrelated to HRQOL or satisfaction (Lam et al., 2003). For women who received chemotherapy, perception of treatment choice was not related to HRQOL. Among women who did not receive chemotherapy, perception of treatment choice was related to HRQOL (Jansen, Otten, van de Velde, Nortier, & Stiggelbout, 2004). However, no study has compared HRQOL between receivers and intentional nonreceivers, or examined the potential influence of level of involvement in TDM on that relationship.

## Methods

This study reports results from the secondary analysis of the baseline data from the Breast Cancer Integrative Oncology Study, in which data were collected from 585 women through integrative oncology clinics in the Seattle area and the Cancer Surveillance System (CSS) registry in western Washington (Standish, Sweet, Naydis, & Andersen, 2013). Sample criteria were as follows: (a) aged 18 years or older, (b) had biopsy-pathology verified diagnosis of breast cancer or ductal carcinoma in situ, (c) had initial diagnosis within two years prior to recruitment, and (d) received either integrative oncology and conventional oncology or just conventional oncology. Women were recruited through six integrative oncology clinics in western Washington and then their matching cohort was recruited through the CSS registry in western Washington (Standish et al., 2013). For detailed information about recruitment procedures, please see Standish et al. (2013). The Institutional Human Subjects Review Committee of the Fred Hutchinson Cancer Research Center and Bastyr University approved the study. Informed written consent was obtained from each patient before participation. For the secondary analysis, the committee from two institutions (Fred Hutchinson Cancer Research Center and Bastyr University) and the University of Washington approved the study, and de-identified data were used.

Among 585 women, 418 women met the following additional criteria for data analysis: (a) received surgery; (b) had physician recommendation to receive at least one adjuvant treatment, such as chemotherapy, radiation therapy, or endocrine-manipulation therapy after surgery; (c) had clear evidence of receiving or not receiving recommended treatment; and (d) completed a questionnaire on HRQOL and involvement in TDM. Power analysis shows 88% power to detect difference between groups of 0.7 standard deviations (Cohen's d = 0.7) between receivers (n = 372) and intentional nonreceivers (n = 46) for all participants. When the analysis was limited to women who were "very involved" in treatment decisions, which included the lowest n, it was 88% power to detect difference between groups of 0.7 standard deviations (Cohen's d = 0.7) between receivers (n = 140) and intentional nonreceivers (n = 23).

### Measures

Data sources include participants' responses to self-reported questionnaires and CSS registry information abstracted from medical charts in western Washington. Self-reported data included household income, comorbidities, involvement in TDM, and HRQOL. CSS data included age and stage at diagnosis, ethnicity, marital status, site of breast cancer, surgery type, estrogen- and progesterone-receptor status, and records on recommended treatments and receiving/not receiving the treatment. Professional abstractors recorded CSS registry data based on individual chart review at conventional medical clinics about six months after cancer diagnosis.

HRQOL was assessed using the SF-36®, a 36-item self-report questionnaire that assesses functional status in eight subscales: limitations in physical activities, limitations in social activities, limitations in usual role activities, bodily pain, general mental health, limitations in usual role activities, vitality, and general health perceptions (Ware et al., 1993). The manual provides normative values for the eight subscales and its scoring system. Scores are weighted and transformed into a scale from 0 (worst possible health, severe disability) to 100 (best health, no disability). No total score is calculated, although two overall scores can be derived, the Physical Component Summary score and the Mental Component Summary score. Reliability and validity for this measure are well established (Cronbach $\alpha$ = 0.6–0.96) (Patel, Donegan, & Albert, 2007; Ware et al., 1993).

TDM involvement was measured using a self-report instrument that records participants' perceived

level of involvement and participation congruence in making decisions about their cancer treatment (Andersen et al., 2009; Andersen & Urban, 1999). Six level of involvement items ask about the perceived level of involvement in making decisions about cancer treatment overall, and specific treatments including surgery, chemotherapy/radiation therapy, additional tests, complementary treatments, and lifestyle changes (e.g., "How involved do you feel you were in making decision about your treatment overall? Would you say you were . . ."). Responses are rated on a three-point Likert-type scale, with scores of 0 (much less involved), 1 (a fair bit), and 2 (very involved). A "not applicable" option was also available. In the current study, responses were categorized as either "very involved" or "not very involved" (i.e., much less involved/a fair bit/not applicable). Two participation congruence items asked participants about their ability to achieve their preferred level of involvement in overall and conventional TDM (e.g., "Would you have preferred to be more or less involved in making decisions about your conventional treatment for cancer?"). Responses are rated on a five-point Likert-type scale with scores ranging from 1 (much less involved) to 5 (much more involved). In this study, responses were categorized as "much less/less involved," "my involvement was just right," and "much more/more involved." Reliability and validity for this measure have been previously published (Cronbach alpha = 0.72–0.81) (Andersen et al., 2018). Reliability was not reported for this study because individual items were used for data analysis, rather than a scale. The current authors were interested in how individuals made decisions on each specific treatment.

### Data Analysis

All data were analyzed using IBM SPSS Statistics, version 20.0. Descriptive statistics were used to compute means for all study variables, and t tests and chi-square tests were used to compare descriptive statistics between receivers and intentional nonreceivers. Correlations were used to examine relationships between HRQOL and descriptive variables. Finally, a comparison of HRQOL between receivers and intentional nonreceivers was examined using ANOVA, controlling for covariates, stratified by involvement in TDM. Alpha was set at 0.05.

## Results

### Sample Characteristics

Table 1 presents demographic characteristics comparing receivers and intentional nonreceivers. Overall, 11% of women (n = 46 of 418) did not receive at least one recommended adjuvant treatment, chemotherapy, radiation therapy, or endocrine-manipulation therapy, after their surgery. A greater proportion of intentional nonreceivers had an earlier stage of breast cancer at the time of diagnosis and positive estrogen-receptor status. A higher proportion of nonreceivers, compared with receivers, received integrative oncology care ($t = 4.15$, $p = 0.051$). No differences were found between the groups in their age at diagnosis, months since diagnosis, race, marital status, household income, site of cancer, surgery type, progesterone-receptor status, and overall comorbidity.

### Involvement in Treatment Decision Making by Group

Overall, 38% (chemotherapy/radiation therapy treatment decision) to 67% (lifestyle changes decision) of receivers were "very involved" in various aspects of their treatment decisions. For intentional nonreceivers, these rates ranged from 67% (chemotherapy/radiation therapy treatment decision) to 93% (overall treatment decision). When the two groups were compared, a significantly greater portion of intentional nonreceivers were "very involved" in their TDM for overall treatment, surgery, chemotherapy/radiation therapy, testing, complementary treatment, and lifestyle change decisions than receivers.

Table 2 depicts participation congruence and correspondence between preferred and actual involvement in TDM. Eighty-four percent (overall treatment decision) and 86% (conventional treatment decision) of receivers reported their involvement in TDM as "just right." For intentional nonreceivers, these rates were 75% (overall treatment decision) and 84% (conventional treatment decision). Participation congruence was not different between groups. Regardless, it was decided to examine differences in HRQOL among receivers and intentional nonreceivers who were "very involved" and those who reported that their level of involvement was "just right," because women failing to receive important treatments not of their own choice would likely describe very different circumstances that would also influence their HRQOL.

### Comparison of Health-Related Quality of Life by Group

Various aspects of HRQOL were significantly correlated with age and stage of cancer at diagnosis, income, months since cancer diagnosis, type of surgery, and oncology care received ($p < 0.05$ to $< 0.001$) and, therefore, these variables were controlled as covariates in further data analysis.

**TABLE 1. Descriptive Statistics by Group**

| | Receivers (N = 372) | | Nonreceivers (N = 46) | | |
|---|---|---|---|---|---|
| **Characteristic** | **$\bar{X}$** | **SD** | **$\bar{X}$** | **SD** | **t** |
| Age (years) at diagnosis | 53.9 | 10.4 | 56.5 | 9.3 | −1.61 |
| Months since diagnosis | 10.7 | 10.5 | 7.7 | 7.2 | 1.89 |
| **Characteristic** | **n** | **%** | **n** | **%** | **$\chi^2$** |
| **Race** | | | | | 2.68 |
| White | 356 | 96 | 42 | 91 | |
| Asian | 11 | 3 | 3 | 7 | |
| Mixed | 3 | 1 | 1 | 2 | |
| Black | 2 | 1 | – | – | |
| **Marital status** | | | | | 3.08 |
| Married or partner | 280 | 79 | 31 | 67 | |
| Single, widowed, or separated | 75 | 21 | 15 | 33 | |
| **Household income ($)** | | | | | 4.1 |
| Less than 50,000 | 125 | 35 | 21 | 51 | |
| 50,000 or greater | 231 | 65 | 20 | 49 | |
| **Stage of cancer at diagnosis** | | | | | 17.32* |
| 0 | 23 | 6 | 9 | 20 | |
| I | 137 | 37 | 23 | 50 | |
| II | 147 | 40 | 11 | 24 | |
| III | 55 | 15 | 3 | 7 | |
| IV | 10 | 3 | – | – | |
| **Site of cancer** | | | | | 0.04 |
| Left | 192 | 52 | 23 | 50 | |
| Right | 180 | 48 | 23 | 50 | |
| **Surgery type** | | | | | 3.61 |
| Lumpectomy | 202 | 54 | 29 | 63 | |
| Modified radical mastectomy | 86 | 23 | 5 | 11 | |
| Total mastectomy | 84 | 23 | 12 | 26 | |
| **Estrogen-receptor status** | | | | | 5.85* |
| Positive | 311 | 88 | 42 | 100 | |
| Negative | 44 | 12 | – | – | |
| **Progesterone-receptor status** | | | | | 0.41 |
| Positive | 290 | 82 | 36 | 86 | |
| Negative | 65 | 18 | 6 | 14 | |
| **Overall comorbidity** | | | | | 0.4 |
| One or more | 275 | 74 | 32 | 70 | |
| None | 97 | 26 | 14 | 30 | |
| **Oncology care received** | | | | | 4.15** |
| Usual care | 243 | 65 | 23 | 50 | |
| Integrative oncology | 129 | 35 | 23 | 50 | |

*$p < 0.01$; ** $p = 0.051$

**Note.** Because of missing data, some characteristics do not total N. Because of rounding, percentages may not total 100.

Tables 3 and 4 depict mean differences in HRQOL between receivers and intentional nonreceivers after controlling for covariates using ANOVAs. Overall, intentional nonreceivers scored higher in role-physical, general health, and vitality than receivers. These significant differences remained when data were re-analyzed, including the subgroup of women who were "very involved" in TDM; intentional nonreceivers who were "very involved" in overall treatment decision, surgery decision, complementary treatment decision, and lifestyle changes decision scored higher in role-physical, general health, and vitality than receivers who were not "very involved" in TDM. For test decision making, a difference between groups was found only in role-physical. Regarding participation congruence, among those who reported that their involvement was "just right" for overall TDM, intentional nonreceivers scored higher in role-physical and general health than receivers.

**TABLE 2. Involvement in Treatment Decision Making by Group**

| | Receivers (N = 372) | | Nonreceivers (N = 46) | | |
|---|---|---|---|---|---|
| **Characteristic** | **n** | **%** | **n** | **%** | $\chi^2$ |
| Level of involvement in making . . . | | | | | |
| **Overall treatment decision** | | | | | 13.43*** |
| Not very involved | 127 | 34 | 3 | 7 | |
| Very involved | 242 | 66 | 40 | 93 | |
| **Surgery decision** | | | | | 9.67** |
| Not very involved | 126 | 35 | 5 | 11 | |
| Very involved | 239 | 66 | 39 | 89 | |
| **Chemotherapy/radiation therapy decision** | | | | | 6.79* |
| Not very involved | 176 | 48 | 11 | 27 | |
| Very involved | 189 | 52 | 30 | 73 | |
| **Test decision** | | | | | 7.74** |
| Not very involved | 174 | 54 | 11 | 30 | |
| Very involved | 149 | 46 | 26 | 70 | |
| **Complementary treatment decision** | | | | | 12.9*** |
| Not very involved | 220 | 62 | 14 | 33 | |
| Very involved | 134 | 38 | 28 | 67 | |
| **Lifestyle changes decision** | | | | | 4.56* |
| Not very involved | 111 | 33 | 6 | 16 | |
| Very involved | 221 | 67 | 31 | 84 | |
| Congruence between preferred and actual involvement | | | | | |
| **Overall treatment decision** | | | | | 3.45 |
| Much less/less involved | 6 | 2 | – | – | |
| Involvement was just right | 309 | 84 | 33 | 75 | |
| Much more/more involved | 51 | 14 | 10 | 24 | |
| **Conventional treatment decision** | | | | | 1.08 |
| Much less/less involved | 6 | 2 | – | – | |
| Involvement was just right | 315 | 86 | 36 | 84 | |
| Much more/more involved | 47 | 13 | 7 | 16 | |

*p < 0.05; **p < 0.01; ***p < 0.001
**Note.** Because of missing data, some characteristics do not total N. Because of rounding, percentages may not total 100.

## Discussion

The current study contributes to the limited body of research comparing HRQOL among women with breast cancer who did and did not receive conventional adjuvant treatments recommended by their physicians after surgery. Overall, 11% of women did not receive at least one recommended adjuvant treatment and 38%–67% of receivers and 67%–93% of intentional nonreceivers were "very involved" in their TDM overall and in specific adjuvant treatment decisions. Andersen et at. (2009) found that, overall, 72% of women with breast cancer reported that they were very involved in TDM regarding their cancer treatment. The results indicating that a significantly higher portion of intentional nonreceivers were "very involved" in their TDM overall and in specific adjuvant treatments compared to receivers was likely related to the fact that intentional nonreceivers made decisions that were against their physicians' recommendations, which likely made those decisions very salient (Kim et al., 2018).

The unique contribution of this current article is finding that intentional nonreceivers in general, and specifically those who were "very involved" in TDM, experienced better role-physical, general health, and vitality than receivers. This finding could be related to the fact that more intentional nonreceivers had their cancers diagnosed at an earlier stage than receivers. Intentional nonreceivers were also likely to not experience side effects and symptoms related to adjuvant treatments. A systematic review of 58 studies (Montazeri, 2008) and another of 10 studies (Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005) found that individuals with breast cancer who received chemotherapy or endocrine-manipulation therapy experienced several side effects and symptoms that negatively affected their HRQOL, although these therapies improved survival. The most frequent side effects included pain, fatigue, arm morbidity, and postmenopausal symptoms (Mols et al., 2005; Montazeri, 2008). Women who received chemotherapy were also at risk for a post-traumatic stress syndrome and had a lower quality of life (Amir & Ramati, 2002). Another study found that 14% of women with breast cancer who received endocrine-manipulation therapy choose to discontinue it because they experienced side effects; they also had more concerns about the treatment and were less likely to perceive taking the prescribed medication as a necessity than receivers (Brett et al., 2018). In addition, a panel of 13 experts on breast cancer from 11 countries identified deescalating breast cancer treatments in early-stage breast cancer without sacrificing outcomes as a priority area of clinical research (Cardoso et al., 2017).

### KNOWLEDGE TRANSLATION

- Intentional nonreceivers had health-related quality of life (HRQOL) similar to the general female population, but still experienced limited role-physical and social functioning.
- Intentional nonreceivers of adjuvant therapy, particularly those who were "very involved" and who had "just right" involvement in deciding to refuse treatment, reported better HRQOL in role-physical, general health, and vitality than receivers.
- High levels of HRQOL among intentional nonreceivers could be attributed to lack of common side effects from adjuvant treatments.

About 75%–86% of women in the current study reported participation congruence. These rates are higher than the 56%–61% of patients reporting congruence in earlier studies conducted in North America (Brom et al., 2014; Colley et al., 2017; Singh et al., 2010), but similar to the 80% rate of congruence found among Chinese women with breast cancer living in Hong Kong (Lam et al., 2003).

When HRQOL was examined among women who reported that their involvement was congruent or "just right" for overall and conventional treatment decisions, intentional nonreceivers experienced better role-physical, general health, and vitality. These findings may be related to the fact that intentional nonreceivers were not experiencing side effects and symptoms related to adjuvant treatments discussed earlier in this article. Because the current study is the first to examine HRQOL among women who reported congruent "just right" involvement in TDM, no previous study is available for comparison. Available previous findings indicate that participation congruence was unrelated to HRQOL among Chinese women with breast cancer living in Hong Kong (Lam et al., 2003), although it was related to HRQOL among women with breast cancer who live in the United States (Andersen et al., 2009).

### Limitations

A few limitations need to be noted. Sample size for intentional nonreceivers was much smaller than for receivers, which became even smaller after limiting the analysis to women who reported either a high level of involvement or congruent "just right" involvement in TDM. However, this small size had good power to detect large effects with a Cohen's d of 0.7, although it

**TABLE 3. Comparison of Physical Functioning, Role-Physical, Bodily Pain, and General Health**

| Variable | Physical Functioning | | Role-Physical | | Bodily Pain | | General Health | |
|---|---|---|---|---|---|---|---|---|
| | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD |
| All participants regardless of their level of involvement[a] | | | | | | | | |
| Receivers (n = 363–371) | 77.4 | 22.7 | 50.3 | 43.7 | 70.2 | 25 | 71.5 | 19.4 |
| Intentional nonreceivers (n = 44–46) | 84.9 | 19.5 | 66.7 | 41.3 | 76.4 | 21.5 | 79.5 | 14.9 |
| F | 3.5 | – | 10.2** | – | 2.39 | – | 6.17* | – |
| Level of involvement: I was "very involved."[b] | | | | | | | | |
| **Overall treatment decision** | | | | | | | | |
| Receivers (n = 227–232) | 79.9 | 21.8 | 50.3 | 43.3 | 71 | 24.5 | 73.1 | 18.4 |
| Intentional nonreceivers (n = 35–36) | 84.1 | 20.1 | 65.6 | 41.5 | 76.6 | 22 | 82.2 | 12.7 |
| F | 2.23 | – | 9.9*** | – | 1.41 | – | 7.63** | – |
| **Surgery decision** | | | | | | | | |
| Receivers (n = 222–228) | 79.6 | 21.7 | 49.6 | 43.6 | 70.5 | 24.9 | 72.9 | 18.4 |
| Intentional nonreceivers (n = 33–35) | 83.9 | 20.6 | 65.8 | 41.7 | 78.6 | 20.3 | 80.8 | 15.3 |
| F | 2.1 | – | 10.39*** | – | 3.76 | – | 5.2* | – |
| **Chemotherapy/radiation therapy** | | | | | | | | |
| Receivers (n = 175–179) | 78.7 | 22.9 | 49.3 | 43.3 | 70 | 24.6 | 73 | 18.6 |
| Intentional nonreceivers (n = 27) | 82.2 | 21.9 | 60.8 | 42.4 | 78 | 20.2 | 80.4 | 13.3 |
| F | 0.59 | – | 2.52 | – | 1.99 | – | 2.46 | – |
| **Test decision** | | | | | | | | |
| Receivers (n = 140–142) | 81.9 | 20.5 | 57.5 | 42.8 | 73 | 23.7 | 75.8 | 17.6 |
| Intentional nonreceivers (n = 23–24) | 83.5 | 22.2 | 77.9 | 35.6 | 75 | 24 | 81.2 | 13.6 |
| F | 0.23 | – | 7.3** | – | 0.02 | – | 0.94 | – |
| **Complementary treatment decision** | | | | | | | | |
| Receivers (n = 126–128) | 80.3 | 18.3 | 45.2 | 42.9 | 68.6 | 22.9 | 73.8 | 17.5 |
| Intentional nonreceivers (n = 26–27) | 84.5 | 21.1 | 69.6 | 40.5 | 73.7 | 23.2 | 83.2 | 13.2 |
| F | 1.88 | – | 7.91*** | – | 0.96 | – | 6.28* | – |
| **Lifestyle changes decision** | | | | | | | | |
| Receivers (n = 205–211) | 79.2 | 21.2 | 50.2 | 42.9 | 71.9 | 24.1 | 74.8 | 18.2 |
| Intentional nonreceivers (n = 27–28) | 82.9 | 22 | 72.6 | 39.5 | 75.9 | 23.3 | 81.7 | 12.9 |
| F | 1.09 | – | 13.21*** | – | 0.67 | – | 4.19* | – |
| Participation congruence: My involvement was "just right."[c] | | | | | | | | |
| **Overall treatment decision** | | | | | | | | |
| Receivers (n = 288–294) | 78.4 | 22 | 51.2 | 43.2 | 71.4 | 24.1 | 72.3 | 19.4 |
| Intentional nonreceivers (n = 27–28) | 82.2 | 21 | 67.2 | 42.3 | 77.3 | 21.4 | 81.6 | 14.2 |
| F | 0.26 | – | 4.95* | – | 1.76 | – | 5.53* | – |
| **Conventional treatment decision** | | | | | | | | |
| Receivers | 79 | 21.6 | 50.7 | 43.4 | 71.6 | 24.4 | 72.6 | 19.2 |
| Intentional nonreceivers | 83.2 | 20.8 | 67.4 | 40 | 76 | 22.6 | 81.8 | 13.6 |
| F | 1.16 | – | 7.94** | – | 1.01 | – | 6.09* | – |

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$
[a] Mean differences between total sample
[b] Mean differences among subgroup of women who were very involved in treatment decision making
[c] Mean differences among subgroup of women who perceived that their participation congruence was just right
**Note.** Covariates were age and stage at diagnosis, income, months since cancer diagnosis, type of surgery, and oncology care received.
**Note.** Scores for each subscale range from 0 (worst possible health, severe disability) to 100 (best health, no disability).

**TABLE 4. Comparison of Vitality, Social Functioning, Role-Emotional, and Mental Health**

| Variable | Vitality | | Social Functioning | | Role-Emotional | | Mental Health | |
|---|---|---|---|---|---|---|---|---|
| | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD | $\bar{X}$ | SD |
| **All participants regardless of their level of involvement[a]** | | | | | | | | |
| Receivers (n = 363–371) | 49.4 | 23.1 | 70.6 | 25.8 | 68 | 41.1 | 72.8 | 16.8 |
| Intentional nonreceivers (n = 44–46) | 60.2 | 20.1 | 71.5 | 23.8 | 75 | 36.7 | 75.7 | 16.9 |
| F | 8.81** | – | 0.16 | – | 2.7 | – | 2.11 | – |
| **Level of involvement: I was "very involved."[b]** | | | | | | | | |
| **Overall treatment decision** | | | | | | | | |
| Receivers (n = 227–232) | 50.1 | 23.1 | 70 | 25.7 | 69.2 | 40.8 | 72.7 | 16.4 |
| Intentional nonreceivers (n = 35–36) | 58.9 | 19.4 | 72.5 | 21 | 73.5 | 37.6 | 76 | 16.7 |
| F | 4.93* | – | 0.16 | – | 0.83 | – | 1.1 | – |
| **Surgery decision** | | | | | | | | |
| Receivers (n = 222–228) | 50.4 | 22.7 | 70 | 25.5 | 68.5 | 41.1 | 73 | 16.1 |
| Intentional nonreceivers (n = 33–35) | 59.5 | 20.5 | 71.8 | 23.8 | 72.1 | 38.1 | 75.6 | 17 |
| F | 5.3* | – | 0.04 | – | 0.85 | – | 0.85 | – |
| **Chemotherapy/radiation therapy** | | | | | | | | |
| Receivers (n = 175–179) | 48.5 | 23.4 | 68.6 | 25.6 | 68.1 | 40.9 | 72.5 | 17.2 |
| Intentional nonreceivers (n = 27) | 58.9 | 19.5 | 72.5 | 21.6 | 77.8 | 34.3 | 78.4 | 15.5 |
| F | 3.45 | – | 0.1 | – | 1.11 | – | 1.31 | – |
| **Test decision** | | | | | | | | |
| Receivers (n = 140–142) | 53.6 | 23.2 | 74.1 | 23.6 | 75.1 | 37.3 | 75.6 | 14.8 |
| Intentional nonreceivers (n = 23–24) | 59.8 | 18.4 | 76.4 | 22.4 | 81.3 | 37.4 | 76.7 | 15.5 |
| F | 1.36 | – | 0.08 | – | 0.32 | – | 0.00 | – |
| **Complementary treatment decision** | | | | | | | | |
| Receivers (n = 126–128) | 48 | 21.3 | 68.2 | 22.7 | 62.6 | 40.9 | 72.5 | 14.3 |
| Intentional nonreceivers (n = 26–27) | 59.8 | 19.1 | 69.2 | 21.9 | 71.6 | 40 | 74.3 | 17.2 |
| F | 6.25* | – | 0.01 | – | 2.31 | – | 0.65 | – |
| **Lifestyle changes decision** | | | | | | | | |
| Receivers (n = 205–211) | 50 | 23.4 | 71.2 | 24.5 | 70.4 | 40 | 74.5 | 15.7 |
| Intentional nonreceivers (n = 27–28) | 60.2 | 19.4 | 72.6 | 22.7 | 75.6 | 40.1 | 76.6 | 17.5 |
| F | 7.03** | – | 0.3 | – | 1.05 | – | 0.72 | – |
| **Participation congruence: My involvement was "just right."[c]** | | | | | | | | |
| **Overall treatment decision** | | | | | | | | |
| Receivers (n = 288–294) | 50.7 | 23 | 72.4 | 24.8 | 71.4 | 40 | 74.4 | 16.2 |
| Intentional nonreceivers (n = 27–28) | 56.1 | 20 | 72.3 | 22.8 | 81.7 | 33.2 | 76.1 | 17.4 |
| F | 1.13 | – | 0.00 | – | 3.89* | – | 0.84 | – |
| **Conventional treatment decision** | | | | | | | | |
| Receivers | 50.5 | 22.5 | 72.1 | 24.8 | 71 | 39.8 | 74.1 | 15.9 |
| Intentional nonreceivers | 59.4 | 19.6 | 74 | 21.4 | 79 | 32.4 | 77.5 | 15.6 |
| F | 4* | – | 0.14 | – | 2.31 | – | 1.44 | – |

*$p < 0.05$; **$p < 0.01$
[a] Mean differences between total sample
[b] Mean differences among subgroup of women who were very involved in treatment decision making
[c] Mean differences among subgroup of women who perceived that their participation congruence was just right
**Note.** Covariates were age and stage at diagnosis, income, months since cancer diagnosis, type of surgery, and oncology care received.
**Note.** Scores for each subscale range from 0 (worst possible health, severe disability) to 100 (best health, no disability).

has poor power to detect smaller effects. Still, the current authors felt it important to restrict the sample to highly involved women and to those whose level of involvement in TDM was "just right" because some women may fail to receive important treatments because they are not offered to them related to age or comorbid illnesses, or because rural residence acts as a barrier to care. The current authors were interested in understanding how the decisions to forgo some adjuvant treatments affect those who make these decisions for themselves voluntarily. Some women might have not received endocrine-manipulation therapy because they desire to have children (Guth, Huang, Alder, & Moffat, 2015; Makubate, Donnan, Dewar, Thompson, & McCowan, 2013) or because of difficulty arranging treatments related to having young children; however, this information was not collected. Conversely, some receivers may not be fully adherent to adjuvant treatments, which this study did not assess. This study used self-report questionnaires to assess HRQOL and involvement in TDM, which can induce a false correlation between any two self-reported measures (Duggal, Carlson, Sroufe, & Egeland, 2001).

## Implications for Nursing

Nurses need to be aware that about 6%–13% of women with breast cancer intentionally do not receive all recommended treatments (Greenlee et al., 2016; Neugut et al., 2012; Saquib et al., 2012). In the current study, 11% of women did not receive at least one chemotherapy, radiation therapy, or endocrine-manipulation therapy that was recommended by their physicians after surgery. Women with more favorable prognoses, such as earlier stage of cancer and positive estrogen-receptor status, tended to be intentional nonreceivers, which is consistent with previous findings (Neugut et al., 2012; Puts et al., 2010; Saquib et al., 2012).

If intentional nonreceivers of some adjuvant therapies are making this choice in an effort to improve their immediate HRQOL, it appears that they are, for the most part, successful because the current study found that intentional nonreceivers had better HRQOL than receivers. Nurses need to note that the means of HRQOL among intentional nonreceivers who were very involved in TDM are more similar to the norms of the general female population in the United States described in Ware et al. (1993). The exception to this is that intentional nonreceivers scored lower in role-physical (77.77 [SD = 36.2] in Ware et al. [1993] versus 66.7 [SD = 41.3] in the current study) and social functioning (81.54 [SD = 23.74] in Ware et al. [1993] versus 71.5 [SD = 23.8] in the current study). These findings may indicate that intentional nonreceivers have HRQOL that is comparable to the general female population because they are not experiencing adjuvant treatment side effects, but they are likely to struggle with some limitation on performing their daily physical activities and continue to experience problems in social functioning associated with their cancer diagnosis and receiving surgery. Another difference that is interesting and difficult to understand is that intentional nonreceivers scored higher in general health (70.61 [SD = 21.5] in Ware et al. [1993] versus 79.5 [SD = 14.9] in the current study); this result needs to be verified with a larger sample of intentional nonreceivers.

Proactively assessing HRQOL among all women with breast cancer is important because of its relationship to improved prognosis among women with breast cancer (Andersen et al., 2009; Montazeri, 2008), but it may be worth noting that receivers may be particularly likely to experience low HRQOL. Finding ways to support women who receive adjuvant treatments is important.

## Conclusion

Nurses should be aware that, among women with breast cancer who were very involved and those who were able to achieve congruence and to be involved in TDM at their preferred level of involvement, intentional nonreceivers had better role-physical, general health, and vitality than women who received all recommended treatments. Future research should explore the longitudinal differences on HRQOL between receivers and intentional nonreceivers to see if the advantage associated with informed decisions to avoid adjuvant treatments continue over time, or instead erode as might occur if avoiding treatment leads to later poor prognoses and earlier return of symptoms.

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The preparation of this manuscript was funded by a grant (Research and Intramural Funding Program from University of Washington

School of Nursing). The original research study, Breast Cancer Integrative Oncology, was funded by a grant (R01 AT005873) from the National Institutes of Health, National Center for Complementary and Integrative Health.

Kim contributed to the conceptualization and design and provided the secondary data analysis. Andersen and Standish completed the conceptualization, design, and data collection for the original study. All authors contributed to the manuscript preparation.



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