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# Interpersonal Influences and Attitudes about Adjuvant Therapy Treatment Decisions among Early Stage Breast Cancer Patients: An Examination of Differences by Age and Race/Ethnicity in the BQUAL Study

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## Abstract

Patients are increasingly involved in cancer treatment decisions and yet little research has explored factors that may affect patient attitudes and beliefs about their therapeutic choices. This paper examines psychosocial factors (e.g., attitudes, social support), provider-related factors (e.g., communication, trust), and treatment considerations in a prospective study of a sample of early stage breast cancer patients eligible for chemotherapy and/or hormonal therapy (BQUAL cohort). The data comes from a multi-site cohort study of white, black, Hispanic, and Asian non-metastatic

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breast cancer patients recruited in New York City, Northern California, and Detroit Michigan. Baseline surveys were conducted over the telephone between 2006 and 2010 among a total of 1145 women. Most participants were white (68%), had more than a high school education (76%), and were diagnosed with stage I disease (51%). The majority of women reported discussing chemotherapy and hormonal therapy with their doctor (90% and 83% respectively); these discussions primarily took place with medical oncologists. Nearly a quarter of women reported that the treatment decision was difficult and the majority were accompanied to the doctor (76%) and involved a friend or family member in the decision (54%). Positive considerations (e.g., beliefs about treatment reducing risk of recurrence) were important in making treatment decisions. Participants preferred a shared decision-making style, but results suggested that there is room for improvement in terms of actual patient involvement in the decision and provider communication, particularly among black patients. Patients 65 years and older reported fewer provider discussions of chemotherapy, poorer patient-provider communication, higher rates of being assisted by family members in making the decision, and more negative attitudes and beliefs towards treatment.

**Keywords**

adjuvant therapy; breast cancer; treatment decisions; quality of care; racial disparities

## Background

Adjuvant therapy for breast cancer, when indicated, has important implications for reducing the risk of breast cancer recurrence and improving the chances of survival [1-3]. Despite evidence of the effectiveness of adjuvant therapy for treating early-stage breast cancer, adherence to recommended therapy is sub-optimal and adjuvant modalities are underused [2, 4-10]. Several recent studies have found that delayed initiation and/or premature discontinuation of recommended adjuvant treatment for breast cancer are more likely among black and Hispanic women, compared to white women [11-14]. Understanding the factors that influence treatment decisions is important, as racial/ethnic minority groups, and blacks in particular, have worse survival outcomes and higher mortality rates for breast cancer than white women [15, 16].

Multiple forces are at play in influencing treatment decisions and disparities. In addition to clinical variables (e.g., tumor size) [17], physician factors (e.g., practice patterns) [18-20], and system failures (e.g., lack of referral) [6], psychosocial and interpersonal factors may also be important [17]. This may include patient knowledge, attitudes, and beliefs about treatment and healthcare experiences [4, 21-23], provider communication and relationship [24-26], patient involvement in making the decision [27, 28], and social relations (e.g., the influence of family) [29]. In our own work among this study population [30, 31], we found that older age was associated with decreased likelihood of receiving chemotherapy, poor patient-provider communication was associated with lower initiation of hormonal therapy, and negative beliefs about efficacy and side effects were associated with lower use of both therapies. These findings also suggest that age may be another important consideration that influences patterns in adjuvant therapy, consistent with prior studies [4, 32, 33].

The BQUAL (Breast Cancer Quality of Care) study is a large, prospective cohort study among racially/ethnically diverse women with non-metastatic breast cancer being treated at several community care sites across the United States. This study takes a comprehensive approach to understanding factors that may influence treatment non-adherence for indicated primary adjuvant therapy (chemotherapy and hormonal therapy) among white, black, Hispanic and Asian women with breast cancer. BQUAL seeks to address many of the limitations of prior studies including limited sample size, retrospective design, or focus on specific subgroups (e.g., the elderly) [34-37].

This paper seeks to describe baseline patient and clinical characteristics of the sample, with a focus on the treatment decision process and factors relevant to treatment decisions for both chemotherapy and hormonal therapy from the perspective of the patient, including psychosocial factors, interpersonal factors (e.g., provider communication), and treatment considerations. Adjuvant therapy was clinically indicated or discretionary (due to health or age) for nearly 90% of our sample according to the National Comprehensive Cancer Network (NCCN) guidelines. Therefore, we have chosen to provide a complete snapshot of the experiences and perceptions of women with early stage breast cancer and include all women who completed the baseline survey. We also explored racial/ethnic and age differences in our findings, with the goal of elucidating which factors may differ across these groups and potentially contribute to the treatment disparities that exist with respect to age and race/ethnicity.

## Methods

### Recruitment and Study Eligibility

Participants were recruited at each site following their diagnosis. Study sites included Columbia University Medical Center (CUMC) and Mount Sinai School of Medicine in New York, Kaiser-Permanente of Northern California (KPNC), and Henry Ford Health System (HFHS) in Detroit, MI. To be eligible for the study, women needed to be: 1) >20 years of age; and 2) newly diagnosed with primary, histologically confirmed invasive breast cancer (stages 1-3). Women who were non-English speaking, had a prior history of cancer (except non-melanoma skin cancer), had ductal carcinoma *in situ* (DCIS) or stage 4 cancer at diagnosis, had a history of significant memory deficit, had completed three cycles of adjuvant chemotherapy, or no telephone were ineligible. Upon receipt of contact information of consented women from each of the recruitment sites, interviewers contacted women by telephone, confirmed eligibility, and conducted the survey(s) by phone. Information about the study sites and recruitment strategies is described elsewhere [38].

### Study Sample

Between May 2006 and June 2010, a total of 1479 women with newly diagnosed non-metastatic breast cancer were identified and invited to participate in the study. Of these, 122 (8.2%) refused participation while 212 (14.3%) were ineligible. We included the remaining 1145 women for these analyses.

### Data Collection

Women provided informed consent before administration of the third cycle of chemotherapy (if they received chemotherapy) or within 3 months of diagnosis. A questionnaire was conducted at enrollment following informed consent (approximately one hour) and at approximately 2 and 4 months after the baseline survey (roughly corresponding to the mid-point and completion of chemotherapy). Medical charts were reviewed to collect information about the tumor and treatment. Participants provided written informed consent. This study was approved by the Institutional Review Boards of each recruitment site and the U.S. Army Medical Research and Material Command Office of Research Protections and Human Research Protection Office. Participants were mailed a $20 gift card for completing the survey.

## Measures

Sociodemographic characteristics were collected in the baseline survey (see Table 1). Tumor characteristics (e.g., stage at diagnosis, tumor grade and size, nodal status) and comorbidities were abstracted from the medical record. The comorbidities reported 12 months before diagnosis and up to 3 months post-diagnosis were used to create a Charlson Comorbidity Index score [39]. Information about medical record review is described elsewhere [38]. Survey measures reported in this paper represent the following domains: 1) Treatment Decision Process and Considerations; 2) Psychosocial Factors; 3) Provider-related Factors and Communication.

## Treatment Decision Process and Considerations

Questions related to the decision process included: if the patient was referred to a medical oncologist, and by whom, and if the patient was currently under the care of a medical oncologist. Participants were also asked if chemotherapy or hormonal therapy were discussed and with which provider(s) (Table 2). Respondents were queried about how difficult the decision to take chemotherapy and/or hormonal therapy had been for them. Participants were asked who was with them at the physician visit, and if those people assisted them in making their treatment decision.

Treatment-related considerations were measured using 15 items for chemotherapy and 13 items for hormonal therapy. Participants were asked whether or not each consideration was an important factor in their decision about treatment, rating each item as not important (0) or important (1). A summary score was calculated for each treatment modality in the following five domains: 1) side effects and physical appearance (1-2 items); 2) negative beliefs about treatment, such as believing that chemotherapy is not effective (5 items, $\alpha$=0.72); 3) positive beliefs, such as not having to worry about the cancer coming back (3 items, $\alpha$=0.64); 4) concrete considerations, such as the ability to pay for treatment (3-4 items, $\alpha$=0.67); and 5) beliefs of family and friends about treatment (1 item).

## Psychosocial Factors

Participants were queried about their attitudes towards treatment using 7 items for chemotherapy and 7 items for hormonal therapy, with 4 response options (‘Not at all’ to ‘Very much’). To measure chemotherapy treatment expectations, participants were asked to rate 5 items, on a scale of 0 to 10, about their expectations related to fatigue, nausea, hearing loss, pain, and side effects based on the Visual Analog Scale [40]. Fatalistic beliefs were assessed using the 8-item subscale of the Mental Adjustment to Cancer scale ($\alpha$ = .62) [41].

The 19-item social support subscale of the Medical Outcome Study [42] was used to assess social support, including sub-scales of emotional/informational support; tangible support; affectionate support; and positive social interaction. Participants were asked about the kinds of support that may be available to them, and how often it is available to them if they need it (1= None of the time to 5= All of the time) ($\alpha$ =.90-.95). Structural social support was assessed by asking: 'About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind?)' (write-in).

## Provider-related Factors and Communication

Patients’ preferred treatment decision-making roles were assessed using a modified version of an existing validated measure [43] (see Table 2). To assess patient involvement in the decision, participants were asked how much they agreed with three statements on a scale of 1 (Very strongly disagree) to 6 (Very strongly agree) (see Table 3) ($\alpha$=0.62). Provider communication for the chemotherapy and hormonal therapy decision was assessed using 4 items for each treatment modality (α =.80) [44, 45] (see Table 3). Response options ranged from 1 (Very strongly disagree) to 6 (Very strongly agree).

Medical mistrust was evaluated using the 12-item Group-based Medical Mistrust Scale (GBMMS) [46], assessed approximately two months post-diagnosis, including the subscales of 1) Lack of Support (3 items); 2) Discrimination (3 items); and 3) Suspicion (6 items) (α = 0.89). Participants were asked how much they agreed with each statement (1=Strongly disagree to 5=Strongly agree).

### Data analysis

Cronbach's alpha was used to assess internal consistency and reliability of scale measures. Summary statistics (means, standard deviations, percentages) were calculated to describe the distribution of variables. Differences across racial/ethnic groups (categorized here as white, black, Hispanic, and Asian) and age (<50; 50-64; >65)_were determined using chi-square statistics and analysis of variance. Key racial/ethnic and age differences are described in the text. All analyses were performed using SAS software version 9.2 [47].

## Results

### Sample and Tumor Characteristics

Information about patient and tumor/disease characteristics is shown in Table 1. Forty-seven percent of women were between the ages of 50 and 64 and half (52%) were married. Most respondents had a household income >$50,000 and had more than a high school education (61% and 76%, respectively).

### Treatment Decision Process and Considerations

Nearly all women (96%) reported being referred to a medical oncologist. Ninety-percent (90%) of participants said that their doctor talked to them about chemotherapy, most commonly their medical oncologist (82%). Women over 65 were less likely to report that their provider discussed chemotherapy with them (84%) (p<.0001) (Table 2). Eighty-three percent (83%) of participants reported discussing hormonal therapy with a doctor, primarily with their medical oncologist (87%). Over half (59%) of women said that the decision to take chemotherapy was somewhat/very easy, compared with 23% of women who said that it was a somewhat/very difficult decision (see Table 2). Women in the 50-64 age group reported most difficulty with the chemotherapy decision (p=.003). Over half (55%) of women said that their decision about hormonal therapy was somewhat/very easy, compared with 19% of women who said that it was a somewhat/very difficult decision.

The majority of participants (76%) reported that someone was with them when the doctor talked to them about choosing their treatment. Over half of participants (54%) stated that this/these person(s) helped them make their decision about breast cancer treatment, predominantly by their husband or partner (55%), parent, child or grandchild (35%), or other relative (25%) (Table 2). Patients older than 65 were much more likely to be helped in making treatment decisions (p=.0005). Hispanics were mostly likely to be helped in decision-making by a parent, child or grandchild (32% vs. 18% of whites and 13% of Asians; p=.0006), while Asians were most likely to be helped by their husband or partner (38% vs. 22% of blacks; p=.005). Decision-making considerations for chemotherapy were evaluated for the following results (Table 3), with higher scores indicating that more women found these factors to be important: Positive Balance (2.4 out of 3); Negative Balance (1.6 out of 5), Concrete Considerations (1.1 out of 4), Physical (.7 out of 2), and Family and friends (.4 out of 1). For hormonal therapy, the corresponding results were: Positive Balance (2.7 out of 3); Negative Balance (1.1 out of 5), Concrete Considerations (0.8 out of 3), Physical (0.6 out of 1), and Family and friends (0.3 out of 1). Patients older than 65 tended to hold higher negative beliefs (p=.01) and lower positive beliefs about both treatments than other age groups (p<.0001) (see Table 3).

### Psychosocial Factors

When asked to answer how much they agreed with 7 statements about chemotherapy and 7 statements about hormonal therapy (to assess treatment attitudes), participants had an overall mean score of 2.9 (SD: 0.6) for each scale, based on a scale of 1 to 4. For each scale, beliefs related to chemotherapy or hormonal therapy reducing their risk of cancer recurrence, were particularly strong (see Table 3). Patients older than 65 years of age tended to have more negative attitudes towards treatment (p<.0001) (Table 3)._Overall, whites had stronger attitudes towards hormonal therapy than blacks (p=.01). Participants' pre-treatment expectations for chemotherapy were highest for fatigue (mean: 6.7; SD: 2.2) and side effects (mean: 6.4; SD: 2.5), and lowest for hearing loss (mean: 1.3; SD: 2.2).

With regard to fatalism, participants had a mean score of 19.6 (SD: 3.2), with a summary score ranging from a possible 8-32, with higher scores indicating higher levels of fatalism. Fatalism was highest among patients 65 and older (p<.0001) (Table 3). The index social support score was 4.3 (SD: 0.7), with a range of 1.4 to 5, and sub-scales were similarly high (see Table 3). Participants reported a mean of 14 close friends and relatives, with a range of 0 to 200.

### Provider-related Factors and Communication

When patients were asked about their preferred treatment decision-making roles (Table 2), many women reported that the doctor and the patient should make the decisions together on an equal basis or that the patient should make the decisions, but strongly consider the doctor's opinion (38% and 33%, respectively). In assessing patient involvement in treatment decisions, patients had a mean score of 12.5 (SD: 2.5), out of a possible range of 3-18 (see Table 3). The mean provider involvement score was lowest among black patients at 11.7 (SD: 2.3) (p<.0001).

With regard to communication about chemotherapy, respondents had a mean score of 18.0 (SD: 3.6), with a possible score ranging from 4 to 24. Respondents reported a mean score of 15.5 (SD: 2.7) for provider communication about hormonal therapy. Provider communication was lower among black patients compared to whites (p<.0001). Provider communication was also lower among patients 65 and older, particularly communication related to chemotherapy treatment (see Table 3). The mean summary score for the GBMMS was 20.6 (SD: 7.1). Medical mistrust was significantly higher among blacks (26.2; SD: 8.5) than whites (19.1; SD: 6.1) (p<.0001).

## Discussion

In this study examining the treatment decision process for adjuvant therapy in a sample of early stage breast cancer patients, nearly a quarter of patients found these decisions to be difficult and the majority brought someone with them to the visit and involved them in the treatment decision. Positive beliefs about treatment were particularly important considerations in making adjuvant treatment decisions. While most participants wanted to be involved in the decision-making process, patients were only moderately satisfied with provider communication and their actual involvement in making the treatment decision. Racial and ethnic differences were explored, and provider communication, patient involvement, and medical trust were rated lowest among black patients. Age differences were also found, with patients 65 and older reporting lower rates of providers discussing chemotherapy, poorer patient-provider communication, higher rates of being assisted by family members in making the decision, and more negative attitudes and beliefs towards treatment.

This study expands upon earlier research by examining psychosocial and interpersonal factors to understand treatment decisions among a large, racially diverse, national sample of early stage breast cancer patients. The complexity and difficulty of these decisions has been indicated in prior research [16, 48, 49] and further documented and quantified in our study. Our research indicates that a sizable proportion of patients may benefit from getting extra support while making this decision. Research is still needed to determine the nature, timing, and amount of services that may better support patients to make treatment decisions.

The importance of friends and family members in treatment decisions and the role of supportive relationships have also been suggested in prior work [48, 50, 51]. In our sample, the majority of women reported high levels of social support. Most women brought someone with them to the doctor (76%) and this person helped them make their treatment decision in about half of the sample. This was most commonly a family member, including their husband/partner (55%) or parent, child or grandchild (35%). More research is needed to identify how members of a patient's social network are involved in the decision, and how they ultimately influence treatment decisions, particularly among women older than 65 who may be more likely to have family members be involved.

Our findings also suggest that certain considerations may be particularly important in making treatment decisions across women. Among factors people may consider in making adjuvant treatment decisions, we found that positive factors (e.g., being able to worry less about recurrence) were particularly important considerations for women in making the chemotherapy and hormonal therapy decision. This research complements prior research studies [45, 52, 53]. Our findings suggest that negative attitudes and beliefs about treatment among older women may be particularly influential, and should potentially be addressed in future interventions.

Prior studies examining patient preferences for involvement in treatment decisions have produced highly variable findings [18, 54-57]. We found that the vast majority of women reported that the doctor and the patient should make treatment decisions together on an equal basis or that the patient should make the decisions, but strongly consider the doctor's opinion. Some research has suggested that although many women may report a preference for active participation in treatment decisions, they may not perceive they have a choice of treatment options in the context of non-surgical decisions (e.g., with adjuvant therapy decisions) [52, 56], which could explain some of the variation in findings.

Notably, actual perceived involvement in making the decision was only moderate, and lowest among black women. If patient involvement in decisions is accepted in clinical practice, this may have positive effects, as prior research suggests that patients who were equally or more involved than they preferred to be had better decision-related outcomes [58-61], and women actively involved in surgical treatment decision-making have been found to subsequently have significantly better quality of life than women who preferred passive involvement [62-64]. More research is needed to investigate both preferred and actual involvement in treatment decision-making, and the influence it has on cancer quality of care and health outcomes.

Provider communication is also important to making informed cancer treatment decisions [65-67]. We found that respondents were only moderately satisfied with patient-provider communication for chemotherapy and hormonal therapy, and ratings were lower among black patients and women older than 65. The need for improving communication between patients and providers in making treatment decisions for early stage breast cancer has been suggested [54, 68], and is critical, as provider communication has important effects on treatment decisions and health outcomes [69-72]. Furthermore, non-white women have reported poorer communication with physicians, worse quality of care, and less involvement in treatment decisions [50, 52, 73-75]. Improving provider communication should be further investigated, as physician communication that can empower patients (e.g. increase self-efficacy, knowledge) has been found to mitigate disparities in receipt of breast-conserving surgery [76]. Based on our data, it is not clear why provider communication scores were lower for Black and older patients, and whether it is related to patient or provider factors, or a combination of both. Understanding why these populations experience or perceive worse provider communication is an important area for future investigation.

Medical mistrust is also thought to influence the treatment decision-making process [56, 77]. One study among women treated in six New York City hospitals found that women who did not receive adjuvant therapy for early stage breast cancer were more likely to be older, have more comorbidities, poorer understanding of the benefit and risks of adjuvant treatments, and greater mistrust of the medical system [4]. We found the mean medical mistrust scores to be comparable to those reported in prior studies [46, 78] and higher among black women [79]. Future research should continue to explore the influence mistrust has on the cancer treatment decision process and outcomes.

Strengths of this study include a large sample size, diverse geographic and racial/ethnic representation, multiple community practice settings, a high participation rate, and an examination of factors influencing treatment decisions for both chemotherapy and hormonal therapy. Limitations of our analyses should also be recognized. These findings rely on self-report only, are cross-sectional, and include participants who are English speaking and largely insured, which may limit the generalizability of findings. We had relatively small samples of black and Asian women, and a very small sample of Hispanic women. As such, our findings related to racial/ethnic differences should be interpreted as suggestive given potential limitations of their generalizability and should be further examined in larger future studies.

Adjuvant treatment decisions for breast cancer are complex and influenced by a range of psychosocial, cultural, healthcare, and patient/provider factors. By better understanding factors that contribute to treatment decisions, including potential differences by race/ethnicity and age, researchers and practitioners will be better able to support treatment decisions and promote better quality of care for breast care patients.

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## Table 1

Patient and tumor characteristics at diagnosis of patients recruited with non-metastatic breast cancer recruited and interviewed within the BQUAL Study, 2006-2010 (n=1145)

| | **n (%)** |
|---|---|
| **Age** | |
| <50 | 268 (23%) |
| 50 – 64 | 543 (47%) |
| 65+ | 334 (29%) |
| **Race/ethnicity** | |
| White | 788 (69%) |
| Black | 181 (16%) |
| Hispanic | 59 (5%) |
| Asian | 100 (9%) |
| Other | 17 (1%) |
| **Site of recruitment** | |
| CUMC/MSSM | 160 (14%) |
| Kaiser | 848 (74%) |
| Henry Ford | 137 (12%) |
| **Household Income** | |
| <15,000 – 24,999 | 142 (12%) |
| 25,000 – 49,999 | 248 (22%) |
| 50,000 – 89,999 | 355 (31%) |
| >90,000 | 342 (30%) |
| Refused | 58 (5%) |
| **Education** | |
| ≤ HS grad | 272 (24%) |
| College | 560 (49%) |
| Graduate School | 312 (27%) |
| **Marital status** | |
| Married | 604 (53%) |
| Not married | 504 (44%) |
| Unknown | 37 (3%) |
| **Employment status** | |
| Full time | 357 (31%) |
| Part time | 125 (11%) |
| Retired | 366 (32%) |
| Not Currently working | 297 (26%) |
| **Insurance Status** | |
| Medicare/Medicaid | 192 (17%) |
| Employer sponsored | 807 (70%) |

| | **n (%)** |
|---|---|
| Self-pay | 136 (12%) |
| Don't know/refused | 10 (1%) |
| **Charlson score** | |
| 0 | 930 (81%) |
| 1+ | 206 (18%) |
| Unknown | 9 (1%) |
| **AJCC Stage** | |
| I | 582 (51%) |
| II | 416 (36%) |
| III | 94 (8%) |
| Unknown | 53 (5%) |
| **Grade** | |
| Well differentiated | 266 (23%) |
| Moderately differentiated | 520 (45%) |
| Poorly differentiated | 277 (24%) |
| Unknown | 82 (7%) |
| **Nodes** | |
| Negative | 804 (70%) |
| Positive | 334 (29%) |
| Unknown | 7 (1%) |
| **Tumor size** | |
| 0-0.5 cm | 102 (9%) |
| >0.5 – 1.0 cm | 218 (19%) |
| >1.0 cm | 783(68%) |
| Unknown | 42(4%) |
| **ER/PR status** | |
| Negative | 212 (19%) |
| Positive | 922 (80%) |
| Unknown | 11 (1%) |

## Table 2

Categorical variables and differences by age related to treatment decision process and considerations among women with non-metastatic breast cancer interviewed in the BQUAL Study, 2006-2010 (n=1145)

| | **All (N=1,145)** | **Age <50 (N=268, 23%)** | **Age 50-64 (N=543, 47%)** | **Age ≥ 65 (N=334, 29%)** | |
|---|---|---|---|---|---|
| | **n (%)** | **n (%)** | **n (%)** | **n (%)** | **p-value** |
| **Referred to Medical Oncologist (Y)** | 1,102 (96%) | 253(94%) | 529(97%) | 320(96%) | 0.05 |
| **Referred to Medical Oncologist By (circle all that apply):** | | | | | |
| Surgeon | 660 (60%) | 144(57%) | 332(63%) | 184(58%) | - |
| PCP | 44 (4%) | 5(2%) | 21(4%) | 18(6%) | - |
| Self | 30 (3%) | 7(3%) | 11(2%) | 12(4%) | - |
| Other | 179 (16%) | 44(17%) | 80(15°%) | 55(17%) | - |
| None of the above | 209 (19%) | 58(22%) | 96(18°%) | 55(17%) | - |
| **Currently under care Of Medical Oncologist (Y)** | 1089 (95%) | 256(96%) | 525(97%) | 308(92%) | 0.01 |
| **Chemotherapy Treatment Discussed (Y)** | 1030 (90%) | 260(97%) | 489(90%) | 281(84%) | <0.0001 |
| **Chemotherapy Discussed the most with:** | | | | | |
| Surgeon | 155 (15%) | 29(11%) | 66(14%) | 60(21%) | - |
| PCP | 1 (<1%) | 0(0%) | 0(0%) | 1(<1%) | - |
| Medical Oncologist | 841 (82%) | 225(87%) | 405(83%) | 211(75%) | - |
| Radiation Oncologist | 9 (1%) | 1(<1%) | 3(1%) | 5(2%) | - |
| Other | 23 (2%) | 4(2%) | 15(3%) | 4(1%) | - |
| Did not respond | 1 (<1%) | 1(<1%) | 0(0%) | 0(0%) | - |
| **Level of Difficulty of Chemotherapy Decision:** | | | | | |
| Somewhat/Very Difficult | 266 (23%) | 80(17%) | 126(23%) | 60(18%) | 0.003 |
| Neutral | 129 (11%) | 31(3%) | 69(13°%) | 29(9%) | |
| Somewhat/Very Easy | 675 (59%) | 147(55%) | 309(57%) | 219(66%) | |
| Did not respond or were in process of making decision | 75 (7%) | 10(4%) | 39(7%) | 26(8%) | |
| **Hormonal therapy Discussed (Y)** | 952 (83%) | 220(82%) | 458(84%) | 274(82%) | 0.83 |
| **Hormonal therapy discussed the most with (circle all that apply):** | | | | | |
| Surgeon | 96 (10%) | 20(9%) | 50(11%) | 26(9%) | - |
| PCP | 2 (<1%) | 0(0%) | 1(<1%) | 1(<1%) | - |

| | All (N=1,145) | Age <50 (N=268, 23%) | Age 50-64 (N=543, 47%) | Age ≥ 65 (N=334, 29%) | |
|---|---|---|---|---|---|
| | **n (%)** | **n (%)** | **n (%)** | **n (%)** | **p-value** |
| Medical Oncologist | 826 (87%) | 192(87%) | 395(86%) | 238(87%) | - |
| Radiation Oncologist | 11 (1%) | 2(1%) | 5(1%) | 4(1%) | - |
| Other | 17 (2%) | 6(3%) | 7(2%) | 4(1%) | - |
| Did not respond | 1 (<1%) | 0(0%) | 0(0%) | 1(<1%) | - |
| **Level of Difficulty of Hormonal Therapy Decision** | | | | | |
| Somewhat/Very Difficult | 185 (19%) | 41(15%) | 87(16%) | 57(17%) | 0.052 |
| Neutral | 144 (15%) | 37(14%) | 74(14%) | 33(10%) | |
| Somewhat/Very Easy | 539 (55%) | 110(41%) | 254(47%) | 175(52%) | |
| Did not respond/Not Asked | 115 (12%) | 80(30%) | 128(24%) | 69(21%) | |
| **Preferred Treatment Decision-making Roles** | | | | | |
| Dr should make the decision using all that is known about treatments | 26 (2%) | 4(1%) | 12(2%) | 10(3%) | 0.09 |
| Dr should make decisions but strongly consider patient's opinion | 258 (23%) | 72(27%) | 110(20%) | 76(23%) | |
| Dr and patient should make decisions together on an equal basis | 435 (38%) | 82(31%) | 224(41%) | 129(39%) | |
| Patient should make decision but strongly consider doctor's opinion | 373 (33%) | 98(37%) | 175(32%) | 100(30%) | |
| Patient should make the decision using all they know or learn about treatments | 53 (5%) | 12(4%) | 22(4%) | 19(6%) | |
| **Accompanied to Dr (Y)** | 873 (76%) | 215(19%) | 414(36%) | 244(21%) | 0.44 |
| **Helped in making treatment decision (Y):** | 621 (54%) | 100(37%) | 246(45%) | 178(53%) | 0.005 |
| **Helped in making treatment decision by (circle all that apply):** | | | | | |
| Husband/partner | 347 (55%) | 104(62%) | 174(59%) | 66(42%) | - |
| Parent/child/Grandchild | 220 (35%) | 44(26%) | 92(31%) | 84(54%) | - |
| Other relative | 156 (25%) | 50(30%) | 73(25%) | 32(21%) | - |
| Other medical Professional | 24 (4%) | 6(4%) | 11(4%) | 7(4%) | - |
| Other | 203 (33%) | 54(32%) | 101(34%) | 48(31%) | - |

### Table 3

Continuously measured variables and differences by age related to treatment decision process and considerations, psychosocial factors, provider communication and involvement among women with non-metastatic breast cancer interviewed in the BQUAL Study, 2006-2010 (n=1145)

| | All (N=1,145) | | | Age <50 (N=268, 23%) | Age 50-64 (N=543, 47%) | Age ≥ 65 (N=334, 29%) | |
|---|---|---|---|---|---|---|---|
| ***Treatment Considerations*** | **Mean (SD)** | **Potential Range** | **Actual Range** | **Mean (SD)** | **Mean (SD)** | **Mean (SD)** | ***pvalue*** |
| **Decision-making considerations for Chemotherapy:** | | | | | | | |
| Physical | 0.7 (0.8) | 0-2 | 0-2 | 0.7(0.8) | 0.7(0.8) | 0.8(0.8) | 0.06 |
| Negative balance | 1.6 (1.4) | 0-5 | 0-5 | 1.2(1.3) | 1.5(1.4) | 2.0(1.3) | <0.0001 |
| Positive balance | 2.4 (1.0) | 0-3 | 0-3 | 2.7(0.7) | 2.4(1.0) | 2.0(1.1) | <0.0001 |
| Concrete considerations | 1.1 (1.2) | 0-4 | 0-4 | 1.2(1.2) | 1.0(1.2) | 1.1(1.2) | 0.39 |
| Family and friends | 0.4 (0.5) | 0-1 | 0-1 | 0.4(0.5) | 0.4(0.5) | 0.3(0.5) | 0.12 |
| **Decision-making considerations for Hormonal Therapy:** | | | | | | | |
| Physical | 0.6 (0.5) | 0-1 | 0-1 | 0.6(0.5) | 0.6(0.5) | 0.6(0.5) | 1.0 |
| Negative balance | 1.1 (1.3) | 0-5 | 0-5 | 1.0(1.3) | 1.1(1.3) | 1.3(1.4) | 0.01 |
| Positive balance | 2.7 (0.7) | 0-3 | 0-3 | 2.8(0.5) | 2.7(0.7) | 2.5(0.8) | <0.0001 |
| Concrete Considerations | 0.8 (1.0) | 0-3 | 0-3 | 0.8(1.1) | 0.7(1.0) | 0.8(1.0) | 0.58 |
| Family and friends | 0.3 (0.5) | 0-1 | 0-1 | 0.3(0.5) | 0.3(0.5) | 0.3(0.5) | 0.99 |
| *Psychosocial Factors* | | | | | | | |
| **Attitude towards Chemotherapy** | 2.9 (0.6) | 1-4 | 1-4 | 3.0(0.5) | 2.9(0.6) | 2.7(0.6) | <0.0001 |
| You are less likely to have the cancer come back if you have chemotherapy | 3.0 (1.0) | 1-4 | 1-4 | 3.2(1.0) | 3.0(1.0) | 2.7(1.1) | <0.0001 |
| Chemotherapy does not help you live longer | 1.9 (1.1) | 1-4 | 1-4 | 1.7(1.0) | 1.9(1.0) | 2.0(1.1) | 0.001 |
| Chemotherapy could cause long-term health problem | 2.8 (1.0) | 1-4 | 1-4 | 2.7(1.0) | 2.8(0.9) | 2.8(1.0) | 0.06 |
| Chemotherapy is not as effective in older women as it is in younger women | 1.7 (1.0) | 1-4 | 1-4 | 1.7(0.9) | 1.7(1.0) | 1.9(1.0) | 0.01 |
| Chemotherapy kills all remaining cancer cells | 2.7 (1.1) | 1-4 | 1-4 | 2.9(1.0) | 2.7(1.1) | 2.5(1.0) | 0.0002 |
| Chemotherapy is experimental | 1.9 (1.0) | 1-4 | 1-4 | 1.8(1.0) | 1.9(1.0) | 2.0(1.1) | 0.35 |
| The side effects of chemotherapy are worse than the disease | 2.2 (1.2) | 1-4 | 1-4 | 2.1(1.2) | 2.1(1.1) | 2.4(1.1) | 0.0007 |
| **Attitude towards Hormonal Therapy** | 2.9 (0.6) | 1-4 | 1-4 | 2.9(0.6) | 3.0(0.5) | 2.9(0.6) | 0.054 |
| You are less likely to have the cancer come back if you have Hormonal Therapy | 3.1 (0.9) | 1-4 | 1-4 | 3.1(0.9) | 3.2(0.9) | 3.1(1.0) | 0.09 |

| | All (N=1,145) | | | Age <50 (N=268, 23%) | Age 50-64 (N=543, 47%) | Age ≥ 65 (N=334, 29%) | |
|---|---|---|---|---|---|---|---|
| ***Treatment Considerations*** | **Mean (SD)** | **Potential Range** | **Actual Range** | **Mean (SD)** | **Mean (SD)** | **Mean (SD)** | ***pvalue*** |
| Hormonal Therapy does not help you live longer | 1.9 (1.0) | 1-4 | 1-4 | 1.8(1.0) | 1.7(1.0) | 2.1(1.1) | <0.0001 |
| Hormonal Therapy could cause long-term health problem | 2.4 (0.9) | 1-4 | 1-4 | 2.5(0.9) | 2.5(0.9) | 2.3(1.0) | 0.02 |
| Hormonal Therapy is not as effective in older women as it is in younger women | 1.7 (0.9) | 1-4 | 1-4 | 1.9(1.0) | 1.5(0.8) | 1.8(1.0) | <0.0001 |
| Hormonal Therapy kills all remaining cancer cells | 1.9 (1.0) | 1-4 | 1-4 | 1.8(1.0) | 1.9(1.1) | 2.0(1.0) | 0.47 |
| Hormonal Therapy is experimental | 2.1 (1.0) | 1-4 | 1-4 | 2.0(1.0) | 2.1(1.0) | 2.1(1.0) | 0.45 |
| The side effects of Hormonal Therapy are worse than the disease | 1.6 (0.9) | 1-4 | 1-4 | 1.6(0.9) | 1.5(0.9) | 1.6(0.9) | 0.41 |
| **Treatment Expectations for Chemotherapy** | | | | | | | |
| Fatigue | 6.7 (2.2) | 0-10 | 0-10 | 6.4(2.2) | 6.8(2.2) | 6.6(2.2) | 0.02 |
| Nausea | 5.7 (2.8) | 0-10 | 0-10 | 5.5(2.8) | 5.8(2.8) | 8.8(2.9) | 0.35 |
| Hearing loss | 1.3 (2.2) | 0-10 | 0-10 | 1.1(1.9) | 1.1(2.1) | 1.7(2.4) | 0.001 |
| Pain | 4.3 (2.8) | 0-10 | 0-10 | 4.1(2.6) | 4.3(2.8) | 4.4(2.9) | 0.45 |
| Side effects | 6.4 (2.5) | 0-10 | 0-10 | 6.5(2.5) | 6.5(2.5) | 6.3(2.6) | 0.71 |
| **Fatalism** | 19.6 (3.2) | 8-32 | 9-31 | 18.9(3.4) | 19.6(3.2) | 20.3(3.0) | <0.0001 |
| **Social Support** | 4.3 (0.7) | 1-5 | 1.4-5 | 4.3(0.7) | 4.3(0.7) | 4.2(0.6) | 0.76 |
| Emotional/Information Support | 34.1 (4.9) | 8-40 | 8-40 | 34.4(4.7) | 34.3(4.9) | 33.5(4.9) | 0.03 |
| Tangible Support | 17.2 (3.2) | 4-20 | 4-20 | 17.2 (3.2) | 17.3(3.3) | 17.1(3.1) | 0.70 |
| Affectionate Support | 13.7 (2.2) | 3-15 | 3-15 | 13.7(2.2) | 13.7(2.2) | 13.6(2.1) | 0.84 |
| Positive Social Interaction | 12.9 (2.3) | 3-15 | 3-15 | 12.8(2.4) | 12.9(2.3) | 12.9(2.1) | 0.86 |
| **Structural Social Support** | 14.0 (13.9) | Write-in | 0 – 200 | 13.7(11.1) | 14.9(15.9) | 13.0(10.0) | 0.11 |
| *Provider-related Factors and Communication* | | | | | | | |
| **Patient Involvement in Treatment Decision** | 12.5 (2.5) | 3-18 | 4-18 | 12.4(2.4) | 12.6(2.6) | 12.4(2.4) | 0.28 |
| The doctor gave me the responsibility for deciding how to deal with my breast cancer | 4.3 (1.1) | 1-6 | 1-6 | 4.2(1.1) | 4.3(1.2) | 4.3(1.0) | 0.56 |
| The doctor asked me to choose a treatment for my breast cancer | 3.6 (1.2) | 1-6 | 1-6 | 3.5(1.2) | 3.7(1.3) | 3.7(1.1) | 0.19 |
| The doctor gave me all the information needed about my breast cancer | 4.6 (1.0) | 1-6 | 1-6 | 4.6(1.0) | 4.7(1.0) | 4.5(1.0) | 0.08 |
| **Provider Communication for Chemotherapy** | 18.0 (3.6) | 4-24 | 4 - 24 | 18.1(3.5) | 18.3(3.5) | 17.3(3.6) | 0.0004 |
| The doctor gave you enough information to make your own decision about chemotherapy treatment | 4.8 (1.0) | 1-6 | 1-6 | 4.8(1.0) | 4.8(1.0) | 4.6(1.0) | 0.08 |

| | All (N=1,145) | | | Age <50 (N=268, 23%) | Age 50-64 (N=543, 47%) | Age ≥ 65 (N=334, 29%) | |
|---|---|---|---|---|---|---|---|
| ***Treatment Considerations*** | **Mean (SD)** | **Potential Range** | **Actual Range** | **Mean (SD)** | **Mean (SD)** | **Mean (SD)** | ***pvalue*** |
| The doctor fully explained the benefits of chemotherapy. | 4.6 (1.1) | 1-6 | 1-6 | 4.7(1.0) | 4.7(1.0) | 4.4(1.1) | <0.0001 |
| The doctor fully explained the risks of chemotherapy | 4.4 (1.1) | 1-6 | 1-6 | 4.5(1.1) | 4.5(1.1) | 4.2(1.2) | 0.0006 |
| The doctor did not ask your opinion about taking chemotherapy. | 2.8 (1.2) | 1-6 | 1-6 | 2.8(1.2) | 2.7(1.2) | 2.8(1.2) | 0.15 |
| **Provider Communication for Hormonal Therapy** | 15.5 (2.7) | 4-24 | 4-24 | 15.3(2.9) | 15.8(2.5) | 15.3(2.7) | 0.04 |
| The doctor gave you enough information to make your own decision about Hormonal Therapy | 4.4 (1.1) | 1-6 | 1-6 | 4.3(1.2) | 4.4(1.1) | 4.3(1.1) | 0.36 |
| The doctor fully explained the benefits of Hormonal Therapy | 4.4 (1.0) | 1-6 | 1-6 | 4.3(1.0) | 4.5(1.0) | 4.3(1.0) | 0.02 |
| The doctor fully explained the risks of Hormonal Therapy | 4.0 (1.1) | 1-6 | 1-6 | 3.9(1.1) | 4.1(1.1) | 3.9(1.1) | 0.05 |
| The doctor did not ask your opinion about taking Hormonal Therapy | 2.9 (1.2) | 1-6 | 1-6 | 2.9(1.2) | 2.8(1.3) | 2.9(1.1) | 0.77 |
| **Medical Mistrust** | 20.6 (7.1) | 13-65 | 3-49 | 21.0(7.2) | 20.6(7.3) | 20.3(6.6) | 0.45 |
| Suspicion | 9.2 (3.6) | 6-30 | 2-24 | 9.3(3.5) | 9.2(3.7) | 9.2(3.5) | 0.94 |
| Discrimination | 6.1 (2.7) | 3-15 | 2-15 | 6.3(2.7) | 6.2(2.9) | 5.9(2.4) | 0.21 |
| Lack of support | 5.3 (2.1) | 3-15 | 2-15 | 5.5(2.1) | 5.3(2.1) | 5.2(1.9) | 0.26 |