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Decision regret following treatment for localized breast cancer: is regret stable over time?

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Abstract

Background—While studies suggest most women have little regret regarding their breast cancer treatment decisions immediately following treatment, to date no studies have evaluated how regret may change over time.

Objective—To measure the stability of post-treatment decision regret over time among women with breast cancer.

Methods—Women diagnosed with breast cancer between August 2005 and May 2007 reported to the Detroit, Michigan or Los Angeles County Surveillance Epidemiology and End Results (SEER) registry completed surveys at 9 months following diagnosis (Time 1) and again approximately 4 years later (Time 2). A decision regret scale consisting of 5 items was summed to create two decision regret scores at both Time 1 and Time 2 (range: 0 to 20). Multivariable linear regression was used to examine change in regret from 9 months to 4 years. Independent variables included surgery type, receipt of reconstruction, and recurrence status at follow-up. The model controlled for demographic and clinical factors.

Results—The analytic sample included 1,536 women. Mean regret in the overall sample was 4.9 at Time 1 and 5.4 at Time 2 ($p < 0.001$). In the multivariable linear model, we found no difference in change in decision regret over time by surgery type. Reporting a new diagnosis of breast cancer at Time 2 was associated with 2.6 point increase in regret over time, compared to women without

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an additional diagnosis ($p=0.003$). Receipt of reconstruction was not associated with change in decision regret over time.

Conclusions—Decision regret following treatment was low and relatively stable over time for most women. Those facing an additional diagnosis of breast cancer following treatment may be at risk for elevated regret-related distress.

INTRODUCTION

There are nearly 3 million breast cancer survivors in the U.S. and over 200,000 women are newly diagnosed with breast cancer each year. (1) Decision making for surgical treatment in early stage breast cancer often requires the patient to make complex choices. For example, breast conserving therapy (lumpectomy plus radiation) and mastectomy have been shown to have equivalent survival outcomes, (2) yet each comes with different risks and benefits for the patient. In thinking about their surgical treatment options, women need to trade off issues related to body image (3) and anxiety, (4) among many others. (5) These decisions often require women to think about what is important to them at the time, as well as what may be important to them in the future. Importantly, because the majority of early stage breast cancer patients can expect to live for years, if not decades, following diagnosis, patients' feelings about their breast cancer treatment decision making may contribute to quality of life in survivorship. (6-8)

Regret is a construct used to describe the negative psychological and emotional state associated with the feeling that one's current situation would be preferable had a different path been chosen. (9) Measurement of regret related to treatment decision making is increasingly being used in health care research to assess the quality of the decision making process. (10) Anticipatory regret, or the worry that taking the wrong course of action may lead to regret in the future, has been hypothesized to be associated with decision making in cancer, (11) and research demonstrates patients tend to express more regret about inactions rather than actions. (12,13) Some research in breast cancer has shown patient preferences for more aggressive surgery to be associated with a desire for future "peace of mind" related to treatment decisions. (4) Thus, some patients may make decisions for more extensive treatment based on the sentiment that they do not want to later regret decisions related to their cancer care.

Prior research indicates that most women are largely satisfied with their treatment decisions, particularly around surgical decision making, and express low levels of decision regret (14-20). However, some vulnerable groups, such as Latinas with low acculturation, have been shown to express less satisfaction and significantly more decision regret compared to whites. (21) Furthermore, although some research has measured the stability of decision satisfaction among breast cancer patients over a short amount of time, (18) to date, we know little about women's feelings of decision regret beyond the phase of immediate treatment and recovery and into the survivorship period. There is no research that has assessed whether decision regret increases or decreases over time as a function of surgical decisions made at the time of diagnosis.

Consequently, the objectives for this study were three-fold. First, to characterize change in decision regret over time in a population-based cohort of breast cancer patients with localized disease, including increases, decreases and maintenance of initial decision regret. Second, to examine factors associated with change in decision regret over time, focusing specifically on whether change is associated with breast surgery type following diagnosis, or whether women had experienced a new diagnosis of breast cancer following their initial treatment. Finally, among those women who underwent unilateral or bilateral mastectomy as a component of their primary breast cancer treatment, to evaluate change in decision regret over time as a function of receipt of breast reconstruction.

We hypothesized that receipt of less extensive surgery following diagnosis (lumpectomy) would be associated with a significant increase in decision regret over time compared receipt of more extensive surgery following diagnosis (mastectomy). We also hypothesized that having a new diagnosis of breast cancer following initial treatment would be associated with increased regret over time. Finally, among women who underwent unilateral or bilateral mastectomy, we hypothesized that change in decision regret would differ significantly by reconstruction status.

METHODS

Sample selection and survey methods

Data for these analyses come from a cohort study of women newly diagnosed with breast cancer between July 2005 and February 2007 reported to either the Los Angeles County or Metropolitan Detroit Surveillance Epidemiology and End Results (SEER) tumor registries. Study recruitment consisted of a 20% random sample of non-Latina white women in both study sites. In both Detroit and Los Angeles all eligible black patients were accrued, and all eligible Black and Latina patients were accrued in Los Angeles. Asian women were not included in this study, because SEER does not allow for concurrent enrollment of patients into studies and there was an ongoing study of Asian breast cancer patients at the LA site during the time of study recruitment. Other exclusions included women with inflammatory breast cancer or metastatic disease, and those who were unable to complete a survey in either English or Spanish.

Sampling and survey methods have been published previously in further detail. (21-25) Briefly, following notification of physicians of record regarding our intent to contact their patient(s), eligible patients were mailed an introductory letter, questionnaire, return envelope and a \$10 gift approximately 6 to 9 months post-diagnosis. Patients with a Spanish surname were mailed all materials in both English and Spanish. (26) A modified version of the Dillman survey method was used to maximize response rates. (27) After three weeks, non-responders received a follow-up post card, followed by a telephone call. For those with Spanish surnames, this phone call was done by a bilingual interviewer. Respondents to the first survey were re-surveyed again approximately 4 years later. The same modified Dillman method was used at Time 2. See Figure 1 for our study flow diagram.

Measures

Decision regret—The primary outcome measure for this analysis was decision regret, measured using the same five-item scale at both Time 1 and Time 2. This scale was based on prior work by Brehaut et al., (28) yet for the purposes of our study, items were customized to reflect elements specific to breast cancer surgery decision making. Prior to survey administration, items were piloted in breast cancer patients and survivors in order to establish content validity. Items were framed in response to the prompt “If I had to do it over...” and were scored on five-point Likert-type scales, ranging from “strongly disagree” (0) to “strongly agree (4).” The five items are as follows (higher scores indicate more regret):

- I would make a different decision about what type of surgery to have (that is, whether to have a lumpectomy or mastectomy)
- I would choose a different surgeon to perform my surgery
- I would take more time to make decisions about my treatment
- I would consult more doctors about my treatment before making a decision
- I would do everything the same (reverse-coded)

Psychometric evaluation of these five items demonstrated a single factor at both Time 1 and Time 2, with relatively high internal consistency (Cronbach’s α : 0.84 at both). Consequently, total regret summary scores were created for both Time 1 and Time 2. Scores consisted of the summed total of response scores from the five decision regret measures.(23) These scores ranged from 0 (least possible regret) to 20 (most possible regret) at each time point.

Independent variables—Type of breast cancer surgery at Time 1 was provided by participant self-report. This was categorized as lumpectomy, unilateral mastectomy, or bilateral mastectomy.

Whether or not the patient had an additional episode of breast cancer following the Time 1 survey was obtained by a question in the Time 2 survey “Have you had another episode of breast cancer since you were first diagnosed and treated?” (yes vs. no).

Receipt of reconstruction (among women who underwent unilateral or bilateral mastectomy only) was provided by participant self-report (yes vs. no).

Additional independent variables—A number of control measures were included in this analysis, including race/ethnicity (and acculturation), age, income, marital status, education, cancer stage and number of comorbidities.

The Short Acculturation Scale for Hispanics (SASH), (29) a language-based measure, was used to measure acculturation. Based on responses to this measure, Latina participants were divided into groups of high and low English proficiency This resulted in four racial/ethnic categories: white, black, high-acculturated Latinas (high English proficiency), and low-

acculturated Latinas (low English proficiency). This measure has previously been used to account for Latina acculturation using these data. (21,26,30-32)

Age was categorized as “50 years or less,” “50 to 64 years,” and “65 years and older,” and marital status was categorized as “married or living with a partner” versus “not married or not living with a partner.” Education was categorized as “high school diploma or less” versus “some college or more.” Annual income was categorized as “less than \$20,000,” “\$20,000 to \$69,999,” “\$70,000 or more,” or “don’t know, refused or missing.” Number of comorbidities served to account for participant health status. This measure was patient-reported and categorized as none, 1, or 2 or more.

Severity of disease was categorized in our analysis as Stage 0, Stage I-II, or Stage III at diagnosis based on American Joint Committee on Cancer (AJCC) staging information provided by SEER.

This study was approved by the Institutional Review Boards of the University of Michigan, the University of Southern California, and Wayne State University.

Sampling and survey weights

To allow our statistical inferences to be more representative of the original targeted population and reduce non-response bias, we applied complex survey weights to the calculation of percentages, means, standard deviations (SD), t-tests and multivariable regression analyses described previously with the ‘survey’ package in R. The survey weights were calculated to account for differential probabilities of sample selection and non-response (for example, patients who did not respond to both surveys were more likely to be black—35.2% v. 26.7%, $p<0.001$; to be Latina—17.2% vs. 13.3%, $p=0.002$; to have stage II-III disease—54.9% v. 37.8%, $p<0.001$; and to have undergone mastectomy—37.5% vs. 30.8%, $p<0.001$). (33) The jackknife resampling method was used to obtain estimates that are robust towards non-normal distributions.

Statistical analysis

To describe the sample characteristics, we reported the number of patients in each patient subgroup with the corresponding weighted percentage. The weighted mean and standard deviation of decision regret were reported for both Time 1 and Time 2. Weighted t-tests were then used to compare the change in decision regret from Time 1 to Time 2 by the sample overall and each variable subcategory. Multivariable linear regression was used to model the decision regret at Time 2, controlling for decision regret at Time 1, as a function of two key independent measures: surgery type at Time 1 (lumpectomy, unilateral mastectomy, or bilateral mastectomy) and report of new diagnosis of breast cancer at Time 2, while adjusting for race/ethnicity (and acculturation), age, income, education, cancer stage, comorbidities at Time 2. Driven by our hypothesis that the relationship between surgery type and change in decision regret could differ between women who had experienced a new diagnosis of breast cancer versus those who had not, we included an interaction term between surgery type and a new diagnosis of breast cancer at Time 2, controlling for all covariates as were in the prior model.

Finally, restricting the sample only to those women who reported receipt of either unilateral mastectomy or bilateral mastectomy and for whom we had data on receipt of reconstruction, we modeled decision regret at Time 2, controlling for decision regret at Time 1, as a function of receipt of breast reconstruction. Because we hypothesized that change in decision regret over time may significantly differ by both type of mastectomy (unilateral or bilateral) and whether or not the participant received reconstruction, we ran a final model including an interaction between mastectomy type and reconstruction receipt.

We originally hypothesized that participant concern about breast cancer recurrence (assessed at Time 1) may be associated with both surgery type at Time 1 as well as change in decision regret over time. We included a measure of concern about recurrence in preliminary adjusted models. This was a composite score based on two questions: “When decisions were being made about your surgery, how important was it that the type of surgery you had...” 1) “would keep you from worrying about the cancer coming back?” and 2) “would reduce the chances of the cancer coming back?” These were both scored on five point scales, ranging from “not at all important” to “very important.” Responses were summed to create a composite score ranging from 0 as “least concern” to 8 as “most concern.” Consistent with prior treatment of this measure, we dichotomized scores of ≥ 7 as “high concern about recurrence” versus ≤ 6 as “average or low concern about recurrence.” (21) This measure was not independently significant in adjusted models, and removal did not alter results. Consequently, in the interest of model parsimony, participant concern about breast cancer recurrence was not included as a covariate in final adjusted models.

All analyses were conducted using R package version 2.13. (34)

RESULTS

The analytic sample included 1,536 women for whom both Time 1 and Time 2 survey data was available. The response rate for the Time 1 survey was 73% and was 68% for the Time 2 survey (Figure 1). Using weights, 42% (n=728) of the sample was white, 17% was black, 19% were high-aculturated Latinas, and another 20% were low-aculturated Latinas. The majority of participants (60%) reported undergoing lumpectomy (with radiation), 31% reported receipt of unilateral mastectomy, and 9% reported having undergone a bilateral mastectomy. Among participants who reported receipt of unilateral or bilateral mastectomy and for whom we had complete data on breast reconstruction (n=336), 57% reported having breast reconstruction (n=234). Of those women who underwent unilateral mastectomy, 52% had reconstruction (n=141), and of those women who underwent bilateral mastectomy, 83% (n=71) had reconstruction. Only 6% of our sample (n=86) reported a second diagnosis of breast cancer by the Time 2 survey. Further sample characteristics are presented in Table 1.

Table 2 presents mean regret scores at Time 1 and Time 2 and associated p-values for change in regret from Time 1 to Time 2 by independent variables. Mean regret at Time 1 for the overall sample was significantly different compared to mean regret at Time 2 (4.90 vs. 5.40, respectively, $p < 0.001$, out of a maximum of 20). While there was no significant change in mean regret score between Time 1 and Time 2 for women reporting receipt of unilateral mastectomy or bilateral mastectomy, women reporting receipt of lumpectomy

reported a change in decision regret from 4.38 points at Time 1 to 5.21 points at Time 2 ($p<0.001$) in the bivariate analysis.

Among women who underwent either unilateral or bilateral mastectomy, mean decision regret at Time 1 was 4.43 for those who also underwent reconstruction, compared to 7.37 for those who did not ($p<0.001$). Change in decision regret from Time 1 to Time 2, however, was not significant for either group.

Mean regret scores increased significantly from Time 1 to Time 2 both for participants reporting a new diagnosis of breast cancer at Time 2 (from 5.83 to 7.99; $p=0.006$) as well as those who did not report an additional diagnosis of breast cancer at follow-up (from 4.86 to 5.26; $p<0.001$). However, the increase in decision regret from Time 1 to Time 2 was larger for those women reporting a new diagnosis, versus those who did not.

Mean regret at Time 1 for white participants was 3.47, compared to 4.77 for black participants, 5.17 for high-acclulturated Latinas, and 7.79 for low-acclulturated Latinas ($p<0.001$). Decision regret increased significantly from Time 1 to Time 2 for white participants ($p=0.001$) and black participants ($p=0.005$), but there was no significant change from Time 1 to Time 2 for low- or high-acclulturated Latinas in unadjusted analyses.

Mean regret increased from 5.09 to 5.89 for participants reporting 2 or more comorbidities ($p<0.001$). However, mean regret did not change significantly from Time 1 to Time 2 for those participants either with one or no comorbidities. Participants who were not married or partnered reported significantly increased regret over time, from 5.06 points at Time 1 to 5.71 points at Time 2 ($p=0.002$). There was no significant change in mean regret from Time 1 to Time 2 for married participants in unadjusted analysis.

Results of the fully adjusted model of change in decision regret from Time 1 to Time 2 in the overall sample are presented in Table 3. There was no association between receipt of unilateral mastectomy or bilateral mastectomy and change in decision regret over time, relative to lumpectomy. Reporting a new diagnosis of breast cancer at Time 2 was associated with a 2.55 point increase in decision regret from Time 1 to Time 2 ($p=0.003$) compared to women who did not report a new diagnosis of breast cancer. Reporting two or more comorbid conditions (versus none) at Time 2 was also associated with a 1.34 point increase in decision regret over time ($p<0.001$). Relative to white participants, low-acclulturated Latinas reported an average 1.78 point increase in decision regret from Time 1 to Time 2 ($p<0.001$). There were no significant changes in decision regret over time by age, income, education, marital status, or disease stage.

In the multivariable model including the interaction term (not shown), the association between surgery type and change in decision regret between Time 1 and Time 2 did not vary significantly by whether or not a report of a new diagnosis of breast cancer at Time 2 occurred.

Table 4 presents the adjusted linear model of decision regret at Time 2, controlling for regret level at Time 1, restricted to those participants who underwent either unilateral or bilateral mastectomy and for whom we had complete data on receipt of reconstruction. In this model

there was no significant association between type of mastectomy (unilateral versus bilateral) or report of a new diagnosis of breast cancer at Time 2 and change in decision from Time 1 to Time 2. Receipt of breast reconstruction was also not associated with change in decision regret in this model.

Table 4 also presents a model including an interaction between surgery type and receipt of reconstruction. The association between surgery type and change in decision regret differed by 2.84 points depending on reconstruction receipt ($p=0.013$): women who underwent bilateral mastectomy and reconstruction reported significantly increased decision regret over time, relative to those who underwent unilateral mastectomy and did not have reconstruction.

DISCUSSION

In our study of change in decision regret over time among women with localized breast cancer, we found low levels of decision regret both 9 months following diagnosis, as well as 4 years later. While there was a statistically significant increase in decision regret from Time 1 to Time 2 in the overall sample, this increase was small. This result is consistent with prior studies of decision regret and/or satisfaction measured earlier in the course of breast cancer treatment that suggest that most women report being satisfied with their treatment and have low levels of decision regret. (14,21)

Our results add to this literature by documenting that this trend tends to stay relatively stable over time, as we found that most women did not shift significantly in their reported decision regret (either increase or decrease) by the Time 2 survey point. Specifically, we found no significant difference in change in decision regret over time by surgery type following diagnosis. We did, however, find a significant increase in decision regret associated with reporting a new diagnosis of breast cancer at Time 2. Thus, findings from our large and diverse population-based sample suggest that most women do not experience great increases in regret the further they are from their primary treatment, yet women who experience a new diagnosis of breast cancer following the completion of initial treatment may experience increasing feelings of regret related to their previous cancer-related decisions.

Our findings are consistent with other studies that found overall low levels of decision regret following initial treatment for breast cancer. (14,21) Published research on the trajectory of decision regret over time in this population, however, is limited. We were able to identify one study related to change in decision regret over a number of years in a cohort of women diagnosed with breast cancer. This study focused specifically on feelings of regret among younger patients (< 50 years). The authors found that decision regret remained low for most patients five years following diagnosis, however, having a recurrence of breast cancer and presence of anxiety during initial treatment were predictive of high decision regret five years later. (12) A number of other studies in this domain are specific to women not yet diagnosed with breast cancer, but with genetic mutations that put them at elevated risk for breast cancer (i.e. BRCA mutations). (16,35-37) These studies of decision regret related to prophylactic bilateral mastectomy have found low levels of regret both following surgery and continued low levels of regret up to 20 years later. (16) Similar studies in prostate cancer patients have

also found both low initial decision regret, (38) and maintenance of low regret over time. (39,40)

This collection of findings of both low and stable levels of decision regret over time is consistent with the theory of cognitive dissonance. This theory posits that individuals seek to reduce internal conflict by aligning cognitions and behaviors.(41) Applied in the context of breast cancer decision making, women living with the result of decisions made following diagnosis (i.e. mastectomy or lumpectomy) may be internally motivated to come to accept their prior decision. The result of this acceptance process would be a tendency towards either stable or lessening of feelings of decision regret over time.

Prior research has shown that breast cancer treatment decision making is largely motivated by the desire to avoid cancer recurrence, and many women report the desire for “peace of mind” as a major factor in surgical decision making. (4) However most women with early stage breast cancer overestimate their risk of breast cancer recurrence (42), as well as the risk of developing a new cancer in the opposite breast.. (43) While mastectomy rates for early stage breast cancer fell between 1995 and 2005, in recent years rates of both unilateral mastectomy and bilateral mastectomy have been increasing steadily. (44,45) Increasing use of bilateral mastectomy in the case where there is no contralateral breast cancer present is increasingly drawing attention for being a possible problem of overuse.. Moreover, bilateral mastectomy may pose significant risks and complications to the patient without commensurate medical benefit. (46,47) In our population-based study of women with localized breast cancer we found no significant differences in change in decision regret from 9 months to 4 years following diagnosis by breast cancer surgery type. This suggests that irrespective of the surgery women choose following diagnosis, they are unlikely to experience significant changes in decision regret.

Among women who undergo mastectomy, research has shown women are largely satisfied with their decision making in regards to breast reconstruction, (48) yet to date little has been known about the stability of these feelings over time. In our sub-analysis of change in decision regret from 9 months to 4 years following diagnosis among women who underwent either unilateral or bilateral mastectomy, we found no differences in change in decision regret over time by receipt of reconstruction. We did, however, find an interaction between type of mastectomy and reconstruction. Specifically, women with bilateral mastectomy who underwent reconstruction reported a significant increase in decision regret over time relative to those women who did not receive reconstruction following unilateral mastectomy. Regret at both time points, however, was substantially lower for women who underwent bilateral mastectomy with reconstruction than those women who underwent unilateral mastectomy without reconstruction. This suggests that that while regret may increase significantly over time for women who undergo bilateral mastectomy with reconstruction compared to those with unilateral mastectomy who do not, women with bilateral mastectomy and reconstruction have lower decision regret, overall.

Due to sample size limitations we did not analytically distinguish between types of reconstruction (e.g. tissue transfer, implants). Different types of reconstruction come with varying risks and benefits to the patient, many of which are borne out in the survivorship

period.(49) While our sample of women with both bilateral mastectomy and reconstruction was small, our findings suggest a need for further research in this population, particularly if use of bilateral mastectomy among women with localized breast cancer continues apace of the current trend.

Previous work has shown that young women with either a new or recurrent breast cancer are more likely to express some regret about their primary treatment decisions. (12) Thus, it is not surprising that in our sample, receipt of a new diagnosis of breast cancer at Time 2 was associated with a larger and significant increase in regret over time compared to those without an additional diagnosis. Participants faced with an additional diagnosis of breast cancer within a relatively short period of time following an initial diagnosis may be at risk for a number of psychosocial issues, including anxiety and depression. (50) Feelings of regret associated with former treatment decisions may compound patient distress. These patients may benefit from provider-led conversations aimed at assuaging guilt or excessive regret associated with prior decisions.

Our study was limited by the fact that our data collection tool did not differentiate between local recurrence, distant recurrence, or diagnosis of a new primary breast cancer. These three groups may experience different trajectories of regret related to initial treatment decisions, particularly surgery. We observed slightly fewer new diagnoses of breast cancer during follow-up than has been reported in prior studies. (51). Future research on changes in decision regret over time may benefit from longer analytic windows to accrue a more robust sample of women with secondary diagnoses of breast cancer in order to facilitate subgroup analysis.

We also observed a notable change in decision regret over time by race/ethnicity (and acculturation). Low-accultured Latinas reported significantly greater increases in decision regret from Time 1 to Time 2, relative to our white study participants. This is consistent with some prior literature (21) which showed higher decision regret immediately following treatment in this group, compared to whites. Results from our study confirm these previous findings, but further suggest that their decision regret may worsen over time. As suggested by others, reasons for higher decision regret in this group may be less associated with type of treatment received (as they were treated at the same rates with the same surgery types) than with the decision making process. Low-accultured Latinas may have had difficulty understanding information or comprehending the complexity of their treatment options following diagnosis. It is possible that dissatisfaction with the decision-making experience could increase over time, especially if they learned more about their decision options during the survivorship period. (31) While it is unclear to what extent increasing decision regret over time may contribute to disparities in quality of life between low-accultured Latinas and white breast cancer survivors, it is an area warranting further study. Our findings suggest low-accultured Latinas may uniquely benefit from clinical or psychosocial support related to decision-associated distress.

This study had several additional limitations. Our data come from two distinct urban areas, Detroit and Los Angeles, and therefore may not be generalizable to women in other dissimilar areas. However, national estimates of use of lumpectomy, unilateral mastectomy

and bilateral mastectomy in localized breast cancer are quantitatively similar to our study cohort. (52) While we had relatively high sample retention of study participants from Time 1 to Time 2, our study experienced some attrition. Experiences of regret or health status may have differed between those women who completed the study at both time points, versus those who were either lost to follow-up or declined to participate. Although we cannot address the bias arisen from differential attrition rates associated with unmeasured confounders, we have incorporated survey weights in all of our analyses to minimize the non-response bias attributable to measured variables. Moreover, while this study spans a three year follow-up period, we only have participant data for two distinct points in time. Consequently, we do not know whether decision regret may have changed in important ways at different points during the follow-up period. Further research examining changes in decision regret over time may benefit from more frequent follow-up contacts with participants.

Our study is additionally limited by our use of a novel measure of decision regret. This constrains our ability to compare our results with other studies of decision regret following breast cancer treatment. Unlike a global measure of decision regret, our measure was designed to evaluate specific and important aspects of decision making for breast cancer surgery. Thus, we may have been able to more accurately capture women's feelings of decision regret specific to their surgical decision making.

Finally, our finding that low-acclulturated Latinas had the most decision regret at both time points may be partially attributable to acquiescence bias (the tendency to respond consistently in one direction – either positively or negatively – regardless of actual feelings about the content of the survey item), as acquiescence bias is more common among survey respondents with lower levels of acculturation. (53) In our study, higher scores on four measures of regret were designated by the endorsement of “strongly agree,” which may be considered an acquiescent response. We did have one reverse-coded question, and the fact the low-acclulturated Latinas endorsed this in the opposite direction suggests they were appropriately responding to the questions. However, future work examining decision regret among low-acclulturated populations should attempt to adjust for this potential source of bias.

Conclusions

In our diverse, population based sample of localized breast cancer patients, decision regret was low at both 9 months and 4 years following diagnosis, and reported feelings of decision regret were stable over time for most patients. Irrespective of surgery type, most women with localized breast cancer are unlikely to experience increasing decision-related regret following diagnosis into the survivorship period. However, women who receive a second diagnosis of breast cancer following initial treatment with curative intent may be at risk of regret-related distress.

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Figure 1.

Table 1
Sample Characteristics

	N* (% [†]) N = 1,536
Race	
White	728 (41.9)
Black	380 (17.1)
Latina (high-acculturated)	191 (19.2)
Latina (low-acculturated)	203 (20.0)
Age (years)	
Under 50	399 (27.8)
50-64	697 (43.6)
65 and over	434 (28.5)
Income (annual)	
Less than \$19,999	257 (18.5)
\$20,000 - \$69,999	576 (36.4)
\$70,000 or more	428 (25.1)
Don't know/refused/missing	275 (20.0)
Education	
High school diploma or less	564 (41.7)
Some college or more	945 (56.1)
Marital status	
Married/partnered	875 (57.0)
Not married/not partnered	641 (41.4)
Comorbidities (number at Time 2)	
0	264 (17.9)
1	340 (21.3)
2 or more	860 (56.5)
Surgery type	
Lumpectomy	997 (60.8)
Unilateral mastectomy	390 (28.7)
Bilateral mastectomy	106 (7.7)
New diagnosis of breast cancer at Time 2 (t2_a6)	
No	1446 (94.0)
Yes	86 (5.6)
Stage	
Stage 0	381 (18.2)
Stage I-II	1002 (69.0)

	N* (% [†]) N = 1,536
Stage III	144 (12.0)
Reconstruction (among women with mastectomy only)	
Yes	228 (41.0)
No	148 (31.6)

* N and weighted % values do not add up to 1536 (100%) due to missing values

[†] Weighted % values weighted by disproportionate survey sampling and non-response

Table 2
Mean regret scores (range 0-20) at Time 1 and Time 2

N = 1536	Time 1		Time 2		
	Mean	SD	Mean	SD	p *
Overall	4.90	4.71	5.40	4.89	<0.001
Race					
White	3.47	4.04	4.09	4.53	0.001
Black	4.77	4.19	5.46	4.68	0.005
Latina (high-acclimated)	5.17	4.47	5.54	4.78	0.241
Latina (low-acclimated)	7.79	5.28	8.14	4.85	0.738
Age (years)					
Under 50	5.43	4.85	5.83	5.00	0.289
50-64	4.87	4.80	5.22	5.02	0.020
65 and over	4.42	4.37	5.26	4.54	0.011
Income (annual)					
Less than \$19,999	6.42	5.18	6.77	4.62	0.715
\$20,000 - \$69,999	4.78	4.45	5.37	4.83	0.008
\$70,000 or more	3.44	4.13	3.93	4.68	0.023
Don't know/refused/missing	5.63	4.85	6.15	5.00	0.145
Education					
High school diploma or less	5.99	4.94	6.34	4.90	0.275
Some college or more	4.09	4.36	4.69	4.77	<0.001
Marital status					
Married/partnered	4.79	4.59	5.20	4.82	0.074
Not married/not partnered	5.06	4.86	5.71	4.98	0.002
Comorbidities (number at Time 2)					
0	4.42	4.33	4.21	4.59	0.570
1	4.74	4.73	4.99	4.91	0.708
2 or more	5.09	4.84	5.89	4.91	<0.001
Surgery type					
Lumpectomy	4.38	4.35	5.21	4.83	<0.001
Unilateral mastectomy	6.11	5.03	6.01	5.01	0.684
Bilateral mastectomy	3.55	4.69	4.02	4.68	0.437
New diagnosis of breast cancer at Time 2					
No	4.86	4.63	5.26	4.78	<0.001
Yes	5.83	5.82	7.99	6.00	0.006
Stage					

N = 1536	Time 1		Time 2		
	Mean	SD	Mean	SD	p *
Stage 0	4.43	4.59	5.48	5.03	<0.001
Stage I-II	4.88	4.61	5.29	4.79	0.043
Stage III	5.84	5.33	5.86	5.30	0.816
Reconstruction (if mastectomy N=336)					
Yes	4.43	4.17	4.90	4.92	0.151
No	7.37	5.90	7.14	5.05	0.314

* Weighted T-Test comparing paired T1 and T2 regret for each subcategory

Table 3
Multivariable linear regression, change in decision regret from 9 months to 4 years
following diagnosis, all participants*

N = 1294		Pseudo R ² =0.33	
	Est.	p-value	
Race			
White			
Black	0.51	0.140	
Latina (high-acculturated)	0.51	0.200	
Latina (low-acculturated)	1.78	<0.001	
Age (years)			
Under 50			
50-64	-0.40	0.270	
65 and over	-0.64	0.131	
Income (annual)			
Less than \$19,999			
\$20,000 - \$69,999	-0.15	0.757	
\$70,000 or more	-0.21	0.693	
Don't know/refused/missing	0.30	0.554	
Education			
High school diploma or less			
Some college or more	0.28	0.384	
Marital status			
Married/partnered			
Not married/not partnered	0.35	0.239	
Comorbidities (number at Time 2)			
0			
1	0.60	0.151	
2 or more	1.34	<0.001	
Surgery type			
Lumpectomy			
Unilateral mastectomy	-0.18	0.589	
Bilateral mastectomy	-0.72	0.115	
Disease type			
Stage 0			
Stage I-II	-0.51	0.130	
Stage III	-0.45	0.451	

N = 1294	Pseudo R ² =0.33	
	Est.	p-value
New diagnosis of breast cancer at Time 2		
No		
Yes	2.55	0.003

* Multivariable model adjusted for all covariates, including Time 1 regret

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Table 4
Multivariable linear regression, change in decision regret from 9 months to 4 years
following diagnosis, women with unilateral or bilateral mastectomy only

N = 336	Model		Model with interaction [†]	
	Pseudo R ² =0.33		Pseudo R ² =0.34	
	Est.	p-value	Est.	p-value
Race				
White				
Black	−1.15	0.131	−1.17	0.121
Latina (high-acculturated)	−0.36	0.659	−0.31	0.696
Latina (low-acculturated)	−1.44	0.306	−1.53	0.279
Age (years)				
Under 50				
50-64	0.27	0.662	0.35	0.572
65 and over	−0.60	0.502	−0.51	0.561
Income (annual)				
Less than \$19,999				
\$20,000 - \$69,999	−0.68	0.575	−0.52	0.667
\$70,000 or more	−1.28	0.329	−1.14	0.381
Don't know/refused/missing	0.01	0.996	0.04	0.979
Education				
High school diploma or less				
Some college or more	−0.95	0.308	−0.93	0.311
Marital status				
Married/partnered				
Not married/not partnered	0.58	0.384	0.55	0.398
Comorbidities (number at Time 2)				
0				
1	−0.47	0.589	−0.55	0.521
2 or more	0.13	0.866	0.18	0.824
Disease type				
Stage 0				
Stage I-II	−0.88	0.280	−0.91	0.261
Stage III	−0.29	0.807	−0.37	0.755
New diagnosis of breast cancer at Time 2				
No				
Yes	0.51	0.755	0.32	0.840

N = 336	Model		Model with interaction [†]	
	Pseudo R ² =0.33		Pseudo R ² =0.34	
	Est.	p-value	Est.	p-value
Surgery type				
Unilateral mastectomy				
Bilateral mastectomy	-0.71	0.296	-2.95	0.002
Reconstruction				
No				
Yes	-0.42	0.587	-0.91	0.297
Surgery type* Reconstruction				
Unilateral Mastectomy + no Reconstruction				
Bilateral Mastectomy + Reconstruction	NA	NA	2.84	0.013

* Multivariable models adjusted for all covariates, including Time 1 regret

[†] Model includes interaction between mastectomy type (unilateral versus bilateral) and receipt of reconstruction (yes versus no)