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POST-TREATMENT REGRET AMONG YOUNG BREAST CANCER SURVIVORS

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Abstract

Objective—The study addresses: (1) what women regret about their breast cancer treatment five years later, and (2) what characteristics of disease and treatment predict post-treatment regret.

Method—Interviews were conducted with breast cancer survivors in the San Francisco Bay Area. Participants were interviewed following diagnosis. Five years later, women were asked whether they had any regrets about their cancer treatment (N=449). Qualitative analysis was used to identify regret content, and logistic regression was used to determine what characteristics of treatment predicted regret.

Results—42.5% of women in the sample regretted some aspect of treatment. The most common regrets were primary surgery (24.1%), chemotherapy and/or radiation (21.5%), reconstruction (17.8%), and problems with providers (13.1%). In addition, women regretted inactions (59.2%) (actions that they did not take) more than actions that they did take (30.4%). This represents a novel finding in the study of post-treatment regret, which has largely focused on regrets over actions. Quantitative analysis revealed that women who were anxious about the future (OR=1.32; $p=.03$) or had problems communicating with physicians (OR=1.26; $p=.02$) during treatment were more likely to express regret 5 years later. In addition, women with new or recurrent cancers 5 years later were significantly more likely to regret some aspect of their primary treatment (OR=5.81; $p<.001$).

Conclusion—This research supports addressing the psychosocial aspects of cancer care and improving physician-patient communication. Evidence is also provided for addressing the unique emotional needs of women with recurrent cancers, who may experience an undue burden of regret.

Keywords

cancer; oncology; regret; breast cancer; psychosocial; survivorship

BACKGROUND

Breast cancer is the most prevalent non-skin cancer among women in the United States. An estimated 12% of women will experience the anxiety and uncertainty associated with a breast cancer diagnosis at some point during their lives [1]. However, the death rate from breast cancer has declined over the past 15 years, due in part to treatment advances and increased screening. The 5-year relative survival rate for women who are diagnosed with breast cancer is eighty-nine percent, and these women can choose from a number of

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treatment options for their cancer. This trend has resulted in more than 2 million women with a history of breast cancer living in the United States who may experience long-term adverse physical and psychosocial consequences associated with their cancer treatment [1–3].

Due to an increase in available treatment options, breast cancer care is increasingly adopting shared or participatory decision-making, in which the patient may play a significant part in making medical decisions surrounding treatment [4]. The patient takes an active role in determining the course of treatment, and both the process and outcome of participation have a substantial impact on her physical and emotional health [5,6]. Many of the decisions surrounding breast cancer care, such as surgery and reconstruction, are also highly intimate and are tied to the woman's self-image, warranting the inclusion of patients' preferences. This approach can engender an increased sense of control over the illness and a sense of responsibility for the treatment decisions [7]. Patient decisions include whether to undergo a mastectomy or breast-conserving surgery (BCS), whether to pursue adjuvant therapies (chemotherapy, radiation, and hormone therapies), and whether to have reconstruction, including implants, latissimus dorsi flap, or transverse rectus abdominus myocutaneous (TRAM) flap. Additional choices concern the pursuit of psychosocial counseling and family involvement in the care process.

These decisions are assumed to be undertaken cautiously and with considerable attention to available information [6,8]. However, the complexity of these decisions combined with a sense of responsibility can potentially lead to regret among breast cancer survivors who feel that one or more of their treatment decisions were suboptimal. Additionally, cancer patients are commonly dissatisfied with the information they receive, and many fail to achieve their preferred role in medical decision-making [9–11]. In some decision-making scenarios, additional options can make a given situation less attractive rather than more so, and people may prefer another individual to make a decision for them [12]. An increased number of alternatives can also create an "intractable information problem" and raise the standards of what defines a successful outcome, overwhelming the person. As a result, a "failure to meet those standards in a domain containing multiple options encourages one to treat failures as the result of personal shortcomings rather than situational limitations, thus encouraging a causal attribution for failure that [is] 'depressogenic'" [13]. Accordingly, regret has received increased attention in the cancer decision-making literature [14–17].

Regret is a psychological construct defined as a negative cognitive and emotional state derived from comparing one's current state to what it might have been had one chosen a preferred, forgone alternative [18–22]. Regret is characterized as (1) aversive and actively avoided, and (2) distinct from emotions such as guilt, disappointment, shame, and general negative affect [15,23]. It results from intrapersonal harm [24] and thus tends to be strongly associated with a sense of responsibility or self-agency for the aversive outcome as well as self-blame [14,25–27].

Certain behavioral patterns are associated with regret. Experiencing regret may prompt a post-decision information search, whereby regretful individuals seek definite knowledge regarding the potential outcomes of forgone alternatives, even when the information has no actionable value [28]. In addition, a temporal pattern of regret is apparent; people tend to regret actions in the short term, but regret inactions over the longer term [18,29]. Individual differences and the outcomes of prior, related events have also been shown to affect whether people have more regret over actions or inactions [14,30,31]. Interestingly, people expect to regret acting against the suggestion of an influential other, such as a physician, more than they expect to regret compliance (and thus tend to act accordingly). In fact, regret is more

likely to be experienced when faced with a loss following compliance rather than reactance [32]. Therefore, regret potentially looms large in any given patient-provider interaction.

Despite its importance in medical practice, regret is a relatively new area in cancer care research [15,33]. Although some research has examined factors associated with regret in breast cancer care, the study of regret among prostate cancer patients is more prevalent because the treatment choices have not been shown to improve survival and often have many side effects [34,35]. In samples of prostate cancer patients, regret has been associated with poor quality of life, fear of recurrence, desiring more information from providers, and being of non-white race [36,37]. In addition, regret is empirically distinct from dissatisfaction with care [36,37]. The few studies that examine post-decision regret among breast cancer patients have noted a positive association with certain aspects of care, such as low participation in decision-making [38] and dissatisfaction with information [8,39], as well as psychosocial characteristics, such as poor body image and anxiety [40].

Notably, these studies have been largely cross-sectional, which may not accurately capture patterns of regret over the longer term [8,38–40]. Also, these studies tend to relegate the measurement of regret to one aspect of treatment, usually primary surgery, prophylactic mastectomy, or reconstruction. Regret over other aspects of treatment, such as adjuvant therapies and physician choice, has not received yet attention in the cancer care literature. In addition, only regret over actions (mastectomy, breast reconstruction) has been studied; research to date has not considered regret over inaction (no mastectomy, not taking tamoxifen, etc.)

The current study addresses two research questions: (1) What do women regret about their breast cancer treatment five years later, and (2) What are the treatment-related predictors of regret five years later? The five-year survival time point was chosen because the probability of women having a recurrence of their cancer decreases markedly, many women complete hormone therapy at that time, and five-year survival is often celebrated as important milestone. The first research question sets limits on the aspects of treatment that breast cancer survivors regret and provides insight into whether women regret previous actions or inactions more.

The second question examines post-treatment regret prospectively. Specifically, sociodemographic information, aspects of health and treatment, psychosocial characteristics, and physician-patient communication/decision-making qualities were measured during treatment and were used to predict regret five years later. Independent variables regarding tamoxifen use, reconstruction, and new or recurrent cancers since initial diagnosis were measured at 5 year follow-up. We hypothesized positive associations between regret and both poor health and recurrent/new cancer. In addition, we expected regret to be negatively associated with psychosocial indicators during treatment, including self-esteem and emotional support. Regret was also expected to be positively associated with worries about the future and problems with physician-patient interactions.

METHOD

Sample

The study made use of data from a larger, interview-based dataset regarding the psychosocial characteristics of young breast cancer survivors in the San Francisco Bay Area [3]. Young survivors were the target population of the original study because existing cancer survivorship research rarely stratifies results by age, and very few studies examine women who were diagnosed at a young age [41]. In the context of regret, young survivors experience the adverse consequences of their illness and treatment for a longer period of

time and may suffer additional role limitations associated with their employment, family life, and activity level. Women who participated in the study were identified through the Rapid Case Ascertainment Procedure (RCA) of the regional Cancer Tumor Registry. All of the women in the sample were diagnosed between 1994 and 1997, prior to their 51st birthday. This was the first cancer diagnosis for all participants. Following physicians' assent, a letter was sent to each woman. An interviewer followed up with a telephone call, and if the woman agreed, an appointment was scheduled for an in-person interview.

Half of the participants were interviewed within 2 months of their diagnosis, and the other half were interviewed 6–7 months following diagnosis. Seven hundred women were identified within 2 months of diagnosis. Of these, 137 were ineligible, 139 were not reached by the study deadline, 61 refused, 31 had scheduling conflicts, and 332 were interviewed. Of the 1659 women identified 6–7 months following diagnosis, 430 were ineligible, 392 could not be reached by the study deadline, 379 refused, 67 had scheduling issues, and 391 were interviewed. All regression analyses controlled for the difference in time since diagnosis. Five years later, 12 % of women interviewed at baseline had died, 17% were lost to follow-up, and 9% refused to participate, resulting in a final sample size of 449.

Measurement

Data used in the analysis were a subset of those collected for the original study. They were collected via in-person, structured interview (between 30 minutes and 2 hours), which included questions about psychosocial, physical, and spiritual wellbeing. Questions about the women's sociodemographic status and social relationships were also asked. The Institutional Review Boards of the collaborating institutions approved all recruitment and interview processes for data collection. The following measures were collected for this study:

Independent Variables

Sociodemographic Information: Age, race/ethnicity (White, Black, Latina, or Asian), marital status (married/partnered, single), education (years), and employment status (part-time, full-time, not working) were collected during the treatment interview.

Health and Treatment Characteristics: Type of treatment (Chemotherapy, radiation, chemotherapy and radiation; tamoxifen, none), and type of surgery (mastectomy-no reconstruction, mastectomy-reconstruction, lumpectomy) were collected as part of the interview. Stage of disease at diagnosis (In-situ, local, regional, remote) was obtained from the Greater Bay Area Tumor Registry. A continuous variable indicating the number of chronic conditions (including asthma, arthritis, diabetes, heart conditions, high blood pressure, gall bladder issues, ulcers, and other) was included. A dichotomous variable indicating whether the women had a new or recurrent cancer was collected during the 5-year interview and was also incorporated into analyses.

Psychosocial Characteristics

Perceived support from others: Emotional support from others (non-physician) was measured using the Likert-type Flamer Emotional Support Scale [42]. The scale includes 11 items that assess whether the women feel that they have been able to rely on someone to provide basic emotional support, such as helping with problems and talking about health, over the past 3 months. Cronbach's alpha was 0.91, and principal component analysis indicated that the scale is unidimensional [43].

Patient's self-esteem: The Rosenberg Self-Esteem Scale [44] measured women's self-concepts. The instrument contains 10 items that are rated on a Guttman scale and assess

feelings of self-worth and self-respect. The test-retest reliability is 0.85, and the scale negatively correlates with depression and shyness scales [44,45].

Mental and Physical Quality of Life: Subjective mental and physical health-related quality of life during treatment were measured using the physical and mental components of the SF-36, standardized scales of self-reported health derived from the Medical Outcomes Study [46]. The widely-used measures have been shown to have high construct validity, and reliability is generally high, exceeding 0.80 in most studies [47].

Worry about the future: Anxiety regarding the future was measured by one of three factor-derived subscales from a problems scale developed for breast cancer patients [48]. The subscale includes three items that measure whether each woman worries about what will happen to her in the future, whether she has difficulty in planning for the future, and whether she thinks about how long she might have to live.

Body Image: Women's body image was measured the second of three factor-derived subscales from a problems scale developed for breast cancer patients [48]. The subscale includes four items that measure, for example, if women feel self-conscious (embarrassed) about their body and find it difficult to look at themselves without clothing.

Patient-provider communication: Perceptions of patient-provider communication were measured by the third of three factor-derived subscales from a problems scale developed for breast cancer patients [48]. The subscale consists of four items that measure whether a patient has experienced difficulty getting information from a doctor, difficulty getting emotional support from a doctor, difficulty in understanding what doctors do or say, and uncertainty regarding doctors' medical decisions.

Shared decision-making: Patients' participation in their surgical decisions was measured via two, multiple choice questions. The first question elicited the patient's ideal level of participation in decisions (the doctor should make the decisions, the doctor should make the decisions but strongly consider my opinion, the doctor and I should make decisions together on an equal basis, I should make the decisions but strongly consider the doctor's opinion, and I should make the decisions). The second question assessed how the decisions regarding surgery were made using the same options phrased in the past tense. This variable was entered into the models both as two separate variables and as combined measures reflecting whether actual participation was congruent with preferences (versus more or less participation than desired).

Outcome—Post-treatment regret is the outcome of interest. Five years following their diagnosis, women were asked the open-ended question, "Looking back, is there anything about your treatment that you would do differently?" This question emphasizes the identification of a preferred, forgone alternative. In addition, the question identifies the survivor as the responsible party with the phrase "that *you* would do differently," thus reflecting the theoretical definition of regret. The question does not contain the word "regret" to preclude further engendering the emotion. Responses to this question were analyzed qualitatively and were also transformed into a dichotomous variable (1=regret, 0=no regret) for use as the dependent variable in multivariable models.

Analysis

To answer the first research question, qualitative analysis was used to examine the content of the open-ended question regarding regret [49]. Responses to the question were analyzed via open coding of the data to identify substantive categories of what women regret about

their treatment. The first author reviewed the data and developed a preliminary coding dictionary for response content in a manner similar to Clark, et al [34]. Affirmative responses were coded for one or more regretted aspects of treatment, and a supplementary code was thus developed to code the number of factors each woman regretted. Because the question elicited a yes/no response, the coders needed to make minimal qualitative distinctions between affirmative and negative responses. Impossible counterfactuals of the type “if X treatment option had been available at the time I was diagnosed, I would have chosen it” were coded as “no regret.”

Given the phrasing of the open-ended question, we were also concerned with whether the respondents expressed regret as we defined it. Although we were prepared for non-regret responses, such as dissatisfaction, in which women did not assume responsibility for the things they wished had been different (e.g., my doctor did X, which adversely affected me), women tended to phrase their responses beginning with “*I wish I had* chosen a different doctor...” or “*I would have* gotten a second opinion...,” recognizing their role as a decision-maker and responsible party. Conversely, women who expressed no regret phrased their responses as, “I made the right decisions” and “I don’t think so. I think they [providers] could have done some things differently...,” revealing that the women perceived the question as an inquiry into their evaluation of decisions they made. The few responses that expressed dissatisfaction without self-blame were coded as “no regret.”

In addition, responses were coded for whether women regretted an action, an inaction, or both (ambiguous/ listed something she would do instead of what she did choose) following Gilovich and Medvec [18]. The responses of women who expressed no regret were not coded for content because the interview protocol did not call for a prompt to elaborate on negative responses. As a result, the vast majority of the negative answers were a simple “no”; any elaboration was unprompted. Following the preliminary development of categories, a second coder reviewed 15% of the data and coded the content to establish interrater reliability and raise any identifiable issues. Differences were discussed and resolved, and the final coding dictionary was developed. The first author performed the final analysis, which informed the variables used in the quantitative analysis.

Quantitative analysis was performed using STATA Version 10 statistical software to address the second research question [50]. Descriptive statistics were used to assess sample characteristics. Chi-squared tests were used for dichotomous variables and t-tests were used for continuous variables to examine bivariate differences. Multivariable logistic regression was used to assess the association between characteristics of treatment and regret five years later. Results are presented as odds ratios with corresponding 95% confidence intervals.

RESULTS

Sample characteristics

At the time of treatment, participants were 44 years old on average, and were predominantly white (Table 1). The largest minority group in the sample was comprised of Asians (14.5%) followed by Hispanics (7.3%), Blacks (5.8%). Eighty-two percent of women were married or partnered. Participants were well-educated, averaging 15.3 years of school, and the majority was employed either full-time (59.2%) or part-time (20.5%). Women had less than one chronic condition on average (0.8).

Approximately half of the women were diagnosed with local disease, 17.9% had ductal carcinoma in situ, and 32.4% had regional or remote cancer. Over half had a mastectomy with (29.8%) or without reconstruction (23.2%), while 47.0% chose breast-conserving surgery. The largest proportion of women had chemotherapy only (38.1%), and 17.1% had

radiation only; 13.8% had both. Following primary treatment, 40.1% took tamoxifen for some period of time, and half of those women were still taking it at the time of the 5-year interview. Fourteen percent of women had a new or recurrent cancer five years after their primary breast cancer diagnosis.

While they were undergoing treatment, women exhibited a mean self-esteem scale score of 34.2 and a mean emotional support score of 40.9 (Table 2). They reported a mean mental quality of life score of 46.9 and a physical score of 45.9, and they expressed some worry about the future and body image concerns, averaging about two problems on each scale. In addition, they had more than one problem communicating with physicians on average. More than two thirds of women reported that they participated in surgical decision-making at the level they desired; 16.1% participated more than they would have liked, and 17.1% participated less than they preferred.

Sources of Regret

Five years after treatment, almost 43% of women expressed regret over some aspect of their treatment. Five percent of women regretted more than one aspect of treatment, with two aspects of treatment being the maximum number of regrets discussed (Table 3).

Action versus inaction—Preliminary interrater reliability for the action/inaction/ambiguous code was .81. Consistent with previous research on long-term regrets, the majority (59.2%) of participants who expressed regret did so over inactions (“I wish I had...”, “I would have...”) as opposed to actions (30.4%) (“I wish I hadn’t...”, “I wouldn’t have...”).

Regret of treatment—The regrets of the women in our sample sorted into eleven categories, and the percentage of the sample that regretted each aspect of treatment is summarized in Table 3. Interrater reliability for regret content was .96. The most common regret was associated with primary surgery. Typical responses included, “I would have had the other breast removed. My doctor talked me out of it at the time, and I gained weight with the chemo” and “I would have had a prophylactic mastectomy. I am unbalanced, and I do not miss my breast.” Some women who experienced a recurrence wondered whether a mastectomy would have prevented such an event. Other women said, “I would explore not having surgery” and

“I don’t know if I would’ve had the mastectomy. Psychologically, it’s difficult. I’m still grieving the loss of my breast. I was in such a panic at the time. I worried that it would grow more. I think I may have done the lumpectomy.”

Women also regretted their adjuvant therapies. They regretted having chemotherapy because it caused premature menopause and side effects (e.g., “Yes, I would not have done the chemo. It made me worse and weakened my immune system. It caused thyroid infections. I can’t get rid of the achy bones” and “My cousin had the same thing. I would not have had radiation so I could radiate if I had a recurrence. I was not informed.”).

In general, women felt ill-informed about the side effects and consequences of their treatment choices. Some of the women who expressed regret over having chemotherapy did not know beforehand that having children might not be possible in the future. Women also regretted not having chemotherapy and/or radiation (e.g., “The only thing I would’ve questioned: Was there any indicator the breast cancer was going to metastasize? I wonder if chemo would have prevented the metastasis.” and “I would insist on radiation. The oncologist told me I didn’t need it, but from my resources, I think it would be better.”). Less commonly, women voiced regret over taking or not taking tamoxifen. Some women

regretted the side effects of taking it (“fatigue and body odor”), while others, particularly those with recurrent cancers, said they would have taken it or stayed on it longer.

Reconstruction was another very common regret, and women said, for example, “I would not have reconstruction because I have no feeling in [my breast] and sometimes I have pain in it,” and “I would have had the reconstruction earlier.” Regrets over flap reconstruction were particularly common due to the aesthetic result and the difficult recovery:

“I possibly would not have gone with the TRAM flap. The stomach was what knocked me down for 7 or 8 months. The plastic surgeon should have given me more information on recovery and other issues regarding taking muscle and not just skin.”

Women also regretted significant problems communicating with physicians and said, “I would not have had the doctor I did. He had no bedside manner. He was awful.” and “I would have gotten a second opinion.” Women often mentioned physicians by name (e.g., “I would have picked a doctor who had more time. Dr. X did not see signs that I was having a bad reaction to chemo. My dose was too high. My neurologist knew what it was right away. If Dr. X took more time, he would have intervened sooner. The visits were too short.”). Although we did not code responses systematically, women who expressed no regret often spontaneously mentioned their positive physician-patient relationships as a contributing factor.

Many women wished they had been more pro-active in their care with respect to seeking information (“I would have pursued my suspicions sooner and been more assertive.”) and having a better understanding of the long-term effects and side effects of their treatment options (“I wish I had been informed about the risks of lymph node dissection.”). Less commonly, women regretted their health habits and self-care. For example, they wished they had taken more leave from work, improved their eating habits, and gotten more exercise. A small percentage of women regretted their choice not to solicit support from family and friends and were ambivalent about their decision not to join a support group. A small number of women also regretted their biopsy type (usually in cases of misdiagnosis) and their choice of a certain hospital for treatment or surgery. Only one woman wished she had considered participating in clinical trials.

Bivariate Analysis

Bivariate analysis of regret at 5-year survival with characteristics during treatment is presented in Table 4. White women were slightly more likely to express regret than non-white women, and Asian women were less likely to regret. In addition, women with a new or recurrent cancer were significantly more likely to regret some aspect of their primary treatment than cancer-free women. Psychosocial characteristics during treatment that were associated with regret five years later included poor body image, worry about the future, problems communicating with physicians, and poorer physical quality of life. Pairwise correlations between psychosocial variables were moderate and did not exceed $\pm .40$. Therefore, multicollinearity was not expected to be an issue.

Multivariable Logistic Regression

A logistic regression with regret as the dependent variable (Table 5) revealed that Asian women, relative to white women, were significantly less likely to express regret 5 years after treatment ($OR=.25$; $p<.001$). In addition, Hispanic women were marginally less likely to have post-treatment regret ($OR=.41$; $p=.07$). Women with better physical quality of life were also somewhat less likely to regret ($OR=.98$; $p=.06$). With respect to psychosocial indicators, women who worried about the future ($OR=1.32$; $p=.03$) or had problems

communicating with physicians during treatment ($OR=1.26$; $p=.02$) were more likely to regret some aspect of their treatment 5 years later. Finally, the odds that a woman with recurrent or new cancer expressed regret were almost 6 times those of a cancer-free woman ($p<.001$). No association was observed between regret and participation in decision-making, mental quality of life, self-esteem, emotional support, or body image. Regret was also not associated with types of treatment and surgery.

DISCUSSION

Forty-three percent of the sample expressed regret of some kind. This is generally higher than the prevalence of regret reported in previous studies, which range from 6% to 23% [8,32,34–37,39,40], with 47.1% reported in one study on prophylactic mastectomy [40]. In this study, regret was measured using an open-ended question regarding treatment in general. In contrast, previous research has measured regret of a specific type, such as regret due to contralateral prophylactic mastectomy [39], regret following breast reconstruction [8], and ambivalence regarding type of treatment for prostate cancer [34,37]. Therefore, the measure in the current study likely captures a broader range of post-treatment regrets.

Qualitative analysis revealed that women make precise and detailed attributions regarding their post-treatment regret. Many regrets were expressed over treatment, surgery, and reconstruction. However, an overarching theme in the responses was dissatisfaction with preliminary information regarding treatment alternatives and adverse side effects. This is unsettling in light of California legislation mandating that such information be given to patients, usually in the form of a pamphlet. Accordingly, research on a single type of treatment regret may fail to capture the range of treatment characteristics that can trigger regret. In this sample, regrets over inaction were most common. Women regretted not having mastectomies, failing to get second opinions, and neglecting to participate in their care. This finding is consistent with the temporal pattern of regret found in previous research [18]. However, the action/inaction distinction and the relative prevalence of regrets over inactions are novel findings in cancer care. Rather, research has focused on decisions made, such as having a prophylactic mastectomy and choosing breast reconstruction. This suggests a significant gap in the cancer literature on regret that warrants attention in future research, namely attention to regret over the failure to take action. This also underscores the significance of the results presented to the literature on post-treatment regret. Future research on post-treatment regret may focus as much on opportunities forgone as mistakes made.

Connolly and Reb [15] have outlined additional research priorities for cancer-related regret. They underscore the importance of understanding the role of anticipated regret in decision-making and the function of other aspects of the decision-making process, such as information gathering, in predicting regret. They also offer suggestions for regret reduction. For example, regret reduction could occur by identifying less damaging comparisons for patients experiencing regret and by developing clear decision justifications at the time a choice is being made. On the whole, additional research with implications for practice is needed to address the psychosocial concerns of cancer survivors.

From the results of the logistic regression, possible ethnic and cultural differences in regret are apparent. In previous work, minority groups have been grouped together as “non-white” [37,38] or the work has been done outside the United States [8,40]. As a result, there is little information on possible cultural patterns in post-treatment regret. One possible explanation for these findings may be captured in unmeasured aspects of decision making, such as including family in medical decisions. In this case, women of certain ethnic backgrounds might be reluctant to counter the wishes of family. Also, there may be certain cultural norms

against expressing regret. For example, dwelling on the past might be socially unacceptable or complaining after surviving a severe illness could indicate ingratitude. Still, additional research is necessary to better qualify cultural contributors to regret.

Patients' level of participation in decision making was not associated with regret in the sample. Although previous work by Lantz and her colleagues [38] found an association between participation in decision-making and regret in breast cancer care, that study was more narrowly focused and did not include other relevant psychosocial covariates. Despite the fact that the decision-making roles of physicians and patients were not associated with patients' subsequent regret in the current study, problems with physician-patient communication during treatment did have persistent effects over the survival period with respect to regret. This is expected given the findings of existing research on physician-patient communication. Generally, high quality physician-patient communication is associated with a greater incidence of physician-patient agreement on treatment [51,52]. In addition, physician-based communication interventions are associated with physicians' giving more clinically relevant information to the patient [52], asking more questions [53,54], using more nonverbal communication (eye contact, nodding) [54], and expressing positive affect [53,54]. Accordingly, problems communicating with physicians could impede positive experiences during treatment, leading to regret later in life.

Worrying about the future during treatment was also positively associated with regret five years later. This is consistent with previous work that has shown an association between anxiety and regret (moderated by coping style) among breast cancer patients [8]. Some anxiety during cancer treatment is expected. However, the psychosocial needs of breast cancer patients may require additional consideration by healthcare providers, particularly given the long term emotional consequences for women who experience an undue burden of anxiety while making medical decisions.

Finally, regret is much more prevalent among women with recurrent disease than cancer-free women. Although screening for psychological morbidity in cancer care has received increased attention in recent years [55], addressing the unique needs of women with recurrence has been the subject of less research. People with recurrent cancer, despite their considerable coping skills and resilience [56], report poorer health, more hopelessness, and more social difficulties than individuals with newly diagnosed disease [57–59]. The research presented here also suggests that these women may disproportionately identify faults and experience subsequent self-blame when reflecting on their primary treatment. Accordingly, programs and interventions designed for people with recurrent cancers may be needed to address the mental health needs of this vulnerable population [58].

Contrary to previous work on regret in cancer care [40], no association was observed between post-treatment regret and psychosocial characteristics, such as body image and mental health during treatment. This may be due to the fact that regret was measured five years after treatment, rather than simultaneously. Regret is likely to be a mutable cognitive-emotional construct [18,30], and psychological factors that are associated with regret in the short-term may not have persistent relationships with regret over the longer term. Further research is needed to better understand the temporal patterns of regret in cancer survivors and the associations with psychosocial factors [60].

Limitations

This work should be interpreted with attention to certain shortcomings. The sample was age 50 or less at diagnosis and was recruited from a specific region of the United States. Therefore, findings may not be generalizable to older women or women from other geographic areas. In addition, women were asked about their post-treatment regret five years

following treatment, creating potential bias due to loss to follow up and death. Nonetheless, using variables measured during treatment to predict later regret represents an improvement over cross-sectional research.

Potential omitted variables include personality characteristics that may contribute to a propensity to regret. Further research taking into account individual differences is necessary to better understand the psychological underpinnings of post-treatment regret in cancer survivors. However, regret in the sample was not correlated with self-esteem, a relatively stable construct, nor was it associated with body image complaints. This suggests that post-treatment regret may be relatively situation-specific. In addition, women did not use the open-ended regret question to vent about the problems with their treatment. Rather, they made concrete, specific statements regarding what they would change about their treatment.

A final limitation of the research involves the measure of regret. Because the question does not contain the word “regret,” there remains the possibility that the respondents expressed an emotion other than regret, such as dissatisfaction, that does not include self-blame. However, given the phrasing of the responses (“I would have..., I wish I had...”), we believe this is unlikely. The open-ended question is effective in identifying the scope of post-treatment regret and the action vs. inaction distinction. However, it does not directly target the intensity of regret. A Likert-type item or scale would better measure intensity. Still, published scales that purport to measure regret also have significant shortcomings [25,36]. Continuous scales may not make a discernable distinction between individuals who have regret and those who do not [36]. In addition, some of the items do not capture the responsibility and self-blame associated with regret and have been omitted from the scale in empirical studies [61]. The measures are also contingent on a specified treatment related decision and therefore neglect both the scope of post-treatment regrets and regrets over inaction. A more appropriate measure of regret may combine an open-ended question with supplementary Likert-type items.

CONCLUSION

This study found that post-treatment regret is a relatively common sentiment among breast cancer survivors. It also established the variety of treatment characteristics that breast cancer survivors regret, from primary surgery and adjuvant therapies to problems with providers and wishing they had been more proactive in their care. In addition, women regretted inactions more than actions. This finding underscores a gap in the current literature on post-treatment regret, which has focused on regrets over actions. Quantitative analysis revealed that women who were anxious about the future and had trouble communicating with physicians during treatment were more likely to express regret 5 years later. Women with new or recurrent cancers were significantly more likely to regret some aspect of their primary treatment.

Overall, this work informs the growing literature addressing the psychosocial aspects of cancer care and improving physician-patient communication, including assessments of women’s emotional state and the use of patient navigators during treatment. We also provide evidence for addressing the unique emotional needs of women with recurrent cancers, who likely experience an undue burden of regret. The study of regret in cancer-related decisions is a burgeoning area of research, and significant work remains to better appreciate the role of regret in medical decision-making and how post-decision justification may mitigate regret over time. Understanding the causes and consequences of regret in cancer care can contribute significantly to interventions designed to ensure improved quality of life over the long term.

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Table 1

Demographic and health characteristics of women during treatment (N=449)

	% or Mean	(SD)
Age	44.0	(4.8)
Education (years)	15.3	(2.6)
Married	81.7%	
Chronic conditions (0–7)	0.8	(0.96)
Race/Ethnicity:		
White	72.4%	
Black	5.8%	
Hispanic	7.3%	
Asian	14.5%	
Employment status:		
Works full time	59.2%	
Works part time	20.5%	
Not working	20.3%	
Stage at Diagnosis:		
In situ	17.9%	
Local	49.7%	
Remote or regional	32.4%	
Adjuvant therapy:		
No chemo or radiation	31.0%	
Chemotherapy	38.1%	
Radiation	17.1%	
Chemo and Radiation	13.8%	
Tamoxifen	40.1%	
New or recurrent cancer	14.3%	
Surgery:		
Mastectomy with reconstruction	29.8%	
Mastectomy no reconstruction	23.2%	
Breast-conserving surgery	47.0%	

Table 2

Psychosocial characteristics of women during treatment

	% or Mean	(SD)
Self-esteem (0–40)	34.2	(4.4)
Emotional support (11–44)	40.9	(4.3)
Worry about the future (0–3)	1.9	(1.0)
Negative body image (0–4)	1.7	(1.5)
Problems communicating with physicians (0–4)	1.2	(1.4)
Physical quality of life (0–100)	45.9	(9.4)
Mental quality of life (0–100)	46.9	(10.9)
Participated in surgical decision less than desired	17.1%	
Participated in surgical decision more than desired	16.1%	
Participated in surgical decision as much as desired	66.8%	

Table 3

Prevalence and content of regrets among young breast cancer survivors (N=449)

Regret:	
Yes	42.5%
No	57.5%
Of those women who regret some aspect of treatment (N=191):	
Primary Surgery	24.1%
Chemotherapy/Radiation	21.5%
Reconstruction	17.8%
Problems with providers	13.1%
Pro-activity in care	10.5%
Tamoxifen/Hormone therapy	10.5%
Health habits/Self care	6.3%
Social Support	3.1%
Biopsy	1.6%
Hospital choice	1.6%
Clinical trial participation	0.5%
Women who regret 2 aspects of treatment	4.5%
Type of Regret	
Action	30.4%
Inaction	59.2%
Ambiguous/Instead	10.4%

Table 4

Bivariate analysis of regret among breast cancer survivors

	Mean or %		
	Regret	No Regret	
Demographic and health characteristics:			
Age	43.9	44.1	
Education (years)	15.5	15.2	
Single	50.0%	50.0%	
Married or partnered	40.9%	59.10%	
Number of chronic conditions	0.9	0.7	
Cancer free	37.9%	62.1%	
New or recurrent cancer at 5 year survival	70.3%	29.70%	**
Race/Ethnicity:			**
White	46.6%	53.4%	
Black	50.0%	50.0%	
Hispanic	33.3%	66.7%	
Asian	23.1%	76.9%	
Employment status during treatment:			
Not working	46.2%	53.8%	
Works part time	42.4%	57.6%	
Works full time	41.1%	58.9%	
Stage at Diagnosis:			
In situ	41.2%	58.8%	
Local	42.8%	57.2%	
Remote or regional	42.8%	57.2%	
Adjuvant therapy:			
No chemo or radiation	48.9%	51.1%	
Chemotherapy	41.5%	58.5%	
Radiation	35.1%	64.9%	
Chemo and Radiation	40.3%	59.7%	
No tamoxifen	40.9%	59.1%	
Tamoxifen	45.0%	55.0%	
Surgery:			
Breast-conserving surgery	39.2%	60.8%	
Mastectomy with reconstruction	50.0%	50.0%	
Mastectomy no reconstruction	38.5%	61.5%	
Psychosocial characteristics during treatment:			
Self-esteem	34.1	34.2	
Emotional support	40.7	41.1	
Negative self image	1.9	1.6	*
Worry about the future	2.1	1.8	**
Problems communicating with physicians	1.4	1.0	**
Participated less than desired in surgery decision	46.5%	53.5%	

	Mean or %		
Participated as much as desired in surgery decision	41.4%	58.6%	
Participated more than desired in surgery decision	37.3%	62.7%	
Physical quality of life	44.6	46.9	**
Mental quality of life	46.1	47.6	†

†
p<0.1

*
p<0.05

**
p<0.01

Table 5

Multivariable logistic regression of regret among breast cancer survivors (N=449)

Demographic and health characteristics:	OR	[95% CI]
Age	0.97	[0.93, 1.02]
Education (years)	1.05	[0.95, 1.15]
Single	1.00	
Married or partnered	0.75	[0.41, 1.36]
Number of chronic conditions	1.12	[0.87, 1.43]
Cancer free	1.00	
New or recurrent cancer at 5 year survival	5.81	[2.86, 11.83] **
Race/Ethnicity:		
White	1.00	
Black	1.16	[0.44, 3.04]
Hispanic	0.41	[0.15, 1.08] †
Asian	0.25	[0.12, 0.54] **
Employment status during treatment:		
Not working	1.00	
Works part time	0.69	[0.34, 1.40]
Works full time	0.91	[0.51, 1.63]
Stage at Diagnosis:		
In situ	1.00	
Local	0.85	[0.42, 1.69]
Remote or regional	0.73	[0.30, 1.79]
Adjuvant therapy:		
No chemo or radiation	1.00	
Chemotherapy	0.93	[0.47, 1.85]
Radiation	0.72	[0.33, 1.60]
Chemo and Radiation	1.04	[0.43, 2.52]
No tamoxifen	1.00	
Tamoxifen	1.27	[0.76, 2.13]
Surgery:		
Breast-conserving surgery	1.00	
Mastectomy with reconstruction	1.58	[0.83, 3.04]
Mastectomy no reconstruction	0.86	[0.44, 1.69]
Psychosocial characteristics during treatment:		
Self-esteem	1.03	[0.97, 1.10]
Emotional support	0.98	[0.92, 1.04]
Negative self image	1.03	[0.86, 1.24]
Worry about the future	1.32	[1.02, 1.70] *
Problems communicating with physicians	1.26	[1.04, 1.51] *
Participated less than desired in surgery decision	1.00	
Participated as much as desired in surgery decision	0.84	[0.46, 1.53]

Demographic and health characteristics:	OR	[95% CI]
Participated more than desired in surgery decision	0.66	[0.30, 1.46]
Physical quality of life	0.98	[0.95, 1.00] [†]
Mental quality of life	1.02	[0.99, 1.04]
LR Chi-sq.(28)=77.73; p<0.001		

[†]
p<0.1

*
p<0.05

**
p<0.01