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The Relationship Between the Belief in a Genetic Cause for Breast Cancer and Bilateral Mastectomy

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Objective: Most women develop causal beliefs following diagnosis with breast cancer and these beliefs can guide decisions around their care and management. Bilateral mastectomy rates are increasing, although the benefits of this surgery are only established in a small percentage of women. In this study we investigated the relationship between causal beliefs and the decision to have a bilateral mastectomy. ***Method:*** Women (N = 2,269) from the Army of Women's breast cancer research registry completed an online survey. Women were asked what they believed caused their cancer and responses were coded into 8 causal categories. Participants were also asked about the type of surgery they underwent following their breast cancer diagnosis. The odds ratios for having a double mastectomy were calculated for each causal category using random/bad luck as a referent category. ***Results:*** Hormonal factors (22%) and genetics (19%) were the most common causal belief, followed by don't know (19%), environmental toxins (11%), negative emotions (9%), poor health behavior (8%), other (6%) and random/bad luck (6%). Compared with the referent category, the odds ratio of having a bilateral mastectomy was significantly higher in both the genetics and hormonal causal belief groups (OR = 2.36, 95% CI [1.38, 4.02] and OR = 1.98, 95% CI [1.16, 3.38], respectively). ***Conclusions:*** Beliefs in a genetic cause for breast cancer are common and are associated with high rates of bilateral mastectomy. This is despite evidence that the actual genetic contribution to breast cancer is much lower than perceived and that bilateral mastectomy is, in most cases, unlikely to improve survival.

Keywords: causal beliefs, illness perceptions, mastectomy, breast cancer, surgery

Individuals diagnosed with a serious illness usually develop a cognitive model of their condition and these beliefs function to guide the patient's decisions about treatment and ongoing management of their illness (Petrie & Weinman, 2012). Causal beliefs are an important part of the patient's cognitive representation of their illness and, following a diagnosis of breast cancer, most women seem to develop beliefs about what caused their cancer (Stewart et al., 2001; Taylor, Lichtman, & Wood, 1984). The most common causal beliefs identified by studies of women with breast cancer are: stress, toxic environmental exposure, genetics, hormones, and poor health behaviors (Rabin & Pinto, 2006; Stewart et al., 2001).

Causal beliefs and other illness perceptions have been shown to have a strong influence on health care behavior in a variety of illnesses, as certain treatment options are better matched with some causal beliefs than with others. For example, first time myocardial infarction patients who believed their heart attack was caused by poor health habits were more likely to have made changes in their diet 6 months later (Weinman, Petrie, Sharpe, & Walker, 2000). In breast cancer patients, women who believed their cancer was caused by a poor diet were more likely to use vitamins and supplements, and women who believed their cancer was caused by stress were less likely to smoke and more likely to use complementary therapies and antidepressants (Stewart et al., 2001).

A treatment choice that is receiving more attention is the decision to undergo bilateral mastectomy surgery following breast

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cancer diagnosis. Studies have shown that rates of bilateral mastectomy have increased dramatically in the U.S. in recent years (Tracy, Rosenberg, Dominici, & Partridge, 2013). For example, Memorial Sloan-Kettering Cancer Center showed an increase in bilateral mastectomy from 6.7% in 1997 to 24.2% in 2005 (King et al., 2011) and the MD Anderson Cancer Center also reported a recent rate of bilateral mastectomy of 23.2% (Yi et al., 2010). The increase in bilateral mastectomy rates contrasts with the fact that the survival benefits of such surgery have not been demonstrated (Lostumbo, Carbine, Wallace, & Ezzo, 2010; Tracy et al., 2013). Current guidelines advise that bilateral mastectomy is only recommended in a small percentage of breast cancer cases, in particular, among women with BRCA mutations (Giuliano et al., 2007). However, only between 0.5%–3.1% of women with breast cancer display these mutations (Peto et al., 1999). Even in women diagnosed with breast cancer aged younger than 40, where genetic mutation rates are generally higher, only approximately 9% of these women will harbor a deleterious BRCA1 or BRCA2 mutation (Golshan et al., 2006).

A primary driver in the decision to have more radical surgery seems to be patient choice, but little is known about what influences this decision (Rosenberg et al., 2013). Nekhlyudov et al. (2005) found that among women with unilateral breast cancer deciding to have contralateral prophalactic mastectomy, 45% reported that their decision was primarily their own. Patient perceptions about breast cancer and their personal risk seem to be important factors in influencing patients' decisions (Fisher et al., 2012; Tracy et al., 2013). Previous research has identified a higher rate of bilateral mastectomy in women who had a family history of cancer (Yi et al., 2010). In the current study we investigated the relationship between the patient's beliefs about the cause of her breast cancer and whether the patient had undergone a bilateral mastectomy. We predicted that women who believed their illness had a genetic cause would be more likely to opt for a bilateral mastectomy.

Method

Participants were recruited from the Dr. Susan Love Research Foundation Army of Women research registry. This organization recruits breast cancer survivors and others to partner with breast cancer researchers with the aim of reducing the morbidity and mortality associated with breast cancer. An estimated 51,000 women with breast cancer were invited, via e-mail, to participate as part of a larger study looking at adherence to endocrine therapy (Stanton, Petrie, & Partridge, 2014). Participants who were at least 18-years-old who had been diagnosed with breast cancer were included if they were currently living the United States and had undergone surgery for their breast cancer. The final sample comprised 2,269 women who completed the online survey and met the eligibility criteria.

We collected basic demographic information including age, marital and employment status, along with time since diagnosis, breast cancer stage, and whether participants had undergone lumpectomy, mastectomy, or bilateral mastectomy. Causal beliefs were assessed with the question: "What do you think was the most important factor that caused your breast cancer?" from the Brief Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006). Two independent researchers coded the open-ended responses into eight categories. In cases where more than one causal belief was reported, the first belief mentioned by the participant was used. The interrater reliability between the two coders produced a Kappa of 0.94. Where raters could not agree a third independent rater made a final decision.

For the data analysis, the percentage of women reporting each causal category was calculated, as well as the percentage of women reporting bilateral mastectomy within each causal category. The odds of having undergone a bilateral mastectomy in each causal category relative to those reporting random/bad luck was calculated using logistic regression, STATA version 13. The random/bad luck category was chosen as the referent group because among those who assign a cause for their cancer it is not directly related to any specific treatment behavior. An alpha level of $p < .05$ was considered significant and 95% confidence intervals were calculated using the binomial method.

Results

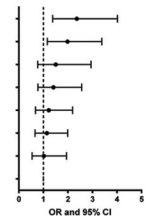
Our study sample consisted of 2,269 women. Among these, 77.5% were married, 14.5% were divorced or separated, and 7.9% were single. The mean age was 55.5 years (*SD* 9.1, range 24–86), and 42.6% reported working full time and 16.9% worked part-time. The average time since the diagnosis of breast cancer was 5.0 years ($SD = 3.8$). Most women had early stage breast cancer with 6.2% reporting Stage 0, 42.2% Stage 1, 37% Stage 2, 12.7% Stage 3, and 7.9% Stage 4. In terms of type of surgery, 50.7% of women had a lumpectomy, 23.5% mastectomy, and 25.8% bilateral mastectomy.

The distribution of the causal beliefs among the sample is presented in Table 1. Most of the sample reported a causal belief for their cancer—only 18.5% said they did not know. Hormonal factors (e.g., hormonal treatment, fertility treatment, early or late menarche) were the most common cause reported, followed by genetics, environmental toxins (e.g., pollution, chemicals), negative emotions (e.g., depression, stress), poor health behavior (poor diet, smoking), random/bad luck, and other reasons. There was a significant relationship between age, stage and marital status and bilateral mastectomy. Women who had bilateral mastectomy were significantly younger ($M = 52.80$, $SE = 0.42$) than those who had not ($M = 57.08$, $SE = 0.22$), $t(833.99) = -9.10$, $p < .001$. Women who had bilateral mastectomy also reported more advanced stage disease ($M = 2.18$, $SE = 0.05$) than women who reported no bilateral mastectomy ($M = 1.73$, $SE = 0.23$), $t(2{,}286) = 8.28$, $p < .001$. Bilateral mastectomy was also more common among married women (26.6%) than unmarried women (21%) $\chi^2(1, n = 2{,}286) = 6.66$, $p = .01$. We controlled for these three factors in the logistic regression examining the association between causal beliefs and the likelihood of bilateral mastectomy.

The percentage of women reporting having undergone bilateral mastectomy varied with causal belief. Bilateral mastectomy was significantly more common among women reporting genetics or hormonal factors as causing their breast cancer (see Table 1). In comparison with women reporting random/bad luck as their causal belief, the women reporting genetic beliefs were 2.36 times more likely to have undergone a bilateral mastectomy ($p < .002$) and those reporting hormonal causal beliefs were 1.98 times more likely ($p = .012$).

Table 1
Frequency and Odds Ratios for Bilateral Mastectomy by Causal Belief

	Number (%) of women in each causal category	Percentage reporting a bilateral mastectomy	Odds ratio for bilateral mastectomy adjusted for age, stage, and marital status; OR [95% CI]	*p* values
Genetics	419 (19.4)	35.1%	2.36 [1.38, 4.02]	0.002
Hormonal factors	480 (22.2)	28.1%	1.98 [1.16, 3.38]	0.012
Other	126 (5.8)	23.8%	1.50 [0.77, 2.94]	0.232
Negative emotions	204 (9.4)	25.5%	1.41 [0.78, 2.56]	0.257
Environmental toxins	230 (10.6)	23.9%	1.22 [0.68, 2.19]	0.504
Don't know	399 (18.5)	21.3%	1.14 [0.66, 1.99]	0.638
Health behaviors	178 (8.2)	19.7%	1.02 [0.54, 1.94]	0.949
Random/bad luck	127 (5.9)	17.3%	*Reference category*	



Discussion

This study found that most women held causal beliefs about why their breast cancer developed, and these beliefs could be reliably coded into eight causal categories. Hormonal factors and genetics were by far the most common beliefs. We found the likelihood of having a bilateral mastectomy was high in this sample, and was significantly related to having a genetic or hormonal causal belief for the development of breast cancer.

Genetic and hormonal factors as well as stress have previously been found to be commonly reported causal beliefs for breast cancer (Panjari, Davis, Fradkin, & Bell, 2012; Rabin & Pinto, 2006; Stewart et al., 2001; Taylor et al., 1984). Although previous studies have not looked at the relationship between causal beliefs and surgical decisions following breast cancer diagnosis, patients' causal beliefs have been shown to influence the use of complementary therapy and other health behaviors (Panjari et al., 2012; Stewart et al., 2001).

The study findings underline the contrast between the established genetic basis for breast cancer, which is usually estimated between 0.5%–3.1% of women with the disease (Peto et al., 1999), and the number of women who believe their breast cancer has a clear genetic cause (e.g., a testable BRCA1 or BRCA2 mutation or another much more rare genetic alteration such as P53 mutation). This discrepancy may be partly explained by the high number of breast cancer cases in the population. As breast cancer is a common malignancy, the probability of having breast cancer among female relatives is high (McPherson, Steel, & Dixon, 2000). Even though germ line mutations in BRCA1 and BRCA2 and other rare breast cancer-predisposing genetic mutations account for only 15%–20% of breast cancer clustered in families (Nathanson, Wooster, & Weber, 2001), having relatives diagnosed with breast cancer may cause women to overestimate the contribution of genetics to their breast cancer.

Another important factor in the overestimation of genetic factors may be due to the disproportionate attention given to genetic risk factors in the media relative to other risk factors for breast cancer (Henderson & Kitzinger, 1999). This was evidenced recently by the media interest in Angelina Jolie's decision to undergo a preventive double mastectomy (Borzekowski, Guan, Smith, Erby, & Roter, 2013). Such media stories may also cause women to more readily adopt hereditary causal beliefs after they have been diagnosed with breast cancer due to the availability heuristic (Tversky & Kahneman, 1973). Consistent with this finding, high rates of genetic causal beliefs for breast cancer have also been found in studies of the general population who have not experienced cancer (Buick & Petrie, 2002; Wang, Miller, Egleston, Hay, & Weinberg, 2010).

The strong association between bilateral mastectomy and a genetic or hormonal causal belief for breast cancer reinforces how illness perceptions can guide actions designed to manage the illness, and how treatment decisions need to fit or cohere with the patient's beliefs about their illness (Petrie & Weinman, 2012). Given a particular causal belief, certain treatments will make more sense to patients than others. Both genetic and hormonal causal beliefs emphasize biological factors as being important in the development of breast cancer and are both associated with an increased use of a bilateral mastectomy, whereas it is likely other causal models impact on the adoption of other sorts of treatments. It is also worth emphasizing that the causal belief on its own is unlikely to lead to bilateral mastectomy without a surgeon who is willing to do the operation.

The study is limited by the cross-sectional design, which makes it difficult to determine the direction of the relationship between causal beliefs and treatment choice. It should also be noted that we only assessed women who had received surgery as part of their treatment following their breast cancer diagnosis. Further, we did not assess whether women had been tested for a genetic mutation or had a family history of breast cancer. It also needs to be established whether these findings in a large Army of Women Web site sample generalize to other breast cancer populations. The self-report nature of the questionnaire means it is impossible to check the veracity of patients' clinical history and data or look at differences between survey respondents and nonrespondents. Bearing these limitations in mind, the study suggests that causal beliefs about the development of breast cancer are an important influence on the type of surgery women choose. It is important that clinicians are aware of patients' causal models of their breast cancer, as these may be critical when women are considering surgical options. Correcting misconceptions about the role of genetic factors and the risk of new primary contralateral breast cancer compared with recurrence of the cancer that they have

already developed is important in helping women make appropriate treatment options (Abbott et al., 2011; Guiliano et al., 2007).

References

Abbott, A., Rueth, N., Pappas-Varco, S., Knutz, K., Kerr, E., & Tuttle, T. (2011). Perceptions of contralateral breast cancer: An overestimation of risk. *Annals of Surgical Oncology, 18,* 3129–3136. doi:10.1245/s10434-011-1914-x

Borzekowski, D. L., Guan, Y., Smith, K. C., Erby, L. H., & Roter, D. L. (2013). The Angelina effect: Immediate reach, grasp, and impact of going public. *Genetics in Medicine*. Advance online publication. doi:10.1038/gim.2013.181

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research, 60,* 631–637. doi:10.1016/j.jpsychores.2005.10.020

Buick, D., & Petrie, K. J. (2002). I know just how you feel: The validity of healthy women's perceptions of breast cancer patients receiving treatment. *Journal of Applied Social Psychology, 32,* 110–123. doi:10.1111/j.1559-1816.2002.tb01422.x

Fisher, C. S., Martin-Dunlap, T., Ruppel, M. B., Gao, F., Atkins, J., & Margenthaler, J. A. (2012). Fear of recurrence and perceived survival benefit are primary motivators for choosing mastectomy over breast-conservation therapy regardless of age. *Annals of Surgical Oncology, 19,* 3246–3250. doi:10.1245/s10434-012-2525-x

Giuliano, A. E., Boolbol, S., Degnim, A., Kuerer, H., Leitch, A. M., & Morrow, M. (2007). Society of surgical oncology: Position statement on prophylactic mastectomy. *Annals of Surgical Oncology, 14,* 2425–2427. doi:10.1245/s10434-007-9447-z

Golshan, M., Miron, A., Nixon., A. J., Garber, J. E., Cash, E. P., Iglehart, J. D., . . . Wong, J. S. (2006). The prevalence of germline BRCA1 and BRCA2 mutations in young women with breast cancer undergoing breast-conservation therapy. *American Journal of Surgery, 192,* 58–62. doi:10.1016/j.amjsurg.2005.12.005

Henderson, L., & Kitzinger, J. (1999). The human drama of genetics: "hard" and "soft" media representations of inherited breast cancer. *Sociology of Health and Illness, 21,* 560–578. doi:10.1111/1467-9566.00173

King, T. A., Sakr, R., Patil, S., Gurevich, I., Stempel, M., Sampson, M., & Morrow, M. (2011). Clinical management factors contribute to the decision for contralateral prophylactic mastectomy. *Journal of Clinical Oncology, 29,* 2158–2164. doi:10.1200/JCO.2010.29.4041

Lostumbo, L., Carbine, N. E., Wallace, J., & Ezzo, J. (2010). Prophylactic mastectomy for the prevention of breast cancer. *Cochrane Database*. Advance online publication. doi:10.1002/14651858.CD002748.pub3

McPherson, K., Steel, C., & Dixon, J. M. (2000). ABC of breast diseases: Breast cancer—Epidemiology, risk factors, and genetics. *British Medical Journal, 321,* 624. doi:10.1136/bmj.321.7261.624

Nathanson, K. N., Wooster, R., & Weber, B. L. (2001). Breast cancer genetics: What we know and what we need. *Nature Medicine, 7,* 552–556, doi:10.1038/87876

Nekhlyudov, L., Bower, M., Herrinton, L. J., Altschuler, A., Greene, S. M., Rolnick, S., . . . Geiger, A. M. (2005). Women's decision-making roles regarding contralateral prophylactic mastectomy. *Journal of the National Cancer Institute Monographs, 2005,* 55–60. doi:10.1093/jncimonographs/lgi038

Panjari, M., Davis, S. R., Fradkin, P., & Bell, R. J. (2012). Breast cancer survivors' beliefs about the causes of breast cancer. *Psycho-Oncology, 21,* 724–729. doi:10.1002/pon.1949

Peto, J., Collins, N., Barfoot, R., Seal, S., Warren, W., Rahman, N., . . . Stratton, M. R. (1999). Prevalence of BRCA1 and BRCA2 gene mutations in patients with early-onset breast cancer. *Journal of the National Cancer Institute, 91,* 943–949. doi:10.1093/jnci/91.11.943

Petrie, K. J., & Weinman, J. (2012). Patients' perceptions of their illness: The dynamo of volition in health care. *Current Directions in Psychological Science, 21,* 60–65. doi:10.1177/0963721411429456

Rabin, C., & Pinto, B. (2006). Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives. *Psycho-Oncology, 15,* 701–712. doi:10.1002/pon.1000

Rosenberg, S. M., Tracy, M. S., Meyer, M. E., Sepucha, K., Gelber, S., Hirshfield-Bartek, J., . . . Partridge, A. H. (2013). Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: A cross-sectional survey. *Annals of Internal Medicine, 159,* 373–381. doi:10.7326/0003-4819-159-6-201309170-00003

Stanton, A. L., Petrie, K. J., & Partridge, A. H. (2014). Contributors to nonadherence and nonpersistence with endocrine therapy in breast cancer survivors recruited from an online research registry. *Breast Cancer Research and Treatment, 145,* 525–534. doi:10.1007/s10549-014-2961-3

Stewart, D. E., Cheung, A. M., Duff, S., Wong, F., McQuestion, M., Cheng, T., . . . Bunston, T. (2001). Attributions of cause and recurrence in long-term breast cancer survivors. *Psycho-Oncology, 10,* 179–183. doi:10.1002/pon.497

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology, 46,* 489–502. doi:10.1037/0022-3514.46.3.489

Tracy, M. S., Rosenberg, S. M., Dominici, L., & Partridge, A. H. (2013). Contralateral prophylactic mastectomy in women with breast cancer: Trends, predictors, and areas for future research. *Breast Cancer Research and Treatment, 140,* 447–452. doi:10.1007/s10549-013-2643-6

Tversky, A., & Kahneman, D. (1973). Availability: A heuristic for judging frequency and probability. *Cognitive Psychology, 5,* 207–233. doi:10.1016/0010-0285(73)90033-9

Wang, C., Miller, S. M., Egleston, B. L., Hay, J. L., & Weinberg, D. S. (2010). Beliefs about the causes of breast and colorectal cancer among women in the general population. *Cancer Causes and Control, 21,* 99–107, doi:10.1007/s10552-009-9439-3

Weinman, J., Petrie, K. J., Sharpe, N., & Walker, S. (2000). Causal attributions in patients and spouses following a heart attack and subsequent lifestyle changes. *British Journal of Health Psychology, 5,* 263–273. doi:10.1348/135910700168900

Yi, M., Hunt, K. K., Arun, B. K., Bedrosian, I., Barrera, A. G., Do, K., . . . Meric-Bernstam, F. (2010). Factors affecting the decision of breast cancer patients to undergo Contralateral prophylactic mastectomy. *Cancer Prevention Research, 3,* 1026–1034. doi:10.1158/1940-6207.CAPR-09-0130

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