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Family History, Genetic, and Other Cause-Related Beliefs among Breast Cancer Survivors

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Abstract

Patients' lay theories about the cause of their cancer may influence patient behavior and adjustment, they have also been found to differ substantially from scientific evidence of cancer risk factors. This report describes beliefs about genetic causes of breast cancer, among 522 recently diagnosed breast cancer survivors participating in an observational study. Patients were asked to respond to an open-ended question about the cause of their cancer. Causes mentioned included family history, genetics, lifestyle, reproductive and environmental factors, often in combination. Of particular interest we found in total, 31% of women described inheritable causes, including family history, genetics, and specific genes. Lay theories about cancer's cause appear to have evolved to include new information about breast cancer genetics including BRCA1/2, epigenetic influence, and other mutations. Other causes seen in prior reports are also described and were used in many cases in combination with genetic explanations. We present evidence that genetics and family history appear to be particularly satisfying answers to questions of cause for many women with breast cancer.

These findings have implications for those seeking to educate and counsel breast cancer patients with and without a family history of cancer**.**

Keywords
Lay theories of illness; breast cancer; genetics

1. Introduction

Patients' lay theories about the cause of illnesses including cancer may predict their adjustment to and coping with cancer and other diseases [1, 2]. People's lay theories may have implications about a patient's role in causing their illness and in their approach to recovery and prevention [3-5]. Few reports have focused on understanding the content of genetic beliefs about breast cancer's cause among patient populations.

Several studies examining lay theories of the cause of breast cancer were conducted more than 20 years ago [1, 6, 7]. These studies described how women's lay theories included familial risk, stress, exposure theories, and reports of injury. Studies conducted in the 1980's assumed that lay theories change over time, but significant differences between lay theories and medically accepted predictors of elevated cancer risk [1, 6, 7], suggested that lay theories may be resistant to change. Studies since have tended to focus on the degree to which women fail to appreciate scientifically supported modifiable, often lifestyle, risk factors [3]. These have often found only a minority of women with and without cancer themselves describe some of the most important known modifiable risk factors for this disease [3, 8], and described a high percentage of women providing familial risk explanations. One noted that 77.6% of women describe family history/genetics as an important cause of breast cancer [8].

While it has long been understood that having a family history of breast cancer is associated with elevated risk, specific genes associated with hereditary breast and ovarian cancer risk, the genes BRCA1/2, were first identified in 1990 [13]. Testing for mutations began in 1994 [17]. These genes and others not yet identified which convey familial risk, are implicated in 5% to 10% of women diagnosed with breast cancer [18]. Women who inherit a mutation in BRCA1/2 are at highly elevated risk for breast cancer by age 70 [19]. Women with breast cancer both with and without a family history frequently are tested for these genes as part of the cancer treatment process. Further, the genetics of breast cancer and epigenetic influences on risk are active areas of research with frequent new developments. In light of the discovery of genetic mutations (BRCA1/2) associated with familial risk [9-13] and the discovery of additional epidemiological risk factors for cancer [14-16], we felt this would be a good time to re-examine women's beliefs about the cause of their breast cancer, and specifically, their theories of familial risk. We aimed to describe the variety of ways women with breast cancer currently discuss cancer risk, and hypothesized that widespread interest in genetics may have changed how women understand familial risk for cancer.

2. Methods

This study is registered with clinical trials as (NCT01366248). Study methods and questionnaires were approved by the Institutional Review Boards of the Fred Hutchinson Cancer Research Center, Seattle, WA and Bastyr University, Kenmore, WA throughout the study's period of recruitment and follow-up 2005-2017, and continues to be reviewed by the IRO of the Fred Hutchinson Cancer Research Center. The women involved are part of a longitudinal assessment of two matched cohorts of women with breast cancer some of whom did and others of whom did not choose to include integrative oncology in their breast cancer treatment plans [20, 21]. Breast cancer patients were eligible for the study if they spoke English fluently enough to complete surveys, were over age 21, and were diagnosed with breast cancer less than 2 years prior to an Integrative Oncology (IO) clinic visit, or were selected from a cancer registry based on their similarity to an enrolled IO clinic patient. Participants included a group of 245 patients receiving (IO) treatment (222 of whom completed questionnaires including the question discussed here), and a larger group recruited from the cancer registry matched demographic characteristics and stage of cancer at time of diagnosis. Analyses describing the similarities and differences between the two cohorts are described elsewhere [22]. Women seeking IO care either consented for the study and completed the forms in the clinic or consented during a telephone call with the documents returned by mail. Women identified through the registry completed consent and recruitment documents by mail. Of 877 women approached through the registry to participate, four were recently deceased, 66 (5%) could not be reached at the address recorded with the registry, 537 did not respond, and 330 (38% of those approached) returned the forms including a completed questionnaire. These analyses describe 552 women.

2.1 Measures

In addition to the standard assessments of age, demographics, stage of cancer, type of conventional breast cancer treatment received (surgery, radiation, and/or chemotherapy), dates of diagnosis, smoking, and BMI, the enrollment questionnaire for the study also included an open-ended question asking women about their theories about the cause of their cancer; responses to that question are the focus of this report.

2.2 Content Analysis

Two of the authors, RA and KA, performed content coding of women's written responses using the Atlas.ti program [23]. Content coding was done for women's responses to the question: "What is your theory about the cause of your cancer?" Space was provided for responses of up to 1/3 of a page in length; some participants continued to the back of the questionnaire to respond to the question with further detail. Responses provided by participants were transcribed verbatim and made available for content coding. In an effort to assure consistent coding throughout, uses of specific codes were discussed and agreed by the coders. When coders agreed the responses expressed similar ideas, they were combined. Eventually a group of 66 codes was developed that allowed for description of every woman's response and described what appear to be key elements of these responses. Excluding rare and apparently idiosyncratic comments, codes were then further combined based on similarity of content to a more manageable number for analyses.

3. Results

3.1 Characteristics of a Population Sample of Breast Cancer Survivors

Of the 552 participating patient survivors from both recruitment sources, 265 (48%) were less than 9 months' post-diagnosis, 150 (27%) were more than 9 months but less than 18 months' post-diagnosis, and 104 (19%) were more than 18 months' post-diagnosis. Table 1 shows the participant demographics with 93 (17%) who reported they presented with stage 3 or 4 disease, 174 (31%) with stage 2, 216 (39%) with stage I, and 21 (4%) with stage 0 disease. Consistent with the geographic area, 92% percent of the sample was white, 5% reported being current smokers, and the average reported BMI was slightly above 'normal' range at 26 (sd; 5.6). As the intent of this study was to understand the influence of integrative oncology on patients' treatment and outcomes, extensive analyses examining the women recruited from both sources were conducted. These revealed no differences between the groups in age, stage, race, ethnicity, smoking status, BMI, or use of surgery or chemotherapy (data not shown; [20]). A paper describing the differences in the frequency with which women discussed stress and randomness as causes of their cancer is published elsewhere but did not include any differences in genetic-related causes as none were found [22]. Based on this, and the inherent interest in the genetic causes described the decision was made to present the responses describing genetic causes of all the women combined.

Table 1 Characteristics of participating breast cancer patients by recruitment source.

		IO cohort	**Usual care cohort**
		N = 245	**N = 307**
Stage of disease at diagnosis	0	13 (5.3%)	8 (2.6%)
	1	77 (31.4%)	139 (45.0%)
	2	83 (33.9%)	91 (29.5%)
	3	34 (13.9%)	43 (13.9%)
	4	11 (4.5%)	5 (1.6%)
Unknown		27 (11.0%)	23 (7.4%)
Race	White	220 (89.8%)	290 (93.9%)
	Non-white	25 (10.2%)	19 (6.2%)
Age (mean and SD)		Mean: 54.5; Std Dev: 11.07	Mean: 54.7; Std Dev: 10.11

3.2 Causes of Cancer Reported

Table 2 presents the codes derived from review of the women's responses and categorizes them.

Codes		**N**	**Percentage**
Genetics and Family History	Family history [*1]	78	14.1
	"I have no family history"	24	4.3
	Genetics [*2]	110	19.9
Lifestyle and Reproduction	Age	8	1.5
	Lack of exercise	36	6.5
	Childbearing	17	3.1
	Poor diet	77	14.0
	Lack of vitamin D	14	2.5
	Lack of sun/ SAD	8	1.4
	Lack of sleep / melatonin	8	1.4
	Overweight / obesity	34	5.2
	Hormones (not in food)	27	4.9
	Alcohol	22	4.0
	Smoking	15	2.7
	"drug use"	2	< 1
	Abortion/not abortion	3	< 1
	IVF or infertility	6	1.1
	Early menopause	2	< 1
	Dense breasts	2	< 1
	"my lifestyle" (unspecified)	14	2.5
	"I did low risk things" / Not my lifestyle	38	6.9
Environment and exposures	Toxins or chemical in environment	65	11.8
	Hormones in environment	17	3.1
	Toxins or chemicals in food	28	5.1
	Hormones in food	15	2.7
	HRT	58	10.5
	Oral contraceptives	21	3.8
	Radiation/x-rays/mammograms	11	2.0
	Treatment for my prior breast disease	1	< 1
	Treatment for some other disease	9	1.6
	DES baby	2	< 1
	Early detection	14	2.5
	Injury to breast	6	1.1
	"Medications" (unspecified)	2	< 1
	Immune system	24	4.3
	Inflammation	4	< 1
	Viral	1	< 1
	Underwire bra	1	< 1
Stress and Coping	Stress	163	29.0
	Coping	26	4.7

Randomness		96	17.0
Multiple causes			
Not causes reported in response to cause question	God or Higher power	35	6.3
	Not interested in cause	36	6.3
	Moving forward	21	3.8
	Benefit finding [*3]	35	6.3
	Not sure / I don't know / no theory	91	16.5

*1 Sub-codes include: Family history / "Mom had breast cancer" / "other family member(s) with breast cancer" / "Other family member(s) with other kinds of cancer"

*2 Sub-codes include: "genetic" / "BRCA1/2" / "genetic testing – positive" / Genetic testing – negative" / some other gene / "Epigenetics"

*3 Sub-codes include: Lessons from god or God has a purpose / I learned so much or valuable changes in my life.

3.2.1 Family History

Seventy-eight women when asked to describe the cause of their cancer said "family history" of cancer or mentioned a relative or list of relatives with, or without, cancer. These criteria were the basis of our code 'family history'. Twenty-eight (36% of those reporting a family history) specifically mentioned a mother with breast cancer. A few women mentioned that they had no family history of breast cancer and then mentioned a family history of other cancers as a possible explanation for their breast cancer (e.g. a father and brother with prostate cancer, or a mother with pancreatic cancer). Two women indicated that they believed their breast cancer to be of "inheritable" origin in spite of the fact that they also clearly stated that they had no family history of cancer.

In contrast, 24 women discussed family history as a cause of breast cancer only to reject it as a cause of their own breast cancer by specifically mentioning that they had no family history of cancer. As a group, these women appeared to believe that a family history often is a cause of breast cancer, but in the absence of such a history in their own family rejected it as the cause of their own cancer. In all but two cases, these women's comments included discussion of some other cause. Examples included, "I believe stress played a big role in my cancer since I had NO family history of breast cancer" or "I have no history of cancer, breast or otherwise in my family. I have lived an 'organic' lifestyle this must have an environmental cause." Two women appeared to believe so strongly in family history as a cause of breast cancer that they found a diagnosis in its absence confusing. One in particular commented, "I'm still stumped about this. I have no family cancer history, no risk."

3.2.2 Genetics

One hundred and ten women used the words "genetic"/"genetics", "gene"/"genes", or named specific genes (including BRCA1/2) in response to our question about their theories about the cause of their cancer, for example, "Genetic disposition – I tested positive for the BRCAII gene." Of these, 14 provided brief answers saying "Genetic disorder", or "genetics".

Some provided answers that indicated both a belief in a genetic cause and in family history, or mentioned both genes and a family member who had been diagnosed with cancer. For example;

"Genetic. My mom had the same type and was first diagnosed at about the same age," but only a minority of the women describing genetic causes for their cancer (n = 36 of 110; 33%) responded in this manner. In many of the instances where no family member was mentioned, it was unclear if there was a family history of disease. Because many women provided short answers, it is difficult to determine the degree to which women reporting a genetic cause also had a family history since they may have felt that by indicating a genetic origin they were also providing information about a family history.

Many of those reporting genetic causes were clearly familiar with recent research on breast cancer specific genetics and discussed BRCA1/2 specifically. Nine women (8.2%, of those indicating a genetic cause) mentioned receiving a positive genetic test result, but, this was not the predominant experience of women reporting a genetic cause for their cancer. Thirteen women (11.8% of those mentioning genetics), reported a negative result from BRCA1/2 gene testing. Women who mentioned both a negative gene test result and a strong family history of cancer frequently knew that there may be genes associated with breast cancer risk that had not yet been identified. One woman said, "My sister was diagnosed 7 yrs previously at age 45 y.o. Although my genetic testing came back as negative BRCAs, I believe there are other genetic markers that have not been clearly identified yet." Another woman said a genetic cause was "highly likely even though I tested negative for BRCA1 & 2, but my mom, great grandmother, and great, great grandmother all had breast cancer." Another woman commented, "Genetic pre- disposition, but not BRCA1 or 2 anywhere in my family. Five of us now diagnosed with a sister whom I believe will be diagnosed in the next 5 to 10 years." Another woman commented, "Genetic – but not BRCA. My mom was diagnosed with the same cancer at the same age."

Even without mentioning a family history, a few women clearly felt that although testing indicated that they were not BRCA1/2 positive, that did not eliminate a genetic cause for their cancer responding "some genetic weakness (I am not BRCA 1 or 2 positive) some other gene that is not identified or tested right now". For a few, the negative result from BRCA1/2 gene testing appears to have caused them to wonder about a genetic cause in their particular case. For some, a negative gene test may not have resulted in eliminating the idea that the cause of their cancer was genetic, but it resulted in them being less confident, less sure, that in their case the cause was genetic. "I don't know, could be genetic although I have no family history and am BRCA1 & 2 negative. Basically, I don't really know."

For some this elimination of genetics as a cause seemed a source of distress as in the case of a woman who said, "Initially I thought it was genetic as my mother had breast cancer at the same age and same location on the breast. But genetic testing came back negative. So who knows? I don't really have any idea." And another wrote, "Possible genetic predisposition (although negative testing). I don't really know". One woman summed up her response and said, "It seems so arbitrary beyond those identified with a gene."

3.2.3 Lifestyle and Reproductive Risks

Seventy-seven women listed diet as a cause of cancer, these references included not only eating "unhealthfully," but also references to diets that included processed foods, foods deficient in vitamins or nutrients, and "eating too much meat." Women who referenced hormones in foods were also included in this "diet" category. Pesticides and toxins in food were also mentioned and

will be discussed separately. Women also mentioned being overweight as a cause of their cancer or lack of exercise or physical activity. An additional 14 women mentioned "lifestyle" as the cause of their cancer without specifying what about their lifestyle caused the cancer. Also mentioned as possible causes were smoking, alcohol, and drug use.

Eight women mentioned age, 17 described late childbearing, not having children and/or not breast-feeding. Two women mentioned early menarche as a cause of cancer. Another 27 women described aspects of their hormonal cycling or indicated that their body in particular responded to or produced hormones in a manner that caused the cancer, e.g. "How my body metabolizes estrogen/progesterone plus" Seven women said "hormones" were a cause without specifying anything about their origin. Two women mentioned abortion as a possible cause of their cancer. An additional woman specifically told us abortion was NOT the cause of her breast cancer since she had not had an abortion.

Belief in the importance of lifestyle and reproductive risk factors for cancer prompted some women to include information about how these risk factors were not the cause of cancer in their case. These women generally listed things they did "right", such things included not smoking, not drinking, having children and breastfeeding, eating organically, and similar activities.

3.2.4 Environmental Factors and Other Exposures

A little over one-fourth of the patients (27%) described some form of theory about the cause of their breast cancer we came to describe as an exposure. "Toxins" or "chemicals" in the environment were described by 65 women (11.8% of the sample), and 29 (5.1% of the sample) described toxins or chemicals in food and products they had used. These theories included references to "Environmental toxicity – including hormone and pesticide treated foods." Toxins and chemicals were sometimes included in multi-cause hypotheses, one of these answers included a reference to genetics saying, "Some people have a genetic disposition towards some DNA breakdown under certain environmental exposures. Our environment is polluted overall, puts us all under a physical strain." Beyond descriptions of toxins and chemicals, women also described exposure theories that included exposure to HRT, radiation, x-rays, and mammography. Other exposures described included treatments for illnesses that included prior cancers, infertility, other illnesses, and exposures associated with other non-cancer breast diseases and their treatments as causes of their breast cancer.

3.2.5 Stress and Coping

In total, 163 women reported "stress" or described stressful life events as a cause of their cancer. A few did not elaborate on the kind of stress they experienced but those that did mention both work and emotional stresses related to traumatic experiences and frequently described cancer-causing stress associated with family problems including divorces and spousal illness. Discussions of poor coping and "failing to take care of myself" were less frequent than descriptions of stress. In total, 26 women described either poor coping or not taking care of themselves in one way or another. However, when women discussed poor coping, they frequently coupled these discussions with discussions of stress or stressors (18 of 26; 69% of those describing poor coping as a cause). For example, one woman wrote, "Maybe the combination of stress and not being able to deal with it. I was questioning my purpose on earth after the divorce".

3.2.6 Multiple Causes and Epigenetics

The concept of multiple causes, sometimes both immediate and ultimate, was also part of the reports of a substantial percentage of women who were coded as presenting multiple cause theories for their cancer. This was the single most used code, recorded for 213 women. Women who were coded as providing multiple cause theories provided a list that described multiple causes or one or more of their listed causes as "triggers" or as a "primary contributor" to their getting cancer. They also included the women describing mediated pathways to increased risk for cancer. One woman clearly summed up her description of her multiple causes theory saying, "It's not just one thing; it's all of the things."

In other cases, multiple cause theories appear to be descriptions of epigenetic theories. In our sample, two used the word specifically. One women said; "I have a strong family hx – mother her older sister I'm my mother's "mini me" so I have literally been waiting for this news all my life. But my grad students study genetics & environment and from them, I've learned about the myriad of ways our toxic environment concatenates risk." The other, "Lack of self-love – sedentary, bad food, alcohol, obesity, - pulled the trigger on Heredity epigenetics in a nutshell."

Epigenetics can be defined as changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself. Women described environment gene interactions that might be described as epigenetic theories without using that specific term. Examples included a woman saying, "I think the cause of my cancer is a combination of genetic and environmental factors." Others described interactions between family history or genetic causes and hormones including the woman who responded, "My cancer was caused by HRT but I do have a family history of breast cancer. So, I probably have a gene and hormone replacement just fertilized it." In other cases, stress and poor coping were coupled with genetic causes in mediated theories of cause as described by this woman, "Genetics, and having a tendency to internalize problems (stress)."

3.2.7 Randomness and "Why is not Important"

Ninety-five women (17.0% of the sample) described chance, fate, or randomness as part of their lay theories. References to randomness included citations of the familiar 1 in 8 figure, and statements about how breast cancer "just happens" in some women who have a long life. Women who included randomness in their theories of cause included women who described multiple theories, those who described a single other cause, and those who included only random chance in their discussions.

In addition, some other women expressed sentiments like those of one respondent who said, "I don't have a theory about the cancer. I don't really care why I got cancer. I'm just learning to deal with the changes and new challenges it has brought to my life." Another said, "At a fundamental level, I'm not especially interested in a 'probable cause' for the illness – It's not the most important feature for me." These sentiments were the basis of a code we called "Cause is not important." We included in this code women who explicitly said, "Cause is not important" or "It doesn't matter why." In total, 35 women expressed views suggesting that cause was not their primary concern as a cancer patient/survivor. Five of these women also described a future oriented focus we coded as 'moving forward' (e.g. "I focus on treating it and doing as much as I can to prevent recurrence" or "It is pointless to spend time asking 'why me?' Time should be spent

on personal care and your waged war on cancer.)" In total, 21 women described sentiments about the importance of "dealing with it" now that it has happened or expressed a focus on their health now which we coded as "moving forward". Thirty-five women described benefits they had found or created from the cancer experience.

3.2.8 Confidence about One's Theory

Many women were not confident about their lay theory of the cause of their cancer. Ninety-one women (16.5% of the sample) indicated they were "not sure"/"Didn't know"/ or "had no theory". Although there were no women who left the question blank, absence of a theory was not enough to be included in this "no theory code" women had to say they had "no theory" specifically. Women indicating that "cause does not matter" were not coded as having "no theory" unless they also said so specifically. Forty-one (45%) of those who were "not sure" indicated at least one possible cause. How women felt about not knowing or having no theory they strongly believed in was mentioned by only a sub-sample of these women, but those respondents appeared to find not knowing a cause distressing. In response to the lay theory question one woman said, "I have none, despite much soul searching" and another concluded by writing, "I wish I knew."

3.3 A Negative Association between Family History and Genetic Causes and "Not Knowing"

While reading participants responses, we noticed that although many women in this study said that they weren't confident with their theories of cause, women who mentioned genetic and family history causes seemed less likely than the sample as a whole to describe themselves as "not sure" or to "not know" the cause of their cancer. Further examination found that although 16.5% of the sample as a whole described "not knowing," only seven percent (8 of 110 women) who mentioned genetics indicated that they were not sure or did not know the cause (this included those women with negative genetic test results who reported a lack of confidence in their genetic theories described above. If we had excluded the women reporting negative test results the level of "not knowing" in the genetic group would have been much lower. Only three of the 78 women (3.8%) who described a family history said they weren't sure or "did not know" the cause of their cancer. Again, this includes women who reported, in addition to their family history information, negative genetic test results that made them "unsure" which was reason to code them as "not knowing". Eliminating these women would make the percentage of women unsure in this group vanishingly small.

In light of this, our review of women's comments appears to suggest that women with a family history of disease strongly believe the family history is the cause of their cancer. Multiple women with a family history described their breast cancer diagnosis as if it was expected, even inevitable. In addition to those comments already listed, women's statements included: "There is a lot of cancer in my family tree – so I figured it was just my turn" or "I always had a feeling I was going to get breast cancer because my mom had it at age 44, so I was ready for it when it came." Similar statements were not made about other causes of cancer within this sample.

However, even when a family history was not mentioned, and sometimes when it was clearly stated that there was no family history of cancer, genetics were felt by many women to be a likely

cause of their breast cancer. Genetic testing appears to have confirmed such beliefs when positive but rarely seems to have disconfirmed such beliefs when negative.

4. Discussion

We found evidence consistent with the suggestion that changes in scientific knowledge change lay theories of the cause of an illness [24]. Lay theories of breast cancer's cause reported by newly diagnosed survivors incorporate recent scientific knowledge about genetics as a breast cancer risk including the names of genes currently under study, the knowledge that more genes associated with breast cancer risk might be identified, and epigenetic influences in suggestions that genes can work in combination with other factors. In this sample, 31.3% of breast cancer patients and survivors named heredity or genetics as a cause of breast cancer. While some of these women reported that a family history is a possible cause of breast cancer, then denied it to be causal in their own case because they had no family history, more than a quarter of the women in our study (26%) reported a genetic or family history cause for their own cancer. Since only 5%-10% of breast cancer is linked fsto hereditary syndromes including but not limited to BRCA1/2 [25], these numbers suggest that there are significantly more women who believe they are affected by hereditary risk and genetic mutations than statistically in fact are. While our modest response rate would allow for some disproportion in recruitment with a greater than population rate of women with a reason to believe in a hereditary cause to be enrolled in our study recruitment materials did not mention genetics making this unlikely. Some of our women referring to "genetic disorder" or "mutated gene" or describing gene environment interactions we described as potentially "epigenetic" may have been referring to non-inheritable somatic mutations, but in no case was it 100% clear that this was the case based on what women wrote.

Of possible interest though is that the 26% percent reporting a family history/genetic cause is remarkably similar to the percentage of breast cancer survivors reporting family history to be the cause of their cancer in some of the earliest studies available (26%; Taylor, 1984). It is also much lower than the 77.6% of unaffected women who report knowing that family history and genetics are a possible cause of breast cancer.

The popularity of belief in inheritable causes of breast cancer and some women's apparent reluctance to abandon inheritable theories in light of conflicting evidence, including negative genetic testing, suggests that many women find hereditary and genetic explanations for their cancer particularly satisfying. Even in cases where inheritable risk appears unlikely (e.g. where there is no family history or a negative genetic test was received), some women clearly cling to a belief in hereditary causes for their breast cancer. Others when faced with a negative test result that led them to question their beliefs in genetics as a cause reported finding that distressing.

Differences between the majority of unaffected women who report knowing genetics can be a cause of breast and the substantially smaller percentage of survivors who report it to be the cause of their personal case is likely a result of many women without a family history of disease who know about genetics and the BRCA1/2 genes as possible causes of breast cancer correctly dismissing an inheritable genetic condition as a possible cause of their own cancer. But, may also explain why some women appear to seek genetic causes as explanations for their personal case of breast cancer in spite of evidence against it, and why others discussed genetic and family history explanations for breast cancer, and told us their family history status when it was negative, as a

prelude to their report of non-genetic causes for their cancer. This phenomenon was not unique to genetic causes. Some lifestyle and reproductive risks (poor diet, smoking, abortion) were also mentioned in this way, but most possible causes of cancer were not. None of the women in our study appeared to question the importance of lifestyle causes, family history, or genetics as a cause of cancer in others.

Limitations of this study include the potential non-generalizability of our sample. While half our sample was selected from the local cancer registry and are thus likely representative of women with breast cancer in this region the region is generally well-educated and predominantly white, and the response rate to our recruitment efforts was modest. Users of integrative oncology in this area did not differ from non-users in this area, in most characteristics, including demographics, and most elements of their treatment [20], as reported elsewhere they were slightly more likely than users of conventional care only to discuss stress as a cause of cancer, and less likely to mention random chance as a cause, but did not differ in the frequency of their descriptions of inheritable causes [22]. These women may, however, differ from users of other forms of Complementary and Alternative Medicine.

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Author contributions

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Competing interests

The authors declare that there is no financial conflict of interest.

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