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Exploring Explanatory Models of Risk in Breast Cancer Risk Counseling Discussions NSABP/NRG Oncology Decision-Making Project (DMP)-1

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Abstract

Background—Explanatory models represent patient understandings of etiology, pathophysiology, illness, symptoms, and treatments, but little attention has been paid to how they are employed by patients ‘at risk’ for future disease.

Objectives—To elucidate what constitutes an explanatory model of risk and to describe explanatory models of risk related to developing breast cancer.

Methods—Thirty qualitative interviews with women identified as at increased risk for breast cancer were conducted. Interviews were coded to identify domains of explanatory models of risk using *a priori* codes derived from the explanatory model of illness framework. Within each domain, a grounded thematic analysis described participants’ explanatory models related to breast cancer risk.

Results—The domains of treatment and etiology remained similar in a risk context compared to illness; whereas course of illness, symptoms, and pathophysiology differed. We identified a new, integrative concept relative to other domains within explanatory models of risk: *Social Comparisons*, which was dominant in risk perhaps due to the lack of physical experiences associated with being ‘at risk.’

Conclusions—Developing inclusive understandings of risk and its treatment are key to developing a framework for the care of high-risk patients that is both evidence-based and sensitive to patient preferences.

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Implications for Practice—The concept of ‘social comparisons’ can assist health care providers in understanding women’s decision-making under conditions of risk. Ensuring that health care providers understand patient perceptions of risk is important as it relates to patient decision-making, particularly due to an increasing focus on risk assessment in cancer.

Introduction

Medical practice is increasingly engaging in individual risk assessment to identify populations that may be susceptible to developing future disease. While there may be benefits to targeting early prevention among some high risk groups, conceptually risk is applied to populations, and making deterministic statements about an individual’s risk based on population estimates is far from certain.¹ When statistical estimates of risk are provided to individuals, it implies that their own personal risk is objective and easily measured² and that individuals should act on this objective risk measure.³ However, risk, when understood from a sociological perspective, represents a complex interplay between individual behaviors, structural and social contexts, and embodied risk, that is, risk residing within the body in the absence of manifest illness (e.g. abnormal biopsies that may increase clinical estimates of risk).⁴ Still, risk estimation is frequently given at the individual level as impetus for adopting preventive behaviors.

With an increasing number of conditions identified at the point of risk (vs. manifest disease) and for which such individualized risk estimates are communicated, it becomes increasingly important to further tease out what happens during one-on-one risk communication. Others have shown that risk estimates differ from individual’s risk understanding and may therefore not be used for individual decision-making.^{5–8} However, they have not investigated how different aspects of perceptions, social influences, and ideas about illness come together to inform decision-making.

Theories of risk perception and health behaviors span several disciplines, adopting a range of perspectives and explanations for how individuals form risk perceptions and how perceptions are related to health behaviors. Psychologically-focused theories tend to represent the process by which perceptions are formed as a two-dimensional process.⁹ One dimension represents the analytical, logical, and probabilistic processing that produces perceptions; the other is experiential; that is, it is intuitive, unconscious, and automatic.¹⁰ Medical anthropology and sociology adopt a ‘meaning-centered’ approach to studying risk by characterizing health beliefs to explain why groups of individuals construct health and illness in particular ways. Broader social science literature expands these understandings of risk further into the social and moral world, examining the various influences on ideas of risk.¹ The application of theory to understanding risk perceptions can help explain individual behaviors that deviate from expectations, yet more research is needed to identify appropriate theory for particular contexts. Arthur Kleinman has developed a patient-centered approach to understanding an individual’s beliefs and behaviors with regards to disease which he termed an “explanatory model”.^{11, 12} Kleinman argued that a patient’s understandings of his/her illness need to be taken into consideration in the patient-doctor interactions to ensure appropriate health care delivery, including treatment. He posited that an individual’s understanding of illness are represented in the following categories: of the Etiology,

Pathophysiology, Course of Illness, Symptoms, and Treatments for a given condition¹¹. Explanatory models recognize that illness is experienced through perceptions rooted in our explanations of sickness, social positions, and systems of meaning¹¹, facilitating a multi-dimensional understanding of perceptions. To date, explanatory models have been examined among patients who have experienced manifest disease.¹²⁻¹⁴ However, the focus on meaning of illness from an individual's perspective which characterizes explanatory models may be a helpful framework in understanding how risk perceptions influence health behaviors. Thus, this study applies the explanatory model framework to the context of discussions about breast cancer risk in women who are counseled about treatment options for breast cancer risk. This analysis allows for an understanding of how women attribute meaning to being at risk.

Breast cancer risk counseling with the aim of prevention is common, and we chose this context to explore the social dimension of risk perceptions using explanatory models given more logically-based theories don't accurately describe women's behaviors. The most common reasons why physicians discuss breast cancer risk and treatment options with women are a family history of breast cancer and/or clinical findings that indicate risk, such as biopsy results indicating Atypical Lobular Hyperplasia (ALH), Atypical Ductal Hyperplasia (ADH) or Lobular Carcinoma in Situ (LCIS). Often in such situations, more formal assessments of risk including genetic testing for BRCA1/BRCA2 mutations and the use of risk prediction algorithms¹⁵⁻¹⁸ are used to quantify a women's risk and help guide treatment decision-making for both women and physicians. After identifying women at high risk, physicians may provide recommendations for enhanced screening, behavior changes, or medical treatments (e.g. chemoprevention medications, surgery) with the goal of risk reduction.

Interestingly, while women often overestimate their risk for breast cancer relative to communicated (objective) risk levels,¹⁹⁻²¹ the use of preventive interventions such as chemoprevention medications are seldom adopted by patients for whom these interventions would provide risk-reduction benefits.^{22, 23}

Again, this suggests a more complex relationship between risk perception and health behavior. We therefore investigated if the explanatory model framework can be applied to risk conditions, such as breast cancer risk. Understanding women's meaning-making about a risk diagnosis could impact the development of more patient-centered approaches to managing risk. For example, eliciting and addressing patient understandings of the etiology of risk and cancer, or women's expectations about the trajectory of risk may assist clinicians in counseling about personal risk, risk-reducing behaviors, and preventive treatments. Therefore, this analysis sought to 1) elucidate what constitutes an explanatory model of risk; and 2) describe the explanatory models of risk held by women identified to be at an increased risk for developing breast cancer.

Materials and Methods

Thirty qualitative interviews were conducted among a subset of women participating in a large, mixed-methods National Surgical Adjuvant Breast and Bowel Project (NSABP)/NRG

Oncology Decision-Making Project (DMP)-1 study of the social, cultural, and psychological factors involved in making decisions about breast cancer risk reduction strategies.²⁴ Institutional Review Board approval was received from the two sites where interviews were conducted, and informed written consent was obtained prior to participation.

Participants

Women were recruited for interviews from two large US medical centers: one safety-net academic medical center and the second, a larger comprehensive cancer center. The sites were purposely selected as they serve very different patient populations. One predominantly serves patients from racial and ethnic minorities and medically-underserved groups, while the other is a renowned cancer center including a predominant cancer prevention department. Participants were at least 35 years of age, English-speaking, and were identified as being at increased risk for breast cancer by the health care provider. Women who previously had invasive breast cancer, prior ductal carcinoma in situ (DCIS), previous lobular carcinoma in situ (LCIS) if treated with mastectomy, radiation therapy, or endocrine therapy, or any previous or current use of tamoxifen, raloxifene, or other Selective Estrogen Receptor Modulator (SERM) therapy for any reason, were excluded. Women were also excluded if participating in any other cancer or osteoporosis prevention studies involving pharmacologic interventions.

Women who met the criteria listed above were approached prior to their clinic visit to inform them about the study. The first 30 who agreed to participate in the video recording/ interviews comprised the final sample. This sample was expected to generate enough data to reach theoretical saturation, defined as no new themes arising from the interview data. Other qualitative investigations have reached saturation in fewer than thirty interviews when conducting thematic analyses using similar techniques.^{25, 26}

Data collection

Data were collected from April 2012 through August 2013. Women provided informed consent prior to their counseling session. The visits in which women were counseled by health care providers regarding their individual risk of developing breast cancer and options for prevention were video recorded. Counseling about risk was completed by the woman's physician as per their usual practice; that is, the session content, format, or recommendations were not standardized. All sessions included some discussion of the use of chemoprevention agents, but it was not recommended for all women. A range of topics including, but not limited to: using risk assessment tools, prior biopsy results, lifestyle risk factors, and the benefits/risks of medical interventions were observed, depending on the woman's individual situation. Within one month following the counseling session, the participants returned for a qualitative in-depth interview with a researcher trained in the social sciences. One interviewer at each site was trained by the principal investigator during an initial site visit, with ongoing feedback provided throughout the course of the study. Group telephone conferences with the study team further ensured consistency in the interviewing process.

The interview guide was developed collaboratively by the research team at the Charité – Universitätsmedizin Berlin, and the interviewers at the two local sites and sought to explore

breast cancer risk perceptions and approaches to decision-making. It was based on the study's overall aim and existing literature in the field. The semi-structured interview guides were used flexibly, allowing a conversational flow to the interview, while ensuring all relevant topics to the research questions were covered. Interviewers asked participants about issues discussed during the counseling session, the participant's experience of being at risk for breast cancer, influences on risk perception, social support, and personal approaches to decision-making, both in general and specific to the risk reduction therapies discussed. Written informed consent included permission to audio-recorded the interview.

Each interview was transcribed verbatim by the principal investigator's staff and cross-checked for accuracy by another member of the research team. Transcripts and audio files were entered into MaxQDA for data management and analysis. All participant identifiers were removed from the transcripts for distribution to the site researchers conducting analyses.

Analysis

This is a secondary analysis of the qualitative interview data²⁷ focusing specifically on the portion of the interview related to perceptions and beliefs about risk. We used a grounded thematic approach, applying analytic strategies derived from grounded theory.^{28, 29} The first seven interviews were jointly coded by two authors, who focused closely on identifying emergent (open) codes, seeking to capture all meaningful phrases represented in the interviews. This grounded approach ensured inclusivity in comprehensively identifying constructs salient to women in the explanatory model analysis. After the first seven interviews, the remaining were open-coded by one investigator and reviewed by the second author, a senior qualitative researcher. New codes identified in subsequent interviews were reviewed jointly before being added to the codebook. In a second phase of analysis, open codes were grouped into *a priori* categories that represented the domains of explanatory models as developed by Kleinman and colleagues: Etiology, Pathophysiology, Onset of Symptoms, Course of Illness, and Treatment.¹¹ After relevant codes were grouped into these categories, iterative amendments were made to original definitions through reflection and joint discussion of participant data to understand participants' explanatory models related to breast cancer risk. Through this process codes that did not fit with the explanatory model framework were identified during joint analysis sessions and in consultation with the entire research group. These additional codes were analyzed and used to expand the explanatory model framework to render it applicable to risk. Based on the explanatory model categories, a framework for explanatory models of breast cancer risk was developed with reflections on areas of conceptual linkage and divergence from explanatory models of illness.

Thematic saturation was reached after 20 interviews, after which no new categories were identified, although the additional 10 interviews contributed new perspectives and added variation within categories. To ensure the anonymity of our participants, quotes were edited, including deleting unrelated medical diagnoses or changing characteristics of others mentioned if it was not relevant for the analysis. Quotes are tagged with a letter in the text below, with one letter assigned to each participant along with a range of 5-year breast cancer risk calculated using the Gail score.

Results

Participants

The purposeful site selection was successful in recruiting a sample of 30 women with a range of ethnicities, experiences, and ages. Table 1 displays the demographics and risk characteristics of participants. A range of Gail Model clinical risk estimates was observed in the sample. Of the 30 women sampled, four (13%) had a <1.66% five-year risk estimate. Twelve (40%) had estimates of 1.7–3%, eight (27%) had estimates of >3–5%, and six (20%) had five-year risk estimates of >5%. Seven of the women also reported that they had a history of untreated LCIS found on biopsy, rendering the Gail model inappropriate, but indicating higher probability of developing future invasive cancer.

Overall adaptation of explanatory model framework

We found evidence that many of Kleinman’s categories related to explanatory models were relevant to the context of breast cancer risk: Overall, four of the five original categories were represented in women’s explanatory models of risk for breast cancer: Etiology, Symptoms, Course of Illness, and Treatment. The fidelity of the Etiology and Treatment domains to the original definitions was maintained. For other domains, e.g., Symptoms and Course of Illness, some of the concepts required revision to reflect risk, described in Table 2. There was a lack of evidence in the data that Pathophysiology played a role in developing explanatory models of risk. Risk was not described as changing bodily function or something that was necessarily sensed. In addition, a category had to be added to the model that was not accounted for by Kleinman’s concepts: Social Comparisons. The Social Comparison element captures the phenomenon that risk is consistently evaluated in comparison to others’ experience in the social world.

Specific findings related to each category are discussed below.

Individual categories of the explanatory model framework

Etiology—The original definition of Etiology encompasses what participants perceive to be the causes of risk or illness. The concept of Etiology of risk was very closely aligned with Etiology as represented in explanatory models of illness. Women described a broad range of causes of breast cancer risk, with most describing a multi-modal etiology. One participant describes this multifactorial exposure perspective:

“I just feel like it’s just-- it’s not all genetics. Who knows? It could be a little cocktail of environmental exposure, a little bit of genetic mix up... it’s just something that just-- it happens and you only have so much control. I call it gravity. You just have so much control over that gravity.”

(Participant N, Gail Risk 2.01–3%)

Although many women described the idea that causes of breast cancer risk are multifactorial, they also described individual causes of risk. The most commonly described cause of being at high risk was family. This presented itself in two ways: First, women described genetics or hereditary components of risk. For example:

“I know enough that this is a genetic disease and hereditary and there’s definitely links so I just assumed that I probably was at a greater risk now.”

(Participant O, Gail Risk <2%)

Others described risk as a more general familial trait that isn’t traced scientifically to genetics:

“My mom’s a breast cancer survivor. She has one breast... cancer runs in my family so I get more worried or paranoid than anything else because I know what I come from.”

(Participant L, Gail Risk <2%)

Other common explanations for why women felt they were at risk included: age, lifestyle, environment, biology, stress, or that being at risk was “up to God.” These explanations of the causes of breast cancer risk were used by women to make sense of the information that was provided to them in consultations. Although some of these causes were explicitly addressed by providers (age, biology), others were more reflective of the participants’ experience outside of the medical setting (stress, environment, spiritual).

Treatment—Treatment encompassed the types of interventions that patients believed can be received to manage risk. Treatment, like Etiology, displayed more commonality than divergence with explanatory models of illness. In both illness and risk, individuals formulated and described actions that could ameliorate or reduce illness or risk. Amongst these participants, three broad categories of ‘Treatments’ for risk were inductively identified and described: *Monitoring, Preventive Health Behaviors, and Medical Interventions*.

Monitoring—Monitoring risk encompassed two distinct phenomena: self-monitoring and screening strategies. Self-monitoring involved many women describing being ‘at risk’ as generating a personal responsibility to be aware of bodily changes:

“I think that’s one of the better preventative methods... **being cognizant and aware of your own body**. If you don’t identify certain changes or aren’t aware of things, you might be missed and it can be easily missed in a physical if you don’t bring something to the attention of your physician.” (Participant A, Gail Risk <2%).

Secondly, women described the use of screening strategies such as mammography, ultrasound, clinical breast exams, or other means of tracking and monitoring risk. The idea of monitoring was the most widely recognized and accepted method of reducing risk. Routine screening brought about a cycle of reassurance that risk was not increasing and cancer had not yet developed. As one woman stated, she’ll be “less worried for another year” (Participant G, Gail Risk 2.01–3%).

Preventive Health Behaviors—Preventive health behaviors included interventions such as diet changes, stress reduction, exercise, weight loss, limiting alcohol intake, and quitting smoking as means to reduce risk. Preventive health behaviors were not always recognized as a method to reduce breast cancer risk, but were regarded as important for staying generally

healthy. For example, one woman spoke about the elevated importance of lifestyle because of her high risk status, *“I mean as far as just conventional wisdom I think I knew the healthy lifestyle and exercising and moderation of alcohol and caffeine and things like that, which more or less we try to follow. But now it seems to be more important given the situation.”* (Participant U, Gail Risk 2.01–3%). At the same time, there were mixed reactions to the acceptability and effectiveness of behavior change in reducing breast cancer risk:

“It’s in my face. You know, I’m looking at this going, he quit smoking [a long time ago], he ended up getting lung cancer. In reality, **what are my chances of not getting cancer just because I stop smoking? Obviously they’re not any better than if I’m smoking as such.**” (Participant W, Gail Risk <2%)

This range of responses to preventive lifestyle behaviors represents the joint influences of medical communications about lifestyle risk factors and cultural beliefs about their impact on disease development.

Medical Intervention—Taking medications or undergoing prophylactic surgeries were the two treatments mentioned in relation to breast cancer risk reduction by both participants’ and providers. Descriptions of Treatments for risk seem to present tradeoffs: the severity of risk and chances of getting cancer, versus the risks of the treatments themselves. An exemplar of these tradeoffs is presented by one woman considered to be at a relatively high risk of developing breast cancer:

“So **that was a little bit alarming of the possibility of the side effects of the drugs**, you know, especially at my age and also with me having a [medical condition] that could possibly lead to a stroke, you know. I don’t know which I would prefer-- cancer or the stroke. I think probably cancer because a stroke, I mean that just renders you, you know, not able to function pretty much in a lot of cases.” (Participant J, Gail Risk >5%)

In contrast to behavioral ‘Treatments’ that posed few risks, descriptions of the risks of medical treatments highlighted the importance of what women understand and interpret about benefits and risks of treatments in conjunction with knowledge and beliefs originating outside the medical encounter.

Symptoms—In explanatory models of illness, the definition of ‘onset of symptoms’ relates to why patients think illness started when it did, and the experience of bodily symptoms. In risk, there is generally a lack of experienced bodily symptoms. We thus defined symptoms as the ‘signs’ women interpreted as representing their level of risk. These signs often were the result of screening activities. Signs of risk that women discussed included: mammogram findings, breast pain, atypical cells identified by biopsy, benign breast lumps, and Gail risk estimates. These were the factors that women worried about as increasing their own risk of developing cancer and often were addressed in discussions with their providers during risk counseling.

Course to Illness—The Course of Illness in explanatory model research has focused on several inter-related concepts: the trajectory, seriousness, and severity of illness. Trajectory encompasses the expected path that an illness will take as well as its chronicity. Seriousness

and severity represent perceptions of the threat of illness to daily life. In examining explanatory models of breast cancer risk, we identified some key departures from these definitions, in particular related to the uncertainty of risk in relation to the illness experience. Based on our findings, *Course of Illness* was re-conceptualized as *Course to Illness*.

Course to Illness was framed around assessing the chances of actually becoming ill as a result of a risk diagnosis. It was described through reflections on how and when risk will turn into disease and whether women felt control over their level of risk. There was also some element of assessing the severity of being at risk: it was minimized by some and elevated to disease status by others.

One of the themes expressed throughout the Course to Illness concepts was the inherent uncertainty about the potential path to illness. Women often articulated this uncertainty, which was unique to discussions of risk versus the experience of breast cancer itself. As one woman stated: “*You don’t know, it’s a roll of the dice.*” (Participant AB, Gail Risk 3.01–5%). Potential courses were described as a combination of three dichotomies: inevitability vs. control, uncertain vs. expected trajectory, and risk as an immediate and constant vs. distant threat. Women constructed narratives about their expected courses to illness, describing these themes as the basis of their assessment. For example, one common narrative was that although breast cancer was inevitable because risk would always rise with age, it was nothing to worry about until later in life. One woman expresses this particular path:

“I think right now for me personally, given my age, I’m real comfortable kind of where we’re at now. I think each year we’ll talk about this and I’ll, you know, have to look at it through a different lens ‘cause (...) and my risk factor’s going to continue to increase as it does with age... When talking about, you know, potential options in the future to take medication that may reduce my risk, you know, that to me is a bit off in the distance. (...) I don’t know how I’ll feel in five years or ten years.” (Participant O, Gail Risk <2%)

Another common Course to Illness included risk as an immediate threat with an expected path to breast cancer that required action in order to change the course: “*I can see that this is going to happen and I am doing the right things to minimize the risk... I will do everything that I have to do, improving my eating habits, doing exercise, eating healthy or taking the medicine, everything to minimize that risk.*” (Participant I, Gail Risk >5%)

Alternatively, risk was described as uncertain and distant, with no expected trajectory, but able to be controlled with actions taken in the present:

“I’m thankful if anything else that ... I got kind of a heads up or a flag that says hey this might be down the road and then also thankful that **I have the possibility of doing something.**” (Participant U, Gail Risk 2.01–3%)

Pathophysiology—Pathophysiology was defined by Kleinman and colleagues as what illness does to the body and how it operates to make one experience illness. This concept had no identified corollary in the setting of risk in this sample. We identified a few descriptions of Pathophysiology, but these were solely related to cancer itself, rather than to cancer risk. For example, one woman described breast cancer as follows:

“It seems like it really progresses and you can see how it just eats away at the tissue in your breast and just how ugly it really gets inside.” (Participant J, Gail Risk >5%)

The nature of risk may not be conducive to thinking about bodily changes in the absence of an illness experience. Alternatively, our questions may not have allowed for this concept to be identified within the context of this interview, as we did not specifically probe for ideas of Pathophysiology. Further work is required to understand the role of Pathophysiology in explanatory models of risk.

Social Comparisons—In addition to the domains previously identified as relevant to individuals’ explanatory models of illness, we identified a critical theme that ran through women’s narratives about risk. When discussing breast cancer risk, women frequently relied on comparing their behaviors and risk to that of others in their social networks as a means of formulating perceptions. Thus we identified the category of ‘social comparisons:’ the process by which individuals produce and describe their explanatory models of risk. Women consider attributes of other people they know in the social world who develop cancer in order to evaluate and personalize their own risk. Social comparisons involved an evaluation or understanding of how personal risk estimates related to others’ risk, the experience of being at risk, or having cancer. This was indeed a critical element of how women conceptualize risk, which informs all the other domains of the explanatory model of risk. It is clear that perceptions were not based solely on what women learned from medical providers or others, but rather were negotiated in relation to the social world where knowledge and belief systems are formulated. This process involved an explicit evaluation of the self in relation to others in the social world that has not previously been described using data related to illness models. Below are examples of how this concept was manifested in this sample of women:

“I understand the whole cell dividing but I have a very different lifestyle than my mother did... where I’m just trying to be very healthy and we’re [of a] different make up... but I feel like I’m mirroring my father.” (Participant N, Gail Risk 2.01–3%)

“I know that, it [cancer] could happen. It is so scary that I might do the same thing [my grandmother] did because I had a knot in my breast [long time ago]... you have something and everybody thinks it’s cancer, it’s cancer, it’s cancer. I stayed in denial for [awhile] without even going to the doctor so I’m thinking, ‘will I be reliving her life now that I’m just sittin’ up here?’” (Participant Q, Gail Risk 2.01–3%)

These quotes demonstrate how women incorporate their knowledge of the social world and contextual experience to compare themselves to others as a means of ascertaining their own risk.

Discussion

Understanding patient perceptions of risk and engagement with a risk diagnosis is critical in a time when we increasingly screen for undetected disease and propose preventive

treatments. Health care activities frequently emphasize risk assessment and preventive activities to minimize risk for conditions such as cardiovascular disease, diabetes, and cancer, with the expectation that discussing these risks will promote patient engagement in preventive behaviors. Patients' understandings of risk are vital in designing prevention activities, yet thus far patient perceptions of risk and the acknowledgement that there is a legitimate gap between epidemiologically calculated risk, a medical perspective on risk, and individuals' perceptions of risk have not factored into the design of prevention strategies.

Explanatory models have been a useful framework for understanding patient perceptions of illness.¹² We have been able to develop the concept of an explanatory model of risk, which helps understand how women attribute meaning to a risk diagnosis. While some categories that are important in creating meaning in illness contexts such as Treatment and Etiology are also of importance in a risk context. However, other categories such as Course of Illness, Symptoms, and Pathophysiology differed. Most importantly, we identified a new category which is important to attribute meaning to a risk diagnosis: Social Comparisons, which perhaps becomes more dominant in a risk context due to the lack of physical experiences associated with being 'at risk.' Before individuals engage in prevention behaviors, they first evaluate if for them disease is a real possibility. The category of Social Comparison seems to be one of the deciding categories in this evaluation.

By using breast cancer risk assessment as an exemplar to examine explanatory models of risk, we identified several examples of divergence between lay and biomedical conceptions of risk. One example of this was related to familial risk in the category of Etiology of risk: Most breast cancers are sporadic in nature, with only 5–10% associated with specific, known genetic mutations. However, many women described holding a perception that once any family member is diagnosed with breast cancer, their own chances of developing breast cancer increase significantly either due to genetics or more general family associations. This broad view of familial associations related to risk is incongruent with the more narrowly-focused, Mendelian genetics view of medical risk. This divergence has been similarly noted by others.^{30–32}

One of the key aspects of explanatory models of risk that we identified in this study was the addition of Social Comparisons. Social Comparisons are a means by which the women in our study integrate and navigate different ways of thinking and are part of broader cultural models. Explanatory models are always formed and negotiated within a social context, but the experience of being 'at risk' without manifest disease elevated the importance of others' experiences. The inherent uncertainty and lack of identifiable illness meant that women looked for outside cues and social evidence to think about their risk status and to make it meaningful for themselves rather than focusing on internal bodily indicators. This is a departure from current illness explanatory model frameworks. It is also an example of the divergence between lay and biomedical assessments of risk. For example, for biomedical conceptions others are only of relevance with regards to their genetic relationship in a risk assessment. In contrast, in our sample, women talked about family broadly and made social comparisons in assessing their own susceptibility to breast cancer. Another analysis of this data, which focused on the decision-making process on SERM use and how the counseling of an HCP influences this decision, developed a similar concept: "proximity to cancer."

Proximity to cancer reflected the idea that for women comparisons with regards to similarity to a person who had experienced breast cancer was more important than a genetic relationship for SERM decision-making.³³ Similarly, Pfeffer³⁴ has described a similar concept that she coined ‘candidacy’ for breast cancer to explain why women do or do not participate in breast cancer screening programs. Candidacy represents the personal characteristics and lifestyles that make some people more/less likely to develop a disease. Pfeffer found that in breast cancer screening, women placed a lot of emphasis on comparing moral and biographical details of candidates’ reproductive histories. The concept of social comparisons is similar, although establishing ‘candidacy’ is more limited in scope. Social comparison includes candidacy, social evidence, and evaluations of positioning of risk are integrated with the social context and other pieces of explanatory models to produce a risk identity.

This study assessed women whom clinical providers knew before the appointment would discuss treatment options for breast cancer risk reduction based on the reason of the clinic visit. This limits the sample to women who either have a family history of breast cancer or who needed to discuss a breast biopsy result. The limited sampling frame restricts inferences that can be made about the broader population undergoing screening. In order to fully explicate what explanatory models of risk look like and their influence on decision making, expanding this work to women at all levels of risk and into other health risks is necessary. The women in the sample had different ethnic, social, and regional background. Interestingly, these differences played no role for the categories of meaning-making of the explanatory model. Thus, we did not add this info to the quotes to ensure anonymity. Further analysis is required to examine if and how different backgrounds (race, ethnicity, culture, socioeconomic status) influence how within these categories decision-making may be influenced differently. Further, these women were primed to discuss their risk following a medical encounter that specifically involved personalized risk counseling. Others who do not undergo these specialized services may provide different perspectives that are not accounted for in these data.

Implications for Practice

The range of conditions that are known to increase the probability of developing manifest disease are on the rise, particularly with new diagnostic tools becoming available. However, what such risk conditions mean for an individual is not well understood. It is evident that risk perception and health behavior are complex and preventive behaviors do not (and perhaps should not) rest on the results of a medical risk assessment alone. Understanding how patients attribute meaning to a diagnosis that tells them that they have a risk for a disease is a necessary pre-requisite to understanding how they may deal with this risk. Health care that aims to guide such decision-making needs to know about the meaning-making processes. Kleinman developed the explanatory model framework particularly for use in clinical settings to help health care providers make sense of their patients’ behaviors. To do so he developed a range of questions based on the categories of the explanatory model to ensure patient-centered care such questions are paramount. Based on the findings of the presented analysis, we suggest that risk counseling for breast cancer should include an assessment of the explanatory model of risk domains that are relevant: the Etiology,

Treatment, Symptoms (signs) of risk, and Social Comparison categories. For example, one may ask, ‘How do you compare yourself to family members who have had a diagnosis of breast cancer?’ and ‘In what ways is breast cancer risk worrisome for you?’. To ensure a patient-centered care approach, using these updated questions in situations related to risk (vs. illness) may guide elicitation of the meaning a woman attributes to her risk diagnosis and guide future preventive interventions.

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Table 1

Study participant characteristics: NSABP DMP-1

	N (%)
Total N	30 (100%)
Race/Ethnicity	
Non-Hispanic white	19 (63%)
Hispanic white	2 (7%)
Hispanic unknown	2 (7%)
African American	6 (20%)
Mixed race	1 (3%)
Marital status	
Married/Living as married	19 (63%)
Widowed	2 (7%)
Divorced	4 (13%)
Never married	5 (17%)
Insurance	
Medicare	3 (10%)
Medicaid	1 (3%)
Private	24 (80%)
Self-Pay/Uninsured	2 (7%)
Highest grade of schooling completed	
High School/GED	6 (20%)
Vocational/Technical/Associates degree	3 (10%)
Some college	5 (17%)
College	9 (30%)
Graduate/Professional degree	7 (23%)
Income	
< \$30,000	4 (13%)
\$30,000 – \$50,000	4 (13%)
\$50,000 – \$80,000	3 (10%)
> \$80,000	16 (53%)
Missing	3 (10%)
5-Year Gail Model Risk	
< 1.66%	4 (13%)
1.7 – 3%	12 (40%)
3 – 5%	8 (27%)
> 5%	6 (20%)
Age (years) (Mean, SD^a)	50.9 (9.3)

^aSD: Standard deviation

Table 2

Brief descriptions of explanatory model domains: NSABP DMP-1

	Original definition	Amended definition
Etiology	Why am I ill? Why do I have this?	Why am I likely to get that?
Onset of symptoms	What am I feeling?	Are there ' signs ' of my risk?
Pathophysiology	What is happening in my body?	<i>Not described in risk context^a</i>
Course of illness	What will happen to me? How serious is this illness? Is it acute, chronic, or will I be impaired?	How will my risk turn into a disease? What are my chances of actually becoming ill? Am I able to control my level of risk? This was re-labeled as Course to Illness
Treatment	What can I take or do to resolve my illness? How acceptable are my options?	What can I take or do to lower my chances of becoming ill? How acceptable are these different options?
Social comparisons	<i>Not described in illness context^b</i>	What is it about people that causes them to be at risk? How am I like or unlike people who get this?

^aNo amended definition.^bNo original (*a priori*) definition.