Published in final edited form as:

Med Decis Making. 2019 April ; 39(3): 217–227. doi:10.1177/0272989X19827258.

Understanding Decision-Making about Breast Cancer Prevention in Action: The Intersection of Perceived Risk, Perceived Control, and Social Context: NRG Oncology / NSABP DMP-1

Christine M. Gunn, PhD^{1,*2}, Barbara G. Bokhour, PhD^{2,*3}, Victoria A. Parker, DBA^{2,*4}, Tracy A. Battaglia, MD, MPH¹, Patricia A. Parker, PhD⁵, Angela Fagerlin, PhD^{6,*7,8}, Wort McCaskill-Stevens, MD, MS^{9,10}, Hanna Bandos, PhD^{9,11}, Sarah B. Blakeslee, MSc¹², and Christine Holmberg, PhD^{9,12,*13}

¹Boston University School of Medicine, Section of General Internal Medicine, Women's Health Unit, Boston, MA

²Boston University School of Public Health, Department of Health Law, Policy, and Management, Boston, MA

³Center for Healthcare Organization and Implementation Research Department of Veterans Affairs, Bedford, MA

⁴University of New Hampshire, Durham, NH

⁵Memorial Sloan Kettering Cancer Center, Psychiatry & Behavioral Sciences, New York, NY

⁶University of Michigan, Ann Arbor, MI

⁷University of Utah School of Medicine, Department of Population Health Sciences, Salt Lake City

Corresponding Author: Christine M. Gunn, PhD, Boston University School of Medicine, Section of General Internal Medicine, 801 Massachusetts Avenue, First Floor, Women's Health, Boston, MA, USA, 02118, Ph: 617-638-8036 / Fx: 617-638-8096, Christine.Gunn@bmc.org.

*where the research was conducted

Contributions

All authors certify that they meet the criteria for authorship, and have given final approval of the submitted contribution, and that they have participated sufficiently in the authorship of the work (i.e., contributing to the content of the work) to take public responsibility for at least part of the content therein.

Christine M. Gunn, PhD: Acquisition of data, analysis and interpretation of data, critical revision for intellectual content, administrative/technical, or material support.

Barbara Bokhour, PhD: Conception and design, analysis and interpretation of data, critical revision for intellectual content, supervision.

Victoria A. Parker, DBA: Analysis and interpretation of data, and support.

Tracy A. Battaglia, MD, MPH: Acquisition of data, analysis and interpretation of data, critical revision for intellectual content, supervision.

Patricia A. Parker, PhD: Acquisition of data, analysis and interpretation of data, critical revision for intellectual content.

Angela Fagerlin, PhD: Conception and design, critical revision for intellectual content, obtaining funding.

Wort McCaskill-Stevens, MD, MS: Conception and design, acquisition of data, critical revision for intellectual content, obtaining funding, administrative/technical or material support and supervision.

Hanna Bandos, PhD: Analysis and interpretation of data, critical revision for intellectual content, administrative/technical, or material support.

Sarah B. Blakeslee, MSc: Acquisition of data, analysis and interpretation of data, critical revision for intellectual content, administrative/technical or material support.

Christine Holmberg, PhD: Conception and design, analysis and interpretation of data, drafting of and critical revision for intellectual content, obtaining funding, administrative/technical or material support.

Potential Conflict(s) of Interest

All authors declare no potential conflict(s) of interest.

⁸Salt Lake City VA Informatics Decision-Enhancement and Analytic Sciences (IDEAS 2.0) Center for Innovation, Salt Lake City, UT

⁹NRG Oncology, Pittsburgh, PA

¹⁰Community Oncology and Prevention Trials Research Group, National Cancer Institute, National Institutes of Health, Bethesda, MD

¹¹The University of Pittsburgh, Pittsburgh, PA

¹²Institute of Public Health, Charité – Universitätsmedizin, Brandenburg, Berlin, Germany

¹³Institute of Social Medicine and Epidemiology, Brandenburg Medical School Theodor Fontane, Brandenburg, Havel, Germany

Abstract

Background: Literature on decision-making about breast cancer prevention focuses on individual perceptions and attitudes that predict chemoprevention use, rather than the process by which women decide whether to take risk-reducing medications. This **secondary analysis** aimed to understand how women's perceptions of breast cancer risk and locus of control influence their decision-making.

Methods: Women were accrued as part of the NRG Oncology/National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1, a study aimed at understanding contributors to chemoprevention uptake. Thirty women participated in qualitative in-depth interviews after being counseled about chemoprevention. Deductive codes grouped women based on dimensions of risk perception and locus of control. We used a constant comparative method to make connections among inductive themes focused on decision-making, deductive codes for perceived risk and perceived locus of control, and the influence of explanatory models within and across participants.

Results: Participants were predominantly non-Hispanic white (63%), with an average age of 50.9. Decision-making varied across groups: The high-perceived risk/high-perceived control group used "social evidence" to model the behaviors of others. High-perceived risk/low-perceived control women made decisions based on beliefs about treatment, rooted in the experiences of social contacts. The low-perceived risk/low-perceived control group interpreted signs of risk as part of the normal continuum of bodily changes in comparison to others. Low-perceived risk/high-perceived control women focused on maintaining a current healthy trajectory.

Conclusion: "Social evidence" plays an important role in the decision-making process that is distinct from emotional aspects. Attending to patients' perceptions of risk and control in conjunction with social context is key to caring for patients at high risk in a way that is evidence-based and sensitive to patient preferences.

Keywords

Breast cancer; prevention; decision-making; risk perception

Introduction

The clinical practice of counseling women on breast cancer screening and prevention has been moving toward a tailored, risk-based approach.^{1,2} One decision to be made is whether or not to use chemoprevention agents to reduce the risk of developing breast cancer. Selective Estrogen Receptor Modulator (SERM) agents such as tamoxifen and raloxifene are efficacious and reduce risk by approximately 50%.³ However, when comparing the proportion of the population that would derive benefit versus those who take SERMs, we find that these agents are underutilized in the United States.⁴ This is due, in part, to complex risk-benefit tradeoffs that are difficult to utilize in decision-making.⁵⁻⁷

To better understand decision-making about chemoprevention, we conducted a national, mixed-methods study, to understand social, psychological, and environmental factors related to SERM use. Quantitative results indicated that health care provider recommendations, perceptions regarding medication use, breast cancer worry, trust in doctors, having family members with blood clots, and others' experiences with SERMs, all independently predicted SERM use.⁸ These factors are consistent with prior research in this area.⁹⁻¹² Using a qualitative cross-case synthesis method to examine the role of provider counseling in SERM decision-making, we found that health care provider framing of the decision as non-urgent or reversible, plus alignment of the provider's recommendation with one's own perceptions of the need for chemoprevention were important decisional factors.¹² To further our understanding of how women conceptualize their own breast cancer risk, we also used these qualitative data to develop an explanatory model of risk.¹³ Explanatory models are individuals' representations of disease developed from their understanding of the etiology, pathophysiology, course of illness, symptoms, and treatments for a given illness and influence how people make choices about their health and illness.¹⁴ We found that explanatory models needed an additional domain, which we called "social comparisons," to be applicable in a risk context. "Social comparisons" were the means by which participants integrated the experiences of others to formulate a representation of personal risk in the absence of experiencing symptoms.¹³ The research presented here builds on our development of an explanatory model of risk, to examine how concepts of risk and control represented in women's explanatory models subsequently contribute to how they experience the decision process.

Both conceptual and applied research have identified that one's perceived ability to control his or her health (locus of control) influences participation in prevention behaviors. The literature on decision-making about breast cancer prevention has focused more on the outcome of use (yes/no) than on the process by which women decide whether to take a preventive medication or not. Existing studies often utilize hypothetical scenarios rather than exploring actual decision-making in real time.^{11,15} How women integrate individual attitudes, perceptions, and practical considerations in the process of making a decision remains unclear. Using explanatory models as a basis for describing participants' conceptualization of risk, this research seeks to understand how the two established factors in decision-making, of women's perceptions of breast cancer risk and locus of control, influence their decision-making process related to breast cancer risk reduction.

Methods

Study Design

This qualitative, secondary analysis used 30 semi-structured interviews conducted with a subset of women participating in the NRG Oncology/National Surgical Adjuvant Breast and Bowel Project (NSABP) Decision-Making Project-1 (DMP-1).^{8,12} Two sites were purposely selected for qualitative interviews to elicit a sample with representation from racial and ethnic minorities that have historically been underrepresented in breast cancer prevention studies.¹⁶ We received Institutional Review Board approval from both sites where interviews were conducted.

Sample

The DMP-1 study included English-speaking women at least 35 years of age, who were identified as being at increased risk for breast cancer by their health care provider, and were expected to discuss breast cancer risk and use of SERMs with their provider. Women with a history of invasive breast cancer, prior ductal carcinoma in situ, previously treated lobular carcinoma in situ, or any use of a SERM therapy, were ineligible. Women were also excluded if they were participating in another cancer or osteoporosis prevention study involving medication. Thirty women were targeted for the qualitative portion of the study because others had reached saturation in fewer than 30 interviews when conducting thematic analyses using similar techniques.^{17,18}

Data Collection

Women who agreed to be interviewed were provided written informed consent before their clinic visit. We video recorded the clinical encounters in which participants were counseled about their individual risk of developing breast cancer and options for prevention. The video data have been described elsewhere, were the focus of the main qualitative analysis, and were not analyzed here.¹² Participants returned for a qualitative in-depth interview within one month, which was audio recorded. The flexible, semi-structured interview guide explored breast cancer risk perceptions and approaches to decision-making. As Blakeslee et al. described, the interview guide was developed based on a literature search, a prior pilot study,¹⁹ and the study aims.¹² 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 generally and specific to the risk reduction therapies discussed.

Each interview was transcribed verbatim by the principal investigator's staff. All analytical materials were uploaded into MaxQDA qualitative coding software (v.11, Foxit Software Company, Fremont, CA USA) in preparation for analysis.

Data Analysis

We used data that had previously been coded into explanatory model domains as an organizing structure to assist in identifying salient sections of interviews relating to perceived risk and control. Coded segments representing the explanatory model domains of "Course to Illness," "Symptoms," "Etiology," "Treatment," and "Social Comparisons," were

examined to characterize whether each participant 1) expressed high or low concern about the risk of developing breast cancer, and 2) expressed high or low levels of control over the stated level of risk. Two authors initially coded 12 transcripts independently, characterizing perceptions of perceived risk and perceived control as high/low for each participant and then coming together to assess coding concordance. Nine of 12 transcripts were coded concordantly at first pass on the perceived risk dimension, and 10 transcripts achieved coding concordance on the perceived control dimension. Salient examples supporting categorizations were discussed and reviewed with a third author to attain consensus. The remaining 18 transcripts followed the same process.

After characterizing each transcript based on deductive codes related to perceived risk and control, we began a process of inductive coding to identify themes related to participants' decision-making processes and to allow for a grounded examination of the study question.^{20,21} Two authors used a line-by-line coding process to capture any instances in which participants were describing how they made a decision. These codes were grouped into themes and reviewed by the team. We then identified commonalities and differences in how participants came to make decisions about risk reduction behaviors by examining how themes were represented within and across groupings of perceived risk and control. We used a constant comparative method²⁰ by making connections among inductive themes, deductive codes for perceived risk and perceived locus of control, and the influence of the explanatory model domains within and across participants.

Results

Demographics of the study sample are shown in Table 1.^{12,13} Briefly, the sample of 30 participants was predominantly white (63%), with 20% African American participants and 14% of Hispanic ethnicity. Eighty percent had private insurance, and 53% of had college or higher degrees. Mean age was 51 years, and a range of 5-year risk values were represented with 47% having greater than 3% 5-year risk.

Participants were grouped into four categories based on deductive coding of their perceptions of risk and **perceived** control over risk: (1) high-perceived risk and high-perceived control over risk (n=8), (2) high-perceived risk and low-perceived control over risk (n=7), (3) low-perceived risk and high-perceived control over risk (n=9), and (4) low-perceived risk and low-perceived control over risk (n=6). Examples of participant quotes supporting these categorizations are presented in Table 2. Provider recommendations and participants' decisions regarding SERM use across groups are in Table 3. One common inductive theme among the groups was a focus on "social evidence." Across groups, participants who perceived high levels of control, regardless of risk perception, appeared to account for their decisions by demonstrating self-efficacy in participating in risk-reduction behaviors established either through "social evidence" or because behavioral interventions were aligned with perceptions of broader health beliefs and behaviors (See Table 2 for examples). Below we highlight distinct themes representing how women proceeded through the decision-making process in each group.

The high-perceived risk/high-perceived control group used positive and negative "social evidence" to model specific behaviors that they had seen others adopt (or not adopt). Participants in the high-perceived risk/low-perceived control group made decisions in part based on beliefs about treatment, which were rooted in the experiences of those around them. The low-perceived risk/low-perceived control group interpreted signs of risk found during the screening process as part of the normal continuum of bodily changes when compared to those in their social context. Finally, the low-perceived risk/high-perceived control group had few identifiable links between "social evidence" and risk reducing behaviors. This group instead focused on their ability to manage and maintain their current health trajectory through a variety of methods. These patterns may be useful in identifying targeted strategies that address the social context related to both risk perceptions and beliefs about control.

High-perceived Risk/High-perceived Control

Eight participants expressed high-perceived risk and feelings of high control in reducing that risk. These participants were characterized by language suggesting that risk was a serious phenomenon prompting action; in fact four of the eight decided to take a SERM.

All participants in this group described either a model of success or a model of failure that was central to how they thought about controlling their own risk, regardless of what type of risk-reduction method they adopted. The "social comparison" domain of explanatory models identified in the adapted risk-focused framework was very important to this group, particularly in relation to their perceived ability to control risk. Inductive coding identified that participants used "social evidence" (the experiences of those around them) to describe how each found control in accomplishing risk-reduction (i.e., through lifestyle changes, medications, or monitoring). Social ties discussed in narratives took a range of forms: some looked to familial experiences, faith, friends, or even physician narratives to describe their reasoning for choosing particular preventive behaviors. For instance, one participant used a friend's cancer experience as a motivator to adopt preventive behaviors, believing that monitoring and SERM use together could control high risk:

"I had a friend [who] brought me the first day, [who was] a [one-] year breast cancer survivor. So my thing is I get a chance. She didn't. She didn't have a chance. She's gone through the chemo, she's gone through the radiation, she's gone through the breast surgery. She had to have a mastectomy. She's gone through all that. So I felt that was my chance; God gave me the chance to try to prevent it."

(Participant K)

This participant describes her friend's missed opportunity for prevention and her subsequent experience with cancer and its treatment as evidence that she should take advantage of prevention options available to her.

A second participant described a form of negative "social evidence" as the rationale for why she decided not to take a SERM. Instead, she focused on her belief that she was the only one who could control her risk.

"I just feel like I don't want to take that pill. I have a personal reason for not wanting to take it. My son had Addison's disease, and they put him on all kinds of prescriptions for that, and when one pill would cause side effects they'd put him on another one. And when he died, I think he was on about 15-20 pills a day, each pill treating another symptom of another pill or an ongoing symptom of his actual disease. And so I watched that happen and I watched the personality changes, the mood swings, and all of the things, and I felt like he got trapped. Not purposefully, just incidentally he got trapped in a lot of the things that doctors are trying to do to help relieve one thing or another. If I can I want to avoid that."

(Participant V)

This participant's perception of treatment was influenced by her son's situation and the level of trust she put in medical institutions. Her interview discussed a sense of control through focusing on making lifestyle changes related to her diet and exercise regimen. Narratives such as this were typical of participants in this group, who used positive and negative "social evidence" to describe their decisions about risk-reduction behaviors.

High-perceived Risk/Low-perceived Control

Seven participants were identified as being highly concerned about their risk, but expressing that they felt little control over it. These participants described risk as serious and perceived breast cancer as an inevitable outcome of their risk trajectories. Still, three of these women chose to take a SERM. One participant expressed these feelings of inevitability, saying,

"I feel, 'Oh nothing's going to happen to me. That's just them. [Cancer's] going to skip me'. No, nothing skips. Sooner or later it comes, you know, so I just gotta deal with it."

(Participant L)

Inductive codes that described the decision-making process in this group related to ideas about treatment for risk. Some suggested that a change in risk should not necessitate medical intervention as illness would. For example, one participant alluded to the conditions under which she would find taking a medication acceptable:

"With the way they went out and the reps would sell it to the physicians to get the physicians to work with the lower cholesterols - - you actually convince a patient they're sick through the conversation through the physician because the pharmaceutical company has sold this off to the physicians... [A drug] is something I take for migraines because it allows me to function when I get my migraine headaches. I take one and it curbs the headache enough that I can continue to work or not be impaired...and the risks [migraine vs breast cancer] just aren't the same."

(Participant B)

This quotation highlights mistrust in the idea that drugs can change the course of risk by drawing parallels between cancer risk and high cholesterol as a risk factor for heart disease. The participant's language suggests that she believes medical interventions for problems that signal risk to be a conspiracy generated by drug companies and physicians. She contrasts

risk situations with the experience of migraines, where she feels medications are needed. Narratives in this group focused around how risk-reduction options fit in with participant's explanatory models related to treatment, with decisions formed around whether or not women accepted the rationale for treatment of risk.

Low-perceived Risk /High-perceived Control

Nine women in the sample felt that they were at low risk for developing breast cancer, despite their objectively high risk defined by the Gail Model, but also felt they were able to manage or control this limited risk. This group had the lowest rate of deciding to take a SERM: Two of nine decided to take a SERM, but also two remained undecided at the time of the interview. These women expressed risk as uncertain and/or something that could become serious over time. Inductive themes emerging in this group related to being healthy and their role in maintaining a positive health state. As one participant said,

“I feel like I'm doing everything I can to obviously monitor my risk and manage it but I just don't feel like I worry about it. I don't really think about it for myself. I think it's one of those things that I think, ‘Oh, that'll never happen to me.’ It could happen, you know, and if it does you deal with it.”

(Participant O)

Through monitoring, women in this group described the way they managed their risk. They expressed how they felt generally healthy and sought to maintain their own health in order to keep breast cancer risk low. Actions to reduce breast cancer risk therefore aligned with other health risks that they managed through behavior. In this way, they expressed feelings of empowerment over their own course of risk. For example:

“I'm just gonna watch my health - - what I eat and drink, and try to work out, and just take care of my body. And it's like I think I'll be fine.”

(Participant M)

This group of participants universally expressed self-efficacy in maintaining current health along with the expectation that this course would continue, which was described as part of their rationale for adopting behavioral and lifestyle mechanisms of risk reduction.

In conjunction with expressions of self-efficacy in maintaining a health trajectory that did not lead to illness, having a personal responsibility to be aware and vigilant emerged as a central theme in these narratives:

“I think you have to take care of your own health and, you know, you can't just let this up to your gynecologist or someone to say, ‘Oh by the way, I think you're at increased [risk] -- you need to do this or that.’ You need to be on top of all these things.”

(Participant AA)

“I would say I'm not hyper vigilant, but I'm rather vigilant about what's going on in my body. I feel like I'm very aware of changes and differences in my body.”

(Participant U)

This group was distinct from the others in how they described awareness as central to their decision-making process and actions they adopted, which is a very personally focused concept rather than a social one. Even the two participants who did choose to take a SERM for risk reduction accounted for this choice using the rationale of being healthy and seeking to maintain this state:

“I can see that this [breast cancer] is not going to happen and I am doing the right things to minimize the risk. Okay, but at the end, you know, I will accept the things that I can. 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. At the end I don't know.”

(Participant I)

This focus on maintaining a course that avoided future illness was key to the decisions of these women, regardless of whether they planned to adopt lifestyle changes, enhanced monitoring and early detection practices, or medical interventions to reduce risk. Many women in this group viewed breast cancer as one health risk among many and spoke about risk-reduction activities as applying to several potential threats.

Low-perceived Risk/Low-perceived Control

Six participants were categorized as having perceptions of not only low risk but also low levels of control over risk. Experiencing "signs" of risk were important to these participants, three of whom had abnormal biopsy findings (I.e., atypical ductal hyperplasia), and another three having other physical findings such as benign cysts. Two of these women decided to take a SERM, whereas another remained undecided. Consistent with perceptions of low risk, their narratives indicated that "signs" of risk were interpreted over time as normal, resulting in little concern regarding breast cancer risk:

“I don't feel like I have a concern right now so that's - - maybe that's why I don't think about it often... It's been like this for probably about five years where I go for a mammogram, go for the ultrasound. They aspirate sometimes, they don't aspirate, the cysts fill back up and they've always been just benign. So I guess no, I'm not concerned right now.”

(Participant N)

“I didn't worry 'cause, you know, like I talked to my sisters and we prayed over it and everything and yeah so... I was thinking it must not be anything if they haven't brought me in before now.

Interviewer So it was kind of reassuring that it wasn't a brand new thing?

Participant "Yeah.”

(Participant W)

These participants interpreted their own signs of risk as normal in light of others in their social context or from cues given by providers. Many had previous experience with abnormal findings, and the fact that abnormalities found on mammograms or ultrasounds

were "not new" was reassuring. These participants used their social contexts to normalize their experiences when they found signs of risk, suggesting that provider communication about increased risk was not of concern to them.

Inductive coding in this group illuminated risk-related beliefs that were unique to this group. First, some described risk is just a chance or possibility: *"Everybody's at risk, I guess. And I guess I am at a small risk now with the breast cancer, 'cause I think everybody's at risk"* (Participant X). Alternately, risk was thought to be theoretical: *"As far as risk factors, I think getting up in the morning and getting out of bed can be a risk and if- to me if there's not some kind of proof..."* (Participant AD). The lack of overt **symptoms** led to a perception of low risk and a rejection of the medical paradigm suggesting that risk should be intervened upon. Instead, this group voiced the importance of regular screening as part of their activities. Women who participated in lifestyle prevention behaviors saw them as a benign way to address a variety of health risks; they were less optimistic about what impact these actions would have on breast cancer risk specifically. Unlike participants who expressed low levels of risk perception and high levels of control, these participants did not hold firm beliefs about the utility of behaviors to manage risk.

Discussion

We have attempted to shed light on the process of decision-making for chemoprevention and on how perceptions of risk and control together create narratives focused on particular aspects of explanatory models. Others have similarly identified these as key features in identifying oneself as "at-risk" for disease.²² A recent national survey suggested that patient knowledge of decisional processes in cancer screening and medication use were poor, and that many patients have little knowledge of the benefits and risks of these risk-reducing interventions.²³ Although providers should certainly strive to maximize knowledge of medication risks and benefits, decision-making does not rely on a rational weighing of risks and benefits.^{19,24} Our study demonstrates that that knowledge and logic are not often the driving forces behind decisions. Physicians require support in assessing risk perceptions, counseling about available options, and engaging patients in effective shared decision-making.²⁵⁻²⁷ Our results suggest that women have deeply held beliefs about treatments, risk, and how it can be minimized, which influenced their decisions. Additionally, these findings highlight the important integration of individual perceptions and social context when women are provided with personalized risk information, suggesting several implications for clinical practice.

There are many noted barriers to counseling about risk and prevention in populations that do not share the biomedical view of breast cancer, symptoms, treatment options, and screening guidelines.^{28,29} Beliefs and personal perceptions that are discordant with actual risk are common³⁰ and remain after personalized risk information is provided.³¹ Women who know the most about the risks and benefits of chemoprevention may actually be less likely to indicate they would take the drug if at high risk,³² especially given perceptions of the negative side effects. In the current study we saw higher rates of deciding to take SERMs than had been previously documented, both in the main study (44.6%) and in the qualitative sample (33%).⁸ This could be an artifact of study participation and/or the settings in which

this study took place. It should also be noted that we have not captured actual use or adherence, which may be correlated with decisions, however, studies have shown considerable differences between self-report and monitoring.³³ It is clear from our results that exploring the integration of different perceptions behind beliefs is also important. For example, the way in which participants described how they used "social evidence" to develop perceptions about the utility of using medication to reduce risk may help providers understand the decision process. The quantitative DMP-1 study showed that knowing someone with a good or a bad experience with tamoxifen or raloxifene influenced uptake.⁸ This is consistent with a recent study of women at high risk of breast cancer, which concluded that prior perceptions about risk and treatments influenced intentions for adopting risk-reducing behaviors and are important to elicit in risk counseling encounters.³⁴ That study also supported our findings related to the importance of treatment perceptions, documenting that concerns were negatively associated with intentions to adopt chemoprevention.³⁴ Our analyses have added to this literature by showing that during the decision process, perceptions about medication, beyond those specific to these classes of drugs, were important. Presenting chemoprevention as another way to maintain health, akin to primary prevention of heart disease with aspirin, for example, may provide a useful comparison in which to frame such discussions. These new insights emphasize the strength of using mixed methods to understand decision-making processes that are occurring in real time.

Interviewing women as they actively sought to make a decision about chemoprevention underscored the interpersonal features of decision-making. We saw that women didn't rely solely on their level of risk or perceptions of control, but on how these fit together with other "social evidence" gathered from family, friends, and providers. This social element, which is distinct from the emotional aspect of decision-making, appears to be a way of relating perceptions of risk and control to anticipated outcomes. Others have characterized this in emotional terms via affective forecasting, or the anticipated stress or benefit one might receive from taking tamoxifen or raloxifene.³⁵ Future research could develop a measure of how connected women feel to "social evidence" along several dimensions and examine its relationship to emotional responses and whether it predicts decisional or utilization outcomes.

Finding a shared understanding of risk and the potential impact of treatment may provide a way to increase adoption of risk-reduction behaviors. Studies have documented that women have greater knowledge about non-modifiable risk factors,³⁶ yet simultaneously feel a sense of control over their breast cancer risk,^{34,37} and view breast cancer as more preventable than do providers.³⁰ When women apply concepts of risk to themselves, some have been found to emphasize the importance of modifiable risk factors,³⁸ whereas others adopt fatalistic approaches to the development of breast cancer, either of which may prevent them from participating in risk reduction. We observed similar disparities in our study, which captured perceptions while women were actively making such decisions, indicating that there may be opportunities to address perceptions that are rooted in "social context." Engaging women in decision-making about cancer prevention requires tools that promote trust, information-sharing, and patient engagement,^{39,40} particularly given the complexity of understanding

risk estimates⁴¹ and the importance of the social context not only in risk perceptions but also in decision-making.

Limitations

This study investigated women's decision-making about treatment choices among those who were identified by clinical providers to be at high risk for developing breast cancer. This likely influences the way that they perceive and talk about their own risk, decision-making, and intentions for risk-reduction. However, we observed a range of predicted clinical risk values among our sample. As our findings suggest, even those with increased risk may not interpret the risk label as threatening. We hypothesize that women at average or low risk might alternatively feel threatened by breast cancer, although further work is required to confirm how varying risk estimates influence evaluations of personal risk and behaviors. 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. Finally, as a secondary analysis of qualitative interviews, there may have been aspects of decision-making that were not included in these interview guides, although these analyses align closely with the aims of data collection in the main study.

Conclusion

Our findings shed light on the important role for "social evidence" in decision-making, and how it might serve to integrate perceptions of individual risk and control over that risk. Attending to these patient perceptions to establish shared understandings about risk and its treatment are key to developing a framework for the care of patients at high risk of breast cancer that is evidence-based and sensitive to patient preferences and values.

Acknowledgements

The corresponding author affirms that everyone who contributed significantly to the work is listed as an author.

Financial support was provided by funding from the National Cancer Institute (U10CA180868, - 180822, UG1-CA189867) and NIH P30CA008748. [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01399359): NCT01399359. The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report. The following author is employed by the sponsor: Dr. Wortia McCaskill-Stevens.

REFERENCES

1. Smith RA, Manassaram-Baptiste D, Brooks D, et al. Cancer screening in the United States, 2015: A review of current American Cancer Society guidelines and current issues in cancer screening. *CA: A Cancer Journal for Clinicians*. 2015;65(1):30–54. [PubMed: 25581023]
2. Siu AL. Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement. *Annals of Internal Medicine*. 2016;164(4):279–296. [PubMed: 26757170]
3. Vogel VG, Costantino JP, Wickerham D, et al. Effects of tamoxifen vs raloxifene on the risk of developing invasive breast cancer and other disease outcomes: The nsabp study of tamoxifen and raloxifene (STAR) P-2 trial.. *JAMA*. 2006;295(23):2727–2741. [PubMed: 16754727]
4. Waters eA, Cronin KA, Graubard BI, Han PK, Freedman AN Prevalence of Tamoxifen Use for Breast Cancer Chemoprevention Among U.S. Women. *Cancer Epidemiology Biomarkers & Prevention*. 2010;19(2):443–446.

5. Pachur T, Galesic M. Strategy Selection in Risky Choice: The Impact of Numeracy, Affect, and Cross-Cultural Differences. *Journal of Behavioral Decision Making*. 2013;26(3):260–271.
6. Galesic M, Garcia-Retamero R. Statistical numeracy for health: A cross-cultural comparison with probabilistic national samples. *Archives of Internal Medicine*. 2010;170(5):462–468. [PubMed: 20212183]
7. Wegwarth O, Schwartz LM, Woloshin S, Gaissmaier W, Gigerenzer G. Do Physicians Understand Cancer Screening Statistics? A National Survey of Primary Care Physicians in the United States. *Annals of Internal Medicine*. 2012;156(5):340–349. [PubMed: 22393129]
8. Holmberg C, Bandos H, Fagerlin A, et al. NRG Oncology/National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1 Results: Decision Making in Breast Cancer Risk Reduction. *Cancer Prevention Research*. 2017;10(11):625–634. [PubMed: 28978566]
9. Martinez KA, Fagerlin A, Witteman HO, Holmberg C, Hawley ST. What Matters to Women When Making Decisions About Breast Cancer Chemoprevention? *The patient*. 2016;9(2):149–159. [PubMed: 26115846]
10. Smith SG, Sestak I, Forster A, et al. Factors affecting uptake and adherence to breast cancer chemoprevention: a systematic review and meta-analysis. *Annals of Oncology*. 2016;27(4):575–590. [PubMed: 26646754]
11. Waters E, Pachur T, Colditz G. Side Effect Perceptions and Their Impact on Treatment Decisions in Women. *Medical Decision Making*. 2016;37(3):193–203. [PubMed: 27216581]
12. Blakeslee SB, McCaskill-Stevens W, Parker PA, et al. Deciding on breast cancer risk reduction: The role of counseling in individual decision-making - A qualitative study. *Patient Educ Couns*. 2017;100(12):2346–2354. [PubMed: 28734560]
13. Gunn CM, Bokhour B, Parker VA, et al. Exploring Explanatory Models of Risk in Breast Cancer Risk Counseling Discussions: NSABP/NRG Oncology Decision-Making Project 1. *Cancer Nurs*. 2017.
14. Kleinman A, Eisenberg L, Good B. Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research. *Annals of Internal Medicine*. 1978;88:251–258. [PubMed: 626456]
15. Blumenthal-Barby JS, Heather K. Cognitive Biases and Heuristics in Medical Decision Making: A Critical Review Using a Systematic Search Strategy. *Medical Decision Making*. 2014;35(4):539–557. [PubMed: 25145577]
16. Cyrus-David M The Future of Women of Minority Race/Ethnicity in Breast Cancer Chemoprevention Therapy. *Ethnicity and Disease*. 2006;16(Winter):216–222. [PubMed: 16599373]
17. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods*. 2006;18(1):59–82.
18. Ando H, Cousins R, Young C. Achieving saturation in thematic analysis: development and refinement of a codebook. *Comprehensive Psychology*. 2014;3(1):Article 4.
19. Holmberg C, Waters EA, Whitehouse K, Daly M, McCaskill-Stevens W. My Lived Experiences Are More Important Than Your Probabilities: The Role of Individualized Risk Estimates for Decision Making about Participation in the Study of Tamoxifen and Raloxifene (STAR). *Medical Decision Making*. 2015;35(8):1010–1022. [PubMed: 26183166]
20. Charmaz K *Constructing Grounded Theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: SAGE Publications, Inc; 2006.
21. Neale J Iterative categorization (IC): a systematic technique for analysing qualitative data *Addiction (Abingdon, England)*. 2016;111(6):1096–1106.
22. Kenen RH. The at-risk health status and technology: A diagnostic invitation and the ‘gift’ of knowing. *Social Science & Medicine*. 1996;42(11):1545–1553. [PubMed: 8771637]
23. Fairfield KM, Gerstein BS, Levin CA, Stringfellow V, Wierman HR, McNaughton-Collins M. Decisions about medication use and cancer screening across age groups in the United States. *Patient Education and Counseling*. 2015;98(3):338–343. [PubMed: 25499004]
24. Holmberg C Decision making in the context of breast cancer chemoprevention: patient perceptions and the meaning of risk. *American Society of Clinical Oncology educational book / ASCO American Society of Clinical Oncology Meeting*. 2015:e59–64.

25. Collins IM, Steel E, Mann GB, et al. Assessing and managing breast cancer risk: Clinicians' current practice and future needs. *Breast*. 2014;23(5):644–650. [PubMed: 24998452]
26. Agoritsas T, Heen AF, Brandt L, et al. Decision aids that really promote shared decision making: the pace quickens. *British Medical Journal*. 2015;350:g7624. [PubMed: 25670178]
27. Groot G, Waldron T, Carr T, et al. Development of a program theory for shared decision-making: a realist review protocol. *Systematic Reviews*. 2017;6:114. [PubMed: 28623941]
28. Davis S, Stewart S, Bloom J. Increasing the accuracy of perceived breast cancer risk: results from a randomized trial with Cancer Information Service callers. *Preventive Medicine*. 2004;39(1):64–73. [PubMed: 15207987]
29. Rauscher GH, Ferrans CE, Kaiser K, Campbell RT, Calhoun EE, Warnecke RB. Misconceptions about Breast Lumps and Delayed Medical Presentation in Urban Breast Cancer Patients. *Cancer Epidemiology Biomarkers & Prevention*. 2010;19(3):640–647.
30. Black WC, Nease RF, Tosteson ANA. Perceptions of Breast Cancer Risk and Screening Effectiveness in Women Younger Than 50 Years of Age. *Journal of the National Cancer Institute*. 1995;87(10):720–731. [PubMed: 7563149]
31. Quillin J, Fries E, McClish D, deParedes E, Bodurtha J. Gail Model Risk Assessment and Risk Perceptions. *Journal of behavioral medicine*. 2004;27(2):205–214. [PubMed: 15171107]
32. Kaplan CP, Kim SE, Wong ST, Sawaya GF, Walsh JME, Pérez-Stable EJ Willingness to use tamoxifen to prevent breast cancer among diverse women. *Breast Cancer Res Treat*. 2012;133(1):357–366. [PubMed: 22315131]
33. Waterhouse D, Calzone K, Mele C, Brenner D. Adherence to oral tamoxifen: a comparison of patient self-report, pill counts, and microelectronic monitoring. *J Clin Oncol*. 1993;11:1189–1197. [PubMed: 8501505]
34. Paquet L, Simmonds L, Yang C, Verma S. An exploratory study of patients' views about being at high-risk for breast cancer and risk management beliefs and intentions, before and after risk counselling: Preliminary evidence of the influence of beliefs on post-counselling prevention intentions. *Patient Education and Counseling*. 2017;100(3):575–582. [PubMed: 27756584]
35. Hoerger M, Scherer LD, Fagerlin A. Affective forecasting and medication decision making in breast-cancer prevention. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association*. 2016;35(6):594–603.
36. Kratzke C, Amatya A, Vilchis H. Breast Cancer Prevention Knowledge, Beliefs, and Information Sources Between Non-Hispanic and Hispanic College Women for Risk Reduction Focus. *Journal of Community Health*. 2015;40(1):124–130. [PubMed: 24989348]
37. Rees G, Fry A, Cull A, Sutton S. Illness perceptions and distress in women at increased risk of breast cancer. *Psychology & Health*. 2004;19(6):749–765.
38. Silverman E, Woloshin S, Schwartz LM, Byram SJ, Welch HG, Fischhoff B. Women's Views on Breast Cancer Risk and Screening Mammography: A Qualitative Interview Study. *Medical Decision Making*. 2001;21(3):231–240. [PubMed: 11386630]
39. Eriksson T, Nilstun T, Edwards A. The ethics of risk communication in lifestyle interventions: Consequences of patient centredness. *Health, Risk & Society*. 2007;9(1):19–36.
40. Gorin SS, Wang C, Raich P, Bowen DJ, Hay J. Decision making in cancer primary prevention and chemoprevention. *Ann Behav Med*. 2006;32(3):179–187. [PubMed: 17107290]
41. Cortez S, Milbrandt M, Kaphingst KA, James A, Colditz G. The readability of online breast cancer risk assessment tools. *Breast Cancer Res Treat*. 2015;154(1):191–199. [PubMed: 26475705]

Previous, related works

Gunn CM, Bokhour B, Parker VA, Parker PA, Bandos H, Holmberg C. Exploring explanatory models of risk in breast cancer risk counseling discussions: NSABP/NRG Oncology Decision-Making Project 1. *Cancer Nursing*. 2017 Jun 28. doi: [10.1097/NCC.0000000000000517](https://doi.org/10.1097/NCC.0000000000000517). [Epub ahead of print]. PMID: PMC5745305.

Blakeslee S, McCaskill-Stevens W, Parker PA, Gunn CM, Bandos H, Fagerlin A, Bevers TB, Battaglia TA, Müller-Nordhorn J, Holmberg C. Deciding on breast cancer risk reduction: The role of counseling in individual decision-making - A qualitative study. *Patient Educ Couns*. 2017. 100(12): 2346-54. PMID: PMC5683919.

Table 1.

Participant Characteristics, NRG Oncology/National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1 Sub study ($n=30$)

	<i>n</i>	%
Race/Ethnicity		
Non-Hispanic white	19	63%
Hispanic white	2	7%
Hispanic unknown	2	7%
African American	6	20%
Mixed race	1	3%
Insurance		
Medicare	3	10%
Medicaid	2	7%
Private	24	80%
Self-pay/Uninsured	1	3%
Highest Grade of Education Completed		
High school/GED	6	20%
Vocational/Technical/Associate degree	3	10%
Some college	5	17%
College	9	30%
Graduate/Professional degree	7	23%
5-Year BCRAT Risk		
<2%	6	20%
2.01–3%	10	33%
3.01–5%	8	27%
>5%	6	20%
Age (Mean, SD)	50.9 (9.3)	

BCRAT= Breast Cancer Risk Assessment Tool

SD = Standard deviation

Table 2:

Representative quotes related to perceived risk, perceived control, and "social evidence" by group for participants the NRG Oncology/National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1 in NSABP DMP-1

Group	Perceived Risk	Perceived Control	"Social Evidence"
High-perceived Risk / High-perceived Control	Participant A "My risk is rather high because of my family history, for the fact that my mother's had it twice, my maternal grandmother died of this, my great-maternal grandmother died of this. My great aunts and my paternal grandmother had ovarian cancer. So I have a high risk."	Participant A "I do exercise, I'm not- I've never smoked, I'm not a heavy drinker. I'm on the right track for that... What can I do to help put it off maybe as long as possible? What's the plan for making sure, to catch anything early?"	Participant W: "Seeing what [my aunt] went through makes me wanna just have a mastectomy and be done, never have to worry about it again. Had she not gone through it, had she breezed through it... I probably wouldn't even be sitting here right now. On the other hand I saw patients come into work all the time... and they'd be telling me about their cancers and every single story was different, so I think about all those stories, too."
		Participant AC "I have to look at where I come from. Everyone in my family has cancer. You know, I lost members from cancer... I feel 'oh nothing's going to happen to me. That's just them. It's going to skip me.' No, nothing skips... Somewhere along the line it's going to invade my body and I know that."	Participant L: "You know, it's kind of nerve racking because some of the [medications] have side effects of blood clotting, strokes. My mom has strokes so it's an issue. You know, I have to like really think about it."
Low-perceived Risk / High-perceived Control	Participant M "I think I'm still in denial! I guess because you feel healthy, you look healthy, or good, and you don't feel any pain, nothing's going on."	Participant M "I don't want to lose control... I want to be in control of my body... I'm gonna be ok, just watch my health, and what I eat, drink, and try to work it out, and just take care of my body."	Participant N: "I understand the whole cell dividing thing, but I have a very different lifestyle than my mother did. And not that she brought that on herself, but she had many diseases, and because she didn't take care of herself, and she was the total opposite of what I am."
	Participant AD "Maybe the numbers in my head aren't right, but my percentage is elevated, but it's not extreme... I think getting up in the morning and getting out of bed can be a risk and if- to me if there's not some kind of proof, if I can't see it, I mostly think it's just not there."	Participant AD "I just need to pay closer attention to what's going on in my body and if anything seems out of sorts to make sure I mention it to my doctor and have conversations around it... there are no guarantees."	Participant E: "I couldn't see any effects in her, or any difference that [tamoxifen] made... and she didn't gain weight either... So I don't know."

Table 3:

Recommendations and SERM decisions by perceived risk and control by group in the NRG Oncology/
National Surgical Adjuvant Breast and Bowel Project Decision-Making Project-1

Group	Provider Recommendation		Decision		
	Yes	No	Yes to SERM	No to SERM	Undecided
High-perceived Risk / High-perceived Control (n=8)	5 (63%)	3 (37%)	4 (50%)	4 (50%)	0
High-perceived Risk / Low-perceived Control (n=7)	5 (71%)	2 (29%)	3 (43%)	4 (57%)	0
Low-perceived Risk / High-perceived Control (n=9)	7 (78%)	2 (22%)	2 (22%)	5 (56%)	2 (22%)
Low-perceived Risk / Low-perceived Control (n=6)	4 (67%)	2 (33%)	2 (33%)	3 (50%)	1 (17%)
TOTAL (N=30)	21 (70%)	9 (43%)	11 (37%)	16 (53%)	3 (10%)