Barriers and Facilitators to Patient-Provider Communication When Discussing Breast Cancer Risk to Aid in the Development of Decision Support Tools

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Abstract

The purpose of this study was to identify barriers and facilitators to patient-provider communication when discussing breast cancer risk to aid in the development of decision support tools. Four patient focus groups (N=34) and eight provider focus groups (N=10) took place in Northern Manhattan. A qualitative analysis was conducted using Atlas.ti software. The coding yielded 62.3%-94.5% agreement. The results showed that 1) barriers are time constraints, lack of knowledge, low health literacy, and language barriers, and 2) facilitators are information needs, desire for personalization, and autonomy when communicating risk in patient-provider encounters. These results will inform the development of a patient-centered decision aid (RealRisks) and a provider-facing breast cancer risk navigation (BNAV) tool, which are designed to facilitate patient-provider risk communication and shared decision-making about breast cancer prevention strategies, such as chemoprevention.

Introduction

Breast cancer is the most common cancer among women in the U.S. Known risk factors include family history, *BRCA* genetic mutations, benign breast disease, and reproductive history[1]. The Gail model or breast cancer risk assessment tool (BCRAT) may be used to calculate a woman's absolute 5-year and lifetime risk of breast cancer, based upon her age, race, reproductive history, family history, and benign breast disease[2]. A woman is considered high risk of developing breast cancer if her 5-year risk is $\geq 1.67\%$ or lifetime risk is $\geq 20\%$. Chemoprevention refers to taking medications for the primary prevention of cancer. Anti-estrogens, such as selective estrogen receptor modulators (SERMs) and aromatase inhibitors (AIs), have been shown in randomized controlled trials to reduce breast cancer incidence by up to 50-65% among high-risk women[3-7]. Based upon this evidence, the U.S. Preventive Services Task Force and other professional organizations recommend that clinicians discuss chemoprevention with high-risk women[8-10]. An estimated 15% of women, age 35-70 years, in the U.S. may be eligible for chemoprevention[11], but fewer than 5% of high-risk women offered an anti-estrogen agree to take it[12]. Reasons for low chemoprevention uptake include lack of routine breast cancer risk assessment to identify high-risk women, insufficient knowledge about anti-estrogens on the part of clinicians and patients, and multiple competing demands in the primary care setting[12,13]. Discussions about chemoprevention represent an opportunity for risk communication and shared decision-making (SDM) to elicit patient preferences and enhance patient-provider communication. Because there is limited knowledge on the part of patients and providers about breast cancer risk assessment and chemoprevention, we developed decision support tools targeting both groups, which will be integrated into clinic workflow. The tools we are developing are a patient-centered decision aid (DA), *RealRisks*, and a provider-facing breast cancer risk navigation (BNAV) tool to increase breast cancer chemoprevention in the primary care setting.

A study that conducted a systematic review on patient-reported barriers and facilitators to SDM concludes that it is not that patients *do not want* to play a role in SDM, but it is because they *can't* due to various structural, pre-disposing, interactional, and preparatory factors. The authors suggest that patient-reported barriers should be considered with provider-reported barriers for intervention and implementation[14]. The purpose of this study was to identify barriers and facilitators in patient-provider communication when discussing breast cancer risk. In order to obtain new information and learn from patient/provider perspectives, we conducted separate focus groups with patients and providers to collect qualitative data. By integrating the results we obtain from this study to the decision support tools, we will be able to further develop the tools to facilitate communication in patient-provider encounters and possibly allow SDM to take place.

Methods

Participants

In June 2013, we conducted four patient focus groups among English-speaking women recruited from Northern Manhattan in New York, NY. Women who participated in a community database through the Columbia Community Partnership for Health were contacted via email or telephone. Each focus group consisted of 7-9 women. A total of 34 women that reside in the Washington Heights/Inwood community participated. Eight key informant interviews of primary care providers (PCPs) of 1-3 participants each (N=10) were conducted at Columbia University Medical Center (CUMC). At CUMC, PCPs practice at 6 locations of the Ambulatory Care Network (ACN) clinics in Northern Manhattan. The patient population is over 80% Hispanic or African American with a predominantly Medicaid/Medicare payer mix. All participants provided written informed consent to audio-recording of a 90-120 minute facilitated session and completion of a brief survey. Patients and providers were given modest incentives of $40-$50 for participation. The study was approved by the institutional review board at CUMC.

Description of the RealRisks Decision Aid

RealRisks is a patient-centered DA that models patient-provider dialogue and incorporates experience-based dynamic interfaces to communicate numeric and probabilistic concepts that are central to breast cancer risk and chemoprevention. It is designed to improve: 1) accuracy of risk perceptions; 2) self-efficacy to engage in a collaborative dialogue about breast cancer risk and chemoprevention; and 3) decision satisfaction. The narrative is based on a fictitious character named Rose, who engages in discussions about breast cancer risk with family, friends, her PCP, and specialists. We have segmented the narrative into the following modules: 1) Risk (what is risk, breast cancer risk factors); 2) Chemoprevention (chemopreventive agents, risks/benefits). *RealRisks* will be tailored to a woman's risk, so she will be reviewing only the modules that are most relevant to her. Embedded within the narrative of *RealRisks* are games of experience-based risk interfaces, based upon our previous work[15]. For example, the first game is about breast cancer risk for an average 50-year-old woman and conveys how time (5-year, lifetime) affects risk with a pictograph of 100 clickable women. Players are instructed to click until they 'find' a woman with breast cancer. Players continue to click (*e.g.,* sample from the population of 100 women) to better learn the meaning of a given pre-set probability (*e.g.,* 12 out of 100 women or 12%). A similar game will be adopted in the chemoprevention module to accurately represent the benefits of chemoprevention and the risk of side effects. Accuracy of risk perceptions is important to informed decision-making given that patients may over-estimate their breast cancer risk[16] or the risks of side effects to chemopreventive agents, such as tamoxifen[17].

Description of the BNAV tool

BNAV uses a two-pronged approach to improve knowledge among PCPs on chemoprevention. One component is the web-based chemoprevention toolbox, a repository of information and resources that is modeled based on the Theory of Planned Behavior[18]. It includes: 1) standard guidelines and a self-paced interactive educational guide (*attitudes*); 2) video testimonials and a social component that includes the ability to compare their performance against aggregate, anonymous data of their peers (*subjective norm*); 3) a repository of their patients' breast cancer risk assessments, along with the action plans based upon their patients' interactions with *RealRisks* (*perceived behavioral control*). Based on appointment scheduling data, a provider would receive a periodic notice of upcoming patients that meet high-risk criteria so as to encourage access to the chemoprevention toolbox, which will be sent as an email or text. The second component of BNAV is embedded within the electronic health record (EHR). Within the ambulatory care dashboard in the EHR used by our PCPs, flagged alerts of patients that meet high-risk criteria for breast cancer with their personalized risk profiles will appear with their mammogram results.

Conducting the Focus Groups

Skilled facilitators (ANA, KDC, RK) led the focus groups using detailed guides. For the patient focus groups, the discussion guide included questions on breast cancer risk factors, *BRCA* genetic testing, chemoprevention, and discussing breast cancer risk or genetic testing with providers. The discussion guide for the provider focus groups covered questions about genetic testing, chemoprevention, EHR, and communicating breast cancer risk with patients. All sessions were audiotaped.

Data Analysis

For the qualitative analysis, two investigators (HY and TX) independently read the transcript from the first completed patient and provider focus groups to develop the initial codes and coding templates. We identified meaningful segments within the responses and assigned codes using an editing style analysis[19]. Discrepancies in coding were negotiated at weekly research meetings. HY and TX independently read and coded the remaining focus group transcripts, applying the coding template, which was iteratively modified as the analysis proceeded. We grouped codes into general themes and discussed the themes among the entire team of investigators. The team collectively selected the themes and representative quotes we presented in this paper. Atlas.ti 7.0 software (Atlas.ti GmbH, Berlin, Germany) was used to facilitate qualitative data management and analysis. All transcripts were uploaded into the software to enable investigators to do coding, build the codebook, and group the codes into themes. A final comparison of coding across patient interviews yielded 62.3%-94.5% agreement.

Results

Participant Characteristics

Patients

The majority (61.8%) were Hispanic and mean age was 53.4 years (range, 35-75). Forty-one percent met criteria for low numeracy, defined as a score of 0-5 (range, 0-9)[20]. Everyone had access to the internet, including 88% who regularly used a computer. In terms of breast cancer risk factors, 8 (23.5%) women had a first-degree family history of breast cancer and 4 (12.9%) had a prior benign breast biopsy. According to the BCRAT (excluding 3 women with a history of breast cancer), mean absolute 5-year and lifetime risk were 1.11% (range, 0.2%-4.3%) and 7.46% (range, 2.8%-14.6%), respectively, and 3 women (9.7%) met high-risk criteria for breast cancer (≥1.67% 5-year risk).

Table 1. Baseline characteristics of patients.

Mean age, years (range)		53.4 (35-75)
Race/Ethnicity	Non-Hispanic White	2 (5.9%)
	Non-Hispanic Black	8 (23.5%)
	Hispanic	21 (61.8%)
	Asian	1 (2.9%)
	Other	2 (5.9%)
Numeracy	High	20 (58.8%)
	Low	14 (41.2%)
Regularly uses computer		30 (88%)
First-degree family history of breast cancer		8 (23.5%)
Benign breast biopsy		4 (12.9%)
High-risk for breast cancer		3 (9.7%)
Mean 5-year breast cancer risk (SD)		1.11% (0.77)
Mean lifetime breast cancer risk (SD)		7.46% (2.87)

Providers

To inform the development of BNAV, we conducted individual interviews of 10 physicians affiliated with New York Presbyterian Hospital-Columbia University Medical Center's Ambulatory Care Network (ACN). The majority were female (70%) and they were diverse by race/ethnicity (5 white, 3 black, 1 Hispanic, 1 Asian). They represented various subspecialties in primary care (6 Internal Medicine, 2, Family Medicine, 2 Gynecology) and a range of years in clinical practice (1-35) and years using an EHR (2-10).

Table 2. Baseline characteristics of providers.

Median age, years (range)	43.5 (28-64)

Gender	Male	3 (30%)
	Female	7 (70%)
Race/Ethnicity	White	5 (50%)
	African American	3 (30%)
	Asian	1 (10%)
	Hispanic	1 (10%)
Medical Specialty	Gynecology	2 (20%)
	Internal Medicine	6 (60%)
	Family Medicine	2 (20%)
Median number of years since completing training (range)		8.5 (1-35)
Median number of years using EHR (range)		6.5 (2-10)

Barriers to communicating risk

Based on the focus groups, time constraints, lack of knowledge, low health literacy, and language barriers emerged as the main barriers to communicating risk. The results showed that time was considered as the most significant barrier for both patient and provider groups when communicating risk. As shown in Table 3, patients thought providers “don’t have so much time to explain” and “the office visit is very hurried.” They also mentioned not being able to discuss personal circumstances with their providers because of the short amount of time. Providers also talked about the limited time they have with patients. Patients having questions towards the end of the visits was another issue related to time pressure. To worsen the situation, they said that “this encounter with the patient and the physician are getting so long” due to various interest groups trying to take part, which means there is less time to have discussions that the patients and providers would like to have. Patient’s lack of knowledge was discussed as a barrier to both groups. Patients said, “Because we don’t have the knowledge and don’t ask, the doctor won’t give it to you.” Providers seemed to think that patients do not know much about medical terms and risk-related numbers, which makes it difficult to communicate risk. Providers mentioned low health literacy as an obstacle for patient-provider communication. Since providers are not aware of the patient’s health literacy level, they said, “My struggle is how to get this information across without creating more anxiety with the health literacy issues.” The language barrier in a largely Spanish-speaking community in Northern Manhattan was also discussed as an obstacle. Providers experienced difficulty when explaining risk to patients mainly due to language and cultural barriers.

Table 3. Quotations on barriers to communicating risk.

Barriers	***Sample quotations***
Time constraints	*Patient* Usually when you go to see the doctor, they don’t have so much time to explain. Since the office visit is very hurried, five or seven minutes, he doesn’t have time to go over my personal circumstances. Even if you have so many questions, the doctor will come out and tell you that they have other patients to see and they don’t have time. *Provider* The time in the doctor’s room is pressured. A lot of time they don't realize what it’s about and they bring it up at the end. In that case, when I've already spent 45 min with them and we only have 15 min., then it does open this Pandora's box.

	15 min? That's a very sick patient. It’s between 6-8 minutes, always with a follow up. You spend 30-45 minutes waiting outside if you are lucky before seeing the doctor, another 3-5 minutes getting weighed, another 3-5 minutes to get undressed especially if its the first time they are seeing you. I see 25-35 new patients every day and I am going in there looking to see if they have 35 gowns. 10 minutes to take your blood pressure, listen to your heart to make sure you have no heart problem, listen to your lungs to make sure you have no lung problem. 3-5 min doing the medications, and 2 minutes to write the note. The mere time with the doctor is 6-8 min. This encounter with the patient and the physician are getting so long. All the interest groups are coming in and wanting a piece. It’s true we don't recommend to anybody to do it all in one sitting but then you have to remember what you did last time. You have to go back and review the history. This leads to less efficiency and this is why primary care is such a difficult field. It can open a potentially disastrous box. They already have a ton of complaints that can't be addressed in a short period of time, then will this [breast cancer risk assessment] add another thing to the list?
Lack of knowledge	*Patient* Because we don’t have the knowledge and don’t ask, the doctor won’t give it to you. *Provider* I think in addition to communicating risk, I think communicating what a screening test is. I think a lot of patients go for their mammogram or pelvic exam that it is an intervention preventing them from disease. I don’t think they even understand what screening is. It’s a difficult discussion. We get a test result and it’s a number and its chance. Our job is to, well you have a 1 in 10,000 chance of having a child with Down’s Syndrome and they are like what does that mean? And then I’m like oh God I said that wrong. We aren’t allowed to say it’s negative. We follow that statement by saying that the only way to know for sure is with an amniocentesis. And try saying that in Spanish. I hate it because I don’t think any of them make an informed decision.
Low health literacy	*Provider* My struggle is how to get this information across without creating more anxiety with the health literacy issues and with that lack of knowledge about science and statistics and how to put it all in perspective creates a lot of anxiety even though they want to be involved. Sometimes the information they get creates more anxiety. I don't know what percentage of my patients are illiterate and part of it may be in terms of having very low education level but also not having good health literacy.
Language barriers	*Provider* *Facilitator: How do you try to go about explaining risk to your patients?* I still don’t have a good way. A lot of it is a language barrier. Yes the form is in English and Spanish. There are people that can speak both languages but can't read it.

Facilitators to communicating risk

Information needs, desire for personalization, and autonomy emerged as facilitators to patient-provider communication through the dialogue (Table 4). Patients showed strong interest in obtaining more information. They said that this information does not have to be from a doctor and they are willing to learn from various sources (“I think it’s important that you have more places to ask questions about breast cancer, even if that person might not be my doctor. It might be a site, a nurse”). Not only will this information help them understand the doctor’s explanation, but also will help them “feel more comfortable”. They also mentioned having many questions they want to ask when they are at their doctor's office ("Half the time when we are at the doctors, we want to ask ten thousand questions"). Providers also had information needs. They said that they are willing to participate in courses that provide information on breast cancer. Desire for personalization was addressed in the patient focus groups. Patients said, "I wouldn't blindly follow a doctor's recommendations if it's a general recommendation. I want it to be individualized." However, providers point out that patients who do not need certain services (*e.g.,* cancer screening, genetic testing) are receiving them, and those who need them are not. Patients are eager to participate in clinical decision-making and are willing to reach out to other medical groups if necessary. Providers also notice this strong interest in autonomy among patients. They think "this patient population really wants to learn and be involved" during the patient-provider encounters. However, providers seem to be frustrated when patients value doctor's opinion less and think they know what should be done.

Table 4. Quotations on facilitators and information needs to communicating risk.

Facilitators	***Sample quotations***
Desire for personalization	*Patient* I wouldn't blindly follow a doctor's recommendations if it's a general recommendation. I want it to be individualized. The doctors are reading off of a script. They recommend the same thing for all of us. […] It doesn't seem personal at all. *Provider* The other point is again what you're discussing is a real public health issue on both sides. Women who do not need mammograms are getting mammograms and women who need genetic testing are not getting that. This is a process of education and it's a long process in that area. The investment has to be done in the high school, PTA, and make mothers and students alike aware that it's very important.
Autonomy	*Patient* Shouldn't they do it for whoever wants to have it done? But unfortunately we all need to be very proactive and never accept no for an answer. I would consult not just my doctor but I would also consult some other medical type groups to see what I could do. We all have to remain clear on what we want. How is it that we learn what we want? If you don't know what breast cancer is, then how do you go to a doctor and say I'd like to get checked for breast cancer. *Provider* I think this patient population really wants to learn and be involved. I've worked with other patient populations where they want my opinion less and they know or they think they know the right answer and that was frustrating. I really think this patient population wants to have these discussions.
Information Needs	***Sample quotations***
	Patient I think it's important that you have more places to ask questions about breast cancer, even if that person might not be my doctor. It might be a site, a nurse. I am more informed so I can have a better discussion and I can understand his responses better. I know more terms. I don't know if it will get me to talk

	about it with my doctor but I will feel more comfortable. You know, you don't want to walk away and not knowing. Half the time when we are at the doctors, we want to ask ten thousand questions, we forget what to ask. *Provider* *Facilitator: Yeah so it would be like those 20 minute talks but more relevant to the primary care providers on how to assess risk and who should get genetic testing and that type of thing. So if we made this a requirement to take this course online, do you think that would be helpful?* Absolutely. Yeah and I would definitely be interested.

Discussion

In summary, patients and providers consider time, lack of knowledge, low health literacy, and language barriers as obstacles to communicating risk. On the other hand, information needs, desire for personalization, and autonomy are discussed as facilitators that may enhance communication in patient-provider encounters. However, discordance between patient and provider expectations about good clinical practice still exists and may hamper SDM. We will use this information to inform the development of *RealRisks* and BNAV to facilitate communication about breast cancer risk.

By integrating an education component in *RealRisks*, the health literacy and lack of knowledge issues can be addressed. Educational materials can be presented in various versions to target patients with different levels of understanding. Including a Spanish version of the material will help overcome language barriers since there are many Hispanic patients. Also, patients can learn about breast cancer through *RealRisks* whenever they want to, which will not only fulfill their information needs, but also their needs to gain information from sources other than doctor visits. When further developing BNAV, a health literacy indicator could help providers determine the health literacy level of each of the patients, and therefore, result in a level-appropriate approach when explaining risk. In addition, an education toolbox can be implemented to educate providers about breast cancer risk that will inform discussions with their patients.

RealRisks and BNAV can address the time issue that was the biggest concern during both patient and provider focus groups. By interacting with *RealRisks*, patients can receive education before meeting with providers, which can reduce time spent on providers explaining risk and related concepts. This could allow time for discussing patients' preferences, which is a component in SDM. Patients' strong interest in autonomy and personalization will also enhance risk communication and SDM. Integrating patient's needs and preferences with provider's expertise and other resources, SDM could help patients make informed medical decisions[21].

This study has several limitations. The sample size of patients and providers was relatively small. In addition, a large proportion of our study patients were Hispanic, an ethnic group which is often under-represented in clinical studies. Our results may not be generalizable to populations from other geographic regions; however, Hispanics are the largest minority group in the U.S. We also only included physicians and did not collect data from other primary care providers (*e.g.,* physician's assistants, nurse practitioners), who may be targeted in future studies.

We believe that *RealRisks* and BNAV can facilitate patient-provider communication and possibly lead to SDM when the barriers are dealt with and facilitators are integrated as discussed. For future studies, since a majority of the patients are Hispanic, it would be interesting to integrate communication facilitators that target this ethnic group. In a study that compared Hispanic and Non-Hispanic women's needs in patient-provider communication, the results showed that Hispanic women experienced difficulty during the communication process because of language barriers and health literacy, which is consistent with our results. Interestingly, while a warm communication style was important for Hispanic women, information needs were crucial for Non-Hispanic women[22]. It would be meaningful to conduct research on how to include ethnic-specific communication styles into our tools and examine whether the further developed tool was effective in enhancing patient-provider communication.

This research will allow patients to gain a better understanding of their breast cancer risk, along with their PCPs, which will inform risk-based screening and prevention strategies (*e.g.,* genetic testing, chemoprevention). Our goal is to maximize benefits, minimize harms, and promote more efficient allocation of health services, particularly for high-risk individuals.

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