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What Women with Breast Cancer Discuss with Clinicians about Risk for Their Adolescent Daughters

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Abstract

Recorded conversations between women undergoing BRCA genetic counseling with clinicians ($N = 16$) and follow-up consultation letters ($N = 16$) were analyzed to determine how and when communicating genetic risk information to women's adolescent daughters is discussed. Themes from conversations included: mothers' worries about their daughters; perceptions of their daughters' coping; educational information; and clinicians' willingness or reluctance to communicate directly with daughters about their genetic risk. Letters discussed daughters when informing about autosomal dominant inheritance patterns, psychosocial considerations, and screening recommendations. Results inform the value of educating mothers about how they might discuss these issues with their adolescent daughters.

Keywords

breast cancer; daughters; genetics; communication; risk information; health promotion

Introduction

Genetic testing is becoming more widespread as genetic abnormalities are implicated in the etiology of more diseases (Daly, 2001), including BRCA 1 and BRCA 2 gene mutations increasing the risk of breast cancer. Women with a mutation have an estimated 56–84% cumulative lifetime risk of developing breast cancer compared to 11% the rest of the population (Elstein, Holzman, Ravitch, et al., 1986; Rebbeck, Kauff, & Domchek, 2009; Wooster, Bignell, Lancaster et al. 1995).

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Whereas 1 in 9 women are affected by breast cancer, only 5–10% of these are hereditary (Campeau et al., 2008). But children of parents with mutations have a 50% chance of inheriting them (Biesecker, Boehnke, Calzone, Markel, Garber, Collins, et al., 1970). Thus, when patients are screened for BRCA 1 and BRCA 2 gene mutations, they are informed of the risks for their blood relatives and encouraged to disclose this to them. The encouragement of such open disclosure is widely supported by guidelines on the family communication of genetic information (Forest, Delatycki, Skene, et al., 2007).

The present study focuses on the communication of genetic risk to one particularly understudied population - adolescent daughters of women being tested. Although studies have documented whether and which family members are informed of test results (e.g., McCann et al., 2009; Tercyak et al., 2001; Tercyak et al., 2002), and the effect that receiving this has on adolescent daughters (e.g., Bradbury et al., 2009; Cappelli et al., 2005), little research has explored the actual conversations that take place between clinicians and mothers about if, when, and how this information should be communicated to their daughters. This study seeks to fill this gap by analyzing 1) transcribed recordings of conversations between women attending genetic counseling and clinicians about communicating this information to their adolescent daughters and 2) follow-up letters summarizing their genetic status. This assessment of current information exchange from an unbiased perspective (i.e., not based on recall) will provide insight into the needs and concerns of mothers about discussing cancer risk with their adolescent daughters.

Adolescent Daughters as a Population of Interest

Adolescence is about the construction of personal identity, including family identities (Borysenko, 1996). Werner-Lin (2008) suggested, “This periodmay be the most crucial time for considering the impact of genetic testing” (p. 114). Early research quickly identified that daughters of women with breast cancer develop greater feelings of vulnerability about the disease (Wellisch et al., 1991). In particular, daughters aged 11–20 years reported feeling significantly more uncomfortable about involvement in their mothers’ illness than daughters older than 20 years of age (Wellisch et al., 1992). This discomfort was largely due to key processes of identification with their mother’s gender, femininity, and sexuality. More recently, Chalmers et al. (2003) found that over half of a sample of daughters and sisters of women with breast cancer reported elevated levels of worry about breast cancer, and Raveis and Pretter (2005) reported that daughters of women with breast cancer indicated that their mothers’ illness heightened their awareness of familial risk and personal sense of vulnerability to the disease. A threat to the mother’s health including such a key symbol of her womanhood, the breast, had the potential to disrupt the confidence and understanding that the adolescent girl held for her own developing body. Clearly cancer risk information has relevance to the development of an adolescent daughter’s own sense of womanhood and personal identity.

One challenge is that many women assume that disclosure of genetic risk to children will cause distress (McInerney-Leo et al., 2005), depression, withdrawal, and may affect the child’s sense of security (Tercyak et al., 2001). Cappelli et al. (2005) compared content-specific knowledge, attitudes, and risk perceptions among women who *had been treated* for

breast cancer and their daughters with those who had not. The likelihood of genetic testing knowledge was equal in both groups, who reported a low level of knowledge and answered “definitely/probably” when asked if they would take a genetic test. Of note, adolescent daughters of women treated for breast cancer experienced elevated levels of perceived risk of breast cancer, of a BRCA mutation and of any other type of cancer. Benefits would flow from helping adolescent girls communicate their cancer worries more openly with their mothers.

Presently, the burden of disclosing genetic information rests primarily on the shoulders of these women (d’Agincourt-Canning, 2001). Conversations between mothers and genetic counselors about sharing risk information with their daughters are likely to influence the actual exchanges between mothers and daughters.

The Present State of Communicating Genetic Test Results to Family Members

Genetic counselors have a general repertoire of information, such as breast cancer genetics and testing, screening and prophylactic surgery, which they routinely convey to their patients (Butow & Lobb, 2004). Most common concepts discussed during consultations include: 1) general population risk for breast cancer, 2) percentage of breast cancer in the general population resulting from BRCA1-2 mutations, 3) each woman’s hypothetical risk of developing breast cancer should mutation be detected, and 4) the chance of other family members having inherited the mutation (Lobb et al., 2003).

The benefits of genetic counseling include significantly decreased anxiety, facilitated understanding, and decreased depression; summary letters of the consultation further lower anxiety and increase the accuracy of knowledge (Lobb et al., 2004). However, when communication is ineffective, women can be left with unmet needs regarding coping and support, feeling their deep emotional concerns remain unaddressed (Butow & Lobb, 2004).

Problematic aspects of communicating genetic risk lie in the inherently uncertain characteristic of the information, as well as the challenge of putting complex concepts into layman’s terms (Sachs et al., 2001). Common criticisms include unstated aims for the sessions, mixing various types of background information and probabilities, not helping patients appreciate how low some predictive values can be, and difficulties in communicating the relationship between probability and conclusions (Sachs et al., 2001). Daughters of women with breast cancer will inevitably form lay health beliefs about breast cancer and its risk to them (Wellisch et al, 1991, 1992 & 1996; Wellisch & Hoffman, 1998). A resultant clinical responsibility is to help shape these beliefs constructively and realistically to advantage the health promotion options for these young women.

Can Communication about Genetic Tests Results be Improved?

Disclosure of sensitive genetic risk information to relatives can have a negative impact on relationships (as some family members may prefer not to know or become extremely worried). Some families decrease their open expressiveness (McInerney-Leo et al., 2005), while others grow closer through sharing the information with their children (Segal et al., 2004). Family-focused interventions can result in decreased conflict and improved relationships (McInerney-Leo et al., 2005).

With increased awareness of how adolescent girls form lay beliefs about their risk to develop breast cancer, the importance of accurate information and the role of communication skills to address this unique population will become increasingly relevant. Currently, discussion between the physician and the mother-daughter dyad (or groups of these) doesn't occur routinely as a component of standard care and it is unclear how much clinicians help mothers to communicate about cancer risk with their daughters. This project seeks to actively explore that prospect, establish the need, and reach consensus about a safe, yet helpful, clinical approach to accomplish such communication. The merit of this study is its potential to lay the groundwork for establishing novel yet meaningful approaches to care provision that improve the outcome for the daughters of women with breast cancer.

Methods

Participants

Participants were women seen in the Clinical Genetics Service at the participating cancer center. Exclusion criteria consisted of: a) does not have a family history of breast cancer, b) does not have a biological daughter(s) in the age range of 12–20 years, and c) not English speaking.

Procedure

Video Recording Procedure—As approved by the institutional review board (IRB), eligible patients were telephoned with their clinicians' consent by a research study assistant (RSA) before the planned visit. The study was explained with the reasons for video recording their consultation. Informed consent was either obtained over the phone as a recorded procedure, or when they first arrived at the clinic, before any contact with clinicians. All genetic counselors and physicians in the genetics service of the participating institution agreed to participate.

Fourteen video recordings were undertaken during participants' first assessment session with the genetic counselor, when a family pedigree was reviewed and basic concepts were presented, and during their first contact with the physician; two additional recordings were undertaken during feedback sessions when the genetic tests were positive for a BRCA mutation.

Qualitative Analysis Method—All recordings were transcribed. Initially, the research team read a small sample of transcripts and identified underlying communication themes. Iteratively, further samples were reviewed to validate themes and identify new themes. The team conducted regular meetings to review progress, discuss themes and reach consensus about the concepts that emerged until we had achieved theoretical saturation. A glossary of themes, definitions and characteristic examples applicable to recognition of these themes was developed. The remaining transcripts were then coded by two independent coders utilizing Atlas Ti software to support the grouping and cataloguing of themes. Here we concentrate on our analysis of the verbal communication; non-verbal data will be reported subsequently.

The consultation debriefing letters were written by clinicians using a template format. An RSA read through each letter and highlighted all references to patients' adolescent daughters. These sections were similarly analyzed thematically.

Results

Participant Characteristics

Sixteen, mostly Caucasian (88%) women with an average age of 48 years were recruited to the study. Detailed characteristics of the participants are provided in Table 1. The sixteen participants were seen by five genetic counselors and three physicians affiliated with XXXX (blinded for peer review). Of the sixteen transcripts, fourteen were taken during participants' first assessment session with the genetic counselor, when a family pedigree was reviewed and basic concepts were presented, and during their first contact with the physician, and two were later taken during feedback sessions involving positive genetic test results. Consultation themes discussed in results are drawn from both transcripts from the fourteen pre-assessment consultations and two post-assessment consultations.

Results indicated that adolescent daughters were commonly discussed in genetic counseling sessions and consultation letters. Four broad themes emerged from analysis of consultation transcripts: 1) mothers' worries about their daughters; 2) mothers' perceptions of daughters' coping; 3) educational information from the clinician (including: daughters' actual risk, screening and risk reduction practices, appropriate age to address genetic testing, possible contributors to the risk, and future methodologies for prevention and control); and 4) clinicians' willingness or reluctance to communicate directly with daughters about their genetic risk. Analysis of consultation letters indicated that daughters are referenced in these letters in three ways: 1) within a standard definition and discussion of autosomal dominant inheritance patterns; 2) within the "psychosocial considerations" section; and 3) within the "screening recommendations" section.

Themes from Consultations

Theme 1: Mothers' worries about their daughters—There was almost universal concern among patients for the well-being of other women in the family, especially daughters, sisters, mothers and nieces. The expression of worry and fear for these other relatives was consistently offered as a reason for seeking genetic testing. What was not universal, however, was whether the concern for a daughters' well-being was associated with a plan to disclose genetic test results. On one side, women pointed out that early awareness of risk status empowers individuals to make informed lifestyle choices. For example, in one conversation in which a clinician suggested that it might be better to hold off testing an 18-year-old until she turns 25, because screening doesn't start until that time, the mother pointed out that her daughter had the right to make this choice by saying:

I thought of one reason for her to get tested. Because we did discuss this 18 versus 25 age issue. Maybe it will make a difference when she decides to have kids. Okay? Like if she has the gene, maybe she'll be more inspired to get married earlier and have kids earlier.

In contrast, some women discussed potential negative psychological ramifications that may stem from having to comprehend issues of breast cancer too early. One mother discussed how the awareness of her breast cancer had a large impact on her daughters' emotional development.

My younger daughter just couldn't deal with it. I mean she was so young. She said 'can I go back and watch TV now?' And how she had to struggle afterwards! As she aged, she said, 'I had to struggle that I was never there for my mom because I couldn't deal with it.' And my other daughter 'oh that's completely different for me. I understood and I thought that I had to be the perfect daughter.' So how challenging that was, always struggling not being able to be a normal teenager. Always knowing that, you know, I couldn't do that because Mom is dealing with so much. I had to be perfect.

Several mothers described protective behaviors as they sought to shield their daughters from any distress. The idyllic time of adolescence can be seen as a developmental experience worth protecting from unnecessary worry. Speaking hypothetically about what she would do if her test came back positive, one mother reasoned: "[M]y daughter's 17... She's getting ready to go to college and filling out applications, and I just don't think it's the right time to tell her, because I don't think that [there's any advantage to] her knowing now."

Despite differences in opinion in terms of timing, what emerged from analysis of these discussions is that clinicians can usually expect that many mothers will have already had open discussions with their daughters, but some may be hesitant and interested in guidance about what to say and do.

Theme 2: Mothers' perceptions of daughters' coping—Women with breast cancer describe a wide range of responses from their daughters, but one clear theme is that daughters are very aware and tuned in to what is happening to their mother. Daughters' coping mechanisms for dealing with this awareness varied greatly. Several mothers noted that their daughters were fearful of their increased risk for breast cancer. This fear manifested itself in different ways. One woman described her daughter as "obsessed" with the idea that she would develop breast cancer. She recounted stories of her daughter convincing herself that she has found a lump in her breast: "One time she had me take her to the pediatrician because she kept saying there's a lump. 'Oh, my God, I'm going to die,' you know."

Other women indicated that their daughters simply didn't want to know and avoided efforts to openly discuss cancer. One mother described:

My daughter...just really...doesn't want to talk about it.... I mean I had the double mastectomy. I came out with drains on me and everything. And she just would walk away. She didn't want to see anything that was going on. She didn't want to know anything that was going on. And I do have a concern because I think sometimes that she's just avoiding it.

Similarly, another mother observed, "She doesn't want to hear it. I don't think she wants to admit it. I don't think she's ready...She's afraid."

In contrast, other mothers felt that their daughters needed *more* information about their own risk to help them cope, including clearing up any misconceptions. One possible outcome, after first hearing the results of a woman's own genetic testing, would be follow-up group or dyadic consultations involving mothers and daughters, in which information about risk, health promotion and future care needs is provided to the daughters.

I think that at that age there might be a tendency to try to ignore, but she might be worried more than she knows. So there might be some benefit of bringing her for a discussion only because we might actually reassure her more as to what is the truth and what is not the truth. This is what you don't need to worry about right now.

Another mother viewed her daughter's college paper comparing the mutilation of a mastectomy to Van Gogh cutting off his ear as a sign that her daughter wanted more information about breast cancer: "And this has happened throughout her education, that every once in a while, she'll want to do a paper on breast cancer. It's when she needs more information and it's almost like this was a pointer to me that she needs more information now about how I look."

A number of mothers maintained that their daughters would worry regardless of whether they were provided with information or not, and so more information could possibly be a mechanism for reducing worry: "They worry so...let's say I get a negative. I think that might help them in that way. I could then say to them...okay, now you don't have to worry quite as much. And if it's positive, we'd have to figure it out. But I know they're strong enough now to be able to deal with that." Consistent with this rationale, one clinician noted that knowledge of an increased risk can be better for the daughter's well-being than the uncertainty of not knowing the exact risk:

But now some 18 to 20 year olds that we talked to have said 'Well, I'm already very worried about it. I already feel I have this risk. The uncertainty is killing me. I would rather know for sure one way or another.' For some people, the uncertainty is worse than knowing they are at risk and just keeping that information until becoming old enough.

Theme 3: Educational information from the clinician—Clinicians educate patients about the process of gaining genetic test results, their daughter's actual risk, screening needs, future age to consider their daughter's getting genetic testing, potential contributors to future risk and methodologies for prevention and control.

3.1 The process of getting genetic test results: Here is an example of a clinician providing information about the process of receiving test results and the typical recommendations for family disclosure:

If someone does test positive, what we do...we have them come back in about six weeks after the test is ordered. We identify other members of the family who are at risk, which would be for you, adult members of the family, so it would be your sisters, your brother. You know if he doesn't have any biological children, some guys just won't do it unless they're curious. And for your girls, we have a while to

wait if you were to test positive. We don't even test children at all. There are no childhood cancers associated with these genes.

3.2 Daughter's actual risk: As consultations evolve with a mother who has daughters, some reference to the daughter's specific risk is inevitable and highly appropriate. Genetic testing is about identifying both personal and family-based risk. Teaching women about their daughter's risk is a basic task, and clinicians appear to do so in a very straightforward manner, as exemplified by the selected quotation below:

The fact that you were diagnosed with a breast cancer means, even if we have a negative genetic test result, that your daughters are at elevated risk for breast cancer when compared to women whose mothers were never diagnosed with the disease.

Even if your test is negative, your [daughters] should still participate in increased breast cancer screening based on your diagnosis, because we know that daughters of women with breast cancer have an increased risk of developing breast cancer themselves. On average, it's about twice that of the general population.

3.3 Screening and risk reduction practices: In the presence of hereditary and familial cancer, very clear recommendations are made about the timing of introducing cancer screening tests to daughters and other family members, with a view towards early detection and successful treatment – a preventive health care approach. Examination of these recommendations can generate uniform guidelines. Typical instructions for cancer screening provided by the clinician are similar to the following: “So, for example, for your daughter, the fact that you were diagnosed with breast cancer at age 40 means that your daughter should start her breast cancer screening, even if your genetic test results come back negative, 10 years earlier, at age 30.”

3.4 Appropriate age to address genetic testing: Unlike the standardized guidelines for introducing cancer screening practices to daughters of women with breast cancer, the appropriate age for adolescent daughters to undergo genetic testing for BRCA 1 and 2 mutations is a much more contentious issue. Recalling the previously noted conversation in which the mother pointed out that testing earlier may provide valuable insight for family planning, it is clear that some people are in favor of an earlier genetic testing age than the current standard 25-years. One mother noted that she personally would not have wanted to know, but her daughters were different from how she used to be: “They want to talk. They want to know. Unlike my generation which...it's different. They're about taking action... information is power.”

Clinicians recognize that some people will be better served by being tested early, but in the main, they were in favor of putting off genetic testing until the age of 25. Clinicians commonly noted the psychological toll that knowledge of a BRCA 1 or BRCA 2 gene mutation can have on a younger girl: “We can start testing around age 18, but it really depends on the actual individual child's emotional status. Can they deal with this appropriately? And are they ready?” They also expressed the limited utility of knowing about one's gene mutation so early on, as regular breast MRIs would not start until age 25 for even those with the highest risk: “What we usually recommend is that when a young

woman is about to reach the age where she would start her breast cancer screening because of her hereditary risk, which is age 25... because if she didn't carry the mutation, she wouldn't need to begin her screening."

The following quotations are typical of the rationale offered in genetic consultations with mothers:

Just in general, we're not going to be pushing for [your daughters] to run to get tested, even though technically they're both 18 and able to be tested. In my own paternal view, I would try to encourage them to just carry on. They're not going to start getting screened with MRIs until 25, so there's really nothing that they're going to be doing differently if they tested positively or negatively, other than having the psychological burden of that.

Every so often, there's an 18-year-old who comes in and says, 'Oh I've gotta know. I can't rest until I know.' For those women, if they really, really want to be tested, we test them. But often we try to suggest that, if they can wait and the information isn't going to be so important to them, that they in fact wait.

I think that's the most important thing for you to know. They'll have a place that they can get this information in a very supportive way. But my bias is not to rush to get the information, unless there's something telling me that they had to do it, like a psychological need, or a medical need. We would be pointing out that they absolutely don't need to do this right now. And that there are actually strong reasons to convince them that they might want to wait awhile. And most of the time I talk to young adults in this age group, I give them that format. They're very relieved. They say, 'Great, I don't really want to get this testing right now.' But there are some who are studying medicine and they want to know everything like that. However, as I said, the majority are happy to wait until they're going to do something.

3.5 Possible contributors to risk (e.g., hormones or oral contraceptives): Some conversations involved contraceptive behaviors in which adolescents and young women are likely to engage. Many questions arise about the impact of oral contraceptive and infertility treatments on risk of breast cancer development. In some of these conversations, however, knowledge of the presence or absence of a gene mutation was assumed, making the advice provided only relevant to those who have undergone BRCA 1 and 2 genetic testing. For example, one clinician explained:

But the oral contraceptive is not really an issue if her only risk is your history, as opposed to a mutation, because the increased risk to her at this point is relatively small, and so if there is any further [risk] from the oral contraceptives, it is also going to be very small. So certainly for women whose only risk is having a mother with breast cancer, we don't really make a big deal about oral contraceptives in that setting. It's only if the breast cancer came about because of the mutation that we'd even raise it as a possibility or as a point of discussion.

3.6 Future methodologies for prevention and control: Future methodologies that could regulate gene transmission were also discussed. For example, discussion of Preimplantation Genetic Testing has become regularly incorporated into the information provision of the Clinical Genetics Service. The following is an example of a more detailed coverage of this approach.

So, for your daughters, if we found a mutation in you, and your daughters were at 50% risk for carrying the same mutation, and let's say when they were 25, they were interested in genetic testing to see whether or not they in fact inherited the same mutation, we would have a conversation about something called Pre-implantation Genetic Diagnosis. So this is actually a way through assisted reproduction, in vitro fertilization, of women who carry mutations actually being able to alter the natural inheritance of the mutation amongst their children. So at the eight cell stage of these embryos, before they're implanted, you can actually pluck off one of the cells. It has no effect on the embryo and do genetic testing on that one cell to see if that cell has the BRCA mutation or not. So then, what you do if this particular embryo...let's say we have four embryos. Two embryos have the mutation. Two embryos don't. They choose these two embryos for implantation and then your daughter would know that her child won't inherit the mutation.

Theme 4: Clinicians' willingness or reluctance to communicate directly with daughters about their genetic risk—One area in which there was variance in terms of informing adolescent daughters about cancer risk was in clinicians' willingness to meet with adolescent daughters personally to provide this information from a professional perspective. Thus, in response to one mother's stated concern about her daughters' maladaptive responses, the clinician both reassured and offered follow-up with the daughter:

That's definitely normal. I mean, let's put it this way, since she happens to be here. You know, you and I will talk and then if there's something you want her to hear from me after it's not as scary as you thought or something, then we could bring her in and just talk with her for 5 minutes if you think that would help. We'll kinda leave that up to you.

Clinicians generally offered constructive advice, providing guidance to the mother to persevere in addressing the basis of any fears, promoting understanding as an adaptive pathway towards eventual mastery over these fears. They offered education about health promoting behaviors like breast self-examination, accompaniment to an OB-GYN specialist, and provided information about the timing for mammography/MRI screening and when to consider referral to a psychooncologist as alternative approaches to premature reassurance.

She can get her clinical breast exams starting age 20, or even age 18 with a gynecologist. Here is a number to call for them. And then our doctor sees our BRCA positive women, however there are other surgeons that will see family members that don't have a BRCA mutation. And then we also mentioned our psychologist, which I think would be a really good resource in this circumstance. 'Cause I didn't realize that your daughter was so apprehensive about the information. It does sound like she's having a bit of a reaction to your diagnosis

and treatment. And now that the family history's gotten even bigger, I would say that she probably needs to at least be made aware of this, but maybe not immediately. I mean it doesn't necessarily, at age 19 or 20...there's really nothing more she can do beside worry.

Other constructive ways to support a mother's concern about a maladaptive coping response were exemplified:

It may be helpful at some point to sit down with [our psychologist] and map out a strategy, if you will, for how to help your daughter really deal with the facts in this family history and what it means for her. 'Cause it sounds somewhat unlikely that just throwing a lasso around her neck and trying to drag her will not necessarily help.

It really depends on where each child is at individually, their maturity level and whether or not they've had to deal with things like this before. They think about their own health. But you've shared your diagnosis with them, which some women don't. That is a good start.

Themes from Follow-Up Consultation Letters

The Clinical Genetics Service has the standard practice of sending a summary of all the family data to each patient so that they can go over the recommendations and integrate a deeper understanding of all that was discussed. A review of all consultation letters provided to participants in this study yielded the following themes in reference to patients' daughters:

Theme 1: Autosomal Dominant Inheritance Pattern—Within the initial consultation letter, there is an explanation of “autosomal dominant” inheritance pattern in which standard language is used, which states:

In rare cases, mutations in single genes may result in a strong predisposition within a family. The cancer in these families generally follows an ‘autosomal dominant’ inheritance pattern. This means that the predisposition (mutated gene) can be passed on by both men and women, and that children or siblings of an individual with the predisposition have a 50% chance of inheriting the predisposition, and therefore the increased risk to develop cancer.

This information reinforces knowledge about the daughters' actual risk that was noted as a sub-theme of the “daughter's actual risk” in the video-recorded genetic consultation meetings.

Theme 2: Discussion of Daughters in Psychosocial Considerations—In this letter, the psychosocial consideration section often includes a direct discussion about the patient's daughter. Some were short statements, such as the following: “The patient indicates that her daughter does not feel comfortable discussing the topic [of breast cancer]”; “She was somewhat concerned about the risk for her daughter to develop breast cancer.” Others were more detailed:

The patient expressed concerns for her daughter in regards to breast cancer risks due to her sister, who was affected with breast cancer at a young age. She did mention how difficult it was for her daughter to see her care for her two sisters throughout their diagnoses, treatments, and death. The patient is also concerned with how her daughter would deal with the patient's own breast cancer risks in that she does not know how the daughter could deal with a diagnosis. She would not want her daughter to see her suffering in the same ways that her sisters suffered.

Theme 3: Discussion of Daughters in Screening Recommendations—The screening recommendation section within the letter includes the patient's daughter in two different ways. First, letters contained a standard general statement at the beginning of the screening recommendations section, which implies that the following recommendations mentioned will apply: "These recommendations should also be followed by the patient's family members, especially her daughter at appropriate ages."

Additionally, in some of the letters, the daughter is specifically referenced within the body of the screening recommendation allowing for better clarification:

The patient and her daughter should undergo breast cancer screening recommended for the general population: monthly breast self-examination beginning at age 18, annual clinical breast examination beginning at age 25, and annual mammogram beginning at age 40.

Discussion

The daughters of women with breast cancer are at increased risk for distress and worry as a result of their mother's diagnosis. Review of these conversations conducted with women seeking genetic testing show the universal presence of the daughter's awareness of their predicament. Many want knowledge as a pathway to a sense of mastery over their predicament. Others are frightened by the prospects of what may lie ahead of them, and may need help and support to come to terms with the situation. Breast clinicians need the skills to counsel mothers about what to say to their daughters and what to do when their daughters cause concern.

Explaining complex scientific knowledge and ensuring understanding and recall of such is a difficult task. Our findings reinforce those of Lobb and colleagues (2003) that the most common concepts discussed include the general population risk for breast cancer, that due to BRCA1-2 mutations, each woman's hypothetical risk and the chance of other family members also inheriting a mutation. Mothers consistently reported worry and fear about communicating genetic testing information with their adolescent daughters. It seems appropriate that discussions about how to communicate cancer risk information to adolescent daughters should be added to clinicians' standard repertoire when meeting with patients who have daughters between the ages of 12 and 20.

Implications for Clinical Practice

In recognizing the potential for the daughters of women with breast cancer to be frightened and worried, clinicians need a range of stratagems to assist mothers to respond appropriately to their daughters. Certain strategies are likely to improve communication in all situations. Support for open questions that clarify the level of understanding and the emotional state of each child are fundamental. Empathic responses create a supportive relationship in which the mother will feel comfortable sharing her concerns about her daughters. Helping the mother rehearse what she will say and offering further support as needed should be routine. Creating a list of appropriate risk information, cancer screening and self examination recommendations, and behaviors and lifestyle factors to optimize the daughter's future well-being is desirable. In situations of high perceived threat and low perceived control, the use of avoidance as a coping mechanism may need to be countered sensitively when the daughter is ready (e.g., Witte & Allen, 2000).

One mechanism to improve communication during genetic testing consultations may be communication skills training, targeting physician communication with women and their adolescents seen jointly as an additional consultation after the mother's needs have been addressed. Another might be to test the benefit of providing mothers undergoing treatment for breast cancer with a "question prompt list" that might help their choice of questions to ask their oncologists. Question prompt lists can be read in a waiting room and patients can mark the questions of particular interest to them to use in the upcoming consultation. This method could help women gain information about approaches to discuss breast cancer risk with their daughters, how to promote healthy behaviors, awareness of screening and self care, and thus optimize their daughters well being in the long term. Such an approach could be routinely provided to mothers during adjuvant treatment for breast cancer. A study that monitored change in the unmet needs of daughters of women with breast cancer would determine the benefit of a question prompt list.

Shared consultations between mother-daughter combinations with breast cancer clinicians would have great utility in promoting adaptation in the daughters. For many, this could happen naturally. For others, the provision of family education sessions focused on cancer genetics would be a wonderful community offering. Knowing that many adolescents would be in attendance would create the atmosphere that would assist many nervous young women to gain knowledge as an antidote to worry.

Future Research

Future research is needed to identify moderators to the relationship between communicating genetic risk information to adolescent daughters and psychological implications for daughters. Such moderators may include: age of daughter (i.e., younger adolescents likely need different information and will react differently than older adolescents), prior knowledge of the probabilities associated with the gene mutations (e.g. a daughter enrolled in pre-med college courses may understand the risks better than one who has not been exposed to this information), and individual characteristics such as anxiety levels. This research may help to guide in the design of targeted interventions to aid mothers in communicating genetic test results with their adolescent daughters.

A number of challenging choices emerge for daughters in this setting of breast and ovarian cancer risk. What risk does the oral contraceptive present to adolescent daughters in settings of hereditary and familial cancers? How protective is the pill against ovarian cancer risk? What impact might fertility treatments have, if needed, in their futures? At what age should cancer screening approaches commence? What technologies will become more widely available in their futures to reduce the risk of transmitting gene mutations to their own children? And if appropriate, at what age might they choose genetic testing for themselves? Teaching these mothers a shared decision-making approach, as modeled in the mother's consultations with her clinicians, should serve as a helpful guide about how to approach their daughters.

Conclusion

The daughters of all women with breast cancer, including those attending a clinical genetics service, have a range of informational and emotional needs that impact on their well being and adaptation. Adolescence is a crucial phase of identification with their mothers as they move to independence in their own lives. Attention to their needs is a basic task for any model of family-centered care and brings a number of communication challenges to the fore. Here we have identified a number of noteworthy issues that merit discussion and a range of concerns that merit future study. Genetics is the remarkable scientific advance of our medical era. Sensitive and skillful communication about these issues is a meritorious accompaniment of this progress.

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Table 1**Participant Characteristics**

Average Age of mother (<i>n</i> = 16)	48 years (Range: 41–57)
Ethnicity (<i>n</i> = 16)	
Non-Hispanic/White	13 (88%)
Hispanic	3 (12%)
Average Age of eligible daughter (<i>n</i> = 20)	16 years (Range: 13–20)
Ashkenazi Jewish Descent (<i>n</i> = 16)	
Yes	4 (25%)
No	12 (75%)
Significant Family Cancer History (<i>n</i> = 16)	
Yes	8 (50%)
No	8 (50%)
Personal History (<i>n</i> = 16)	
Yes	13 (81%)
No	3 (19%)
Treatment Modalities * (<i>n</i> = 13)	
Lumpectomy	7
Mastectomy	10
Radiation Therapy	6
Chemotherapy	10
Hormone Therapy	10
Total Abdominal Hysterectomy & Bilateral Salpingo Oophorectomy	5

* Each of the women with a personal history of breast cancer had the option to select more than one treatment when applicable.