This qualitative study explores the communication and decision-making strategies of five families with hereditary breast and ovarian cancer (HBOC) risk. Investigators asked female carriers of \textit{BRCA1} and \textit{BRCA2} genetic mutations to recall early knowledge and experiences concerning cancer risk. Husbands and children (aged 15–25 years) of women with HBOC risk also were interviewed on knowledge, experiences, and expectations for future decisions regarding their risk. Themes derived from the interviews suggested a need for additional studies of families with HBOC risk to address how family history and other factors influence decision making. Nurses should assess patients and their families for issues with body image and adjustment after cancer treatment and offer appropriate support. In addition, parents should be advised on when and how to tell children about their potential risk and support their testing and health-promotion decisions.

\textbf{At a Glance}

\begin{itemize}
  \item Parents thoughtfully and informally communicate hereditary breast and ovarian cancer risk to their children; however, many parents do not talk about the risk.
  \item Breast cancer is viewed as a women’s issue, so men often are overlooked in discovering risk status.
  \item Discussing risk status can be threatening to parents and their children.
\end{itemize}

Much has been learned about the identification of \textit{BRCA1} and \textit{BRCA2} genetic mutations and related risks for families with hereditary breast and ovarian cancer (HBOC). Specific information about surveillance and preventive interventions for risk reduction and early detection is available for family members who have been tested and have received their results. Although genetic counseling is available, research and informal evidence show that many at risk do not seek genetic testing and counseling; those who do often fail to follow recommendations for surveillance or prevention (Tinley et al., 2004).

Women with a \textit{BRCA} mutation have a 41%–90% lifetime risk for breast cancer and a 8%–24% risk for ovarian cancer (Risch et al., 2006). Children of a parent with a \textit{BRCA} mutation have a 50% chance of inheriting the mutation because \textit{BRCA} genes are autosomal dominant genes (i.e., males and females are equally likely to carry a mutation and have a 50% chance of passing it on to a child, regardless of gender) (Nussbaum, McInnes, & Huntingdon, 2004). The literature shows no consensus about responses to awareness of risk on psychological morbidity; some investigators reported no differences from the general population (Coyne, Kruus, Kagee, Thompson, & Palmer, 2002; Schwartz et al., 2002), but Van Oostrom et al. (2005) found increased anxiety and depression in carriers of HBOC one to five years after disclosure. Women with a history of breast cancer reported increased anger and worry after receiving genetic test results that confirmed their high risk for disease (Bonadona et al., 2002; Dorval et al., 2000; Robertson, 2000). Many at-risk women have even greater concern for their children (Kenen, Arden-Jones, & Eeles, 2004). Men and women who were carriers and believed that their spouses were anxious and unsupportive, experienced clinical distress for two years after testing (Wylie, Smith, & Botkin, 2003). In addition, husbands of carriers wanted counseling for themselves and believed that their wives had received inadequate support at the time of disclosure (Metcalfe, Liede, Trinkaus, Hanna, & Narod, 2002).

The studies provided information on responses to being a carrier or a spouse but did not discuss how families experience intergenerational vulnerability. Although HBOC clearly is a family matter, families rarely have been asked to provide a group perspective on their experiences in living with the risk.

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As a result, the present study initiated a family-focused look at living with HBOC risk. The investigators sought to develop an intergenerational perspective on families’ stories to highlight aspects of the family context as influences on communication of risk and decision making about testing and follow-up.

Methods

The purpose of this preliminary study was to establish the feasibility of examining the influences of family experiences on members’ adaptations and responses to awareness of hereditary cancer risk. A descriptive, qualitative design described by Sandelowski (2000) was used. Families were selected from a hereditary cancer center database based on the presence of a parent who was a BRCA1 or BRCA2 carrier with one child or more aged 15–25 years. Parents and their children were invited to participate. Efforts were made to include single as well as married parents with diverse socioeconomic and educational backgrounds from four different states.

Participants

The institutional review board at Creighton University in Omaha, NE, approved the present study with precautions to protect the participants’ confidentiality by retaining the families’ informed consent forms in confidential, locked medical records. Parents determined which of their children were included, and all participants signed a consent or assent form. The investigators were experienced in counseling, and the sponsoring center protected the participants’ confidentiality by retaining the families’ contact information.

An investigator who worked in the center made all initial contacts with the parents (N = 109) with letters that included a description of the study and copies of the informed consent and assent forms. Parents interested in participating (N = 10) returned a postcard, and the investigator contacted them by phone to discuss the study, answer questions, and identify children who the parents were willing to include. When signed consent and assent forms were returned, the investigator filed them with the family’s locked, confidential medical records and scheduled telephone interviews with each of the participants at times of their convenience. Of the 10 who initially agreed to participate, 2 later declined, 2 no longer had children who met the age requirements, and 1 tentatively agreed but was undecided about whether the daughter should know about her risk for having the genetic mutation and participate. The sample included 17 family members (five mothers and three of their husbands, six daughters, and three sons) (see Table 1) from four different states. All responding families were Caucasian; attempts to include ethnically diverse families, male carriers, and carriers whose families chose not to be tested were unsuccessful.

Design

Sandelowski (2000) described basic descriptive, qualitative studies as “low inference,” naturalistic inquiry methods designed to present a comprehensive summary of patterns or themes in everyday language. In the studies, sampling is purposeful, data collection uses minimally to moderately structured open-ended questions and observations, and content analysis derives codes from the data. Data collection and analysis are conducted simultaneously, allowing investigators to modify codes and generate insights and questions based on new data. Results can be described from the view of the participants (Sandelowski & Barroso, 2002).

Interviewing

A nurse from the center was present for all interviews and two other nurses with experience in qualitative interviewing alternated holding discussions with the families. The fourth investigator was knowledgeable in genetic counseling and participated only in the analyses. Two researchers were assigned to each family and interviewed each member by telephone initially and then together in a group interview. Two families were interviewed in their homes and videotaped by the investigator. Because of distance, the other three families were interviewed on a closed-circuit television broadcast between Creighton University and a university in the participants’ city. All interviews were taped and transcribed for analysis.

Table 1. Family Characteristics

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<th>VARIABLE</th>
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<th>B</th>
<th>C</th>
<th>D</th>
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<tr>
<td>Participating</td>
<td></td>
<td>family members</td>
<td>Low income, high school</td>
<td>Upper-middle income, college</td>
<td>Low income, high school</td>
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<tr>
<td>Maternal aunt</td>
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<td>died of breast cancer.</td>
<td>education</td>
<td>graduates</td>
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their family, the effect of that awareness on them, and whether any subsequent events heightened their awareness. The family members were asked about their concerns, how they coped, and what decisions they made based on their risk. All were encouraged to voice their feelings, questions, and concerns about the risk as their awareness grew. Participants also were asked about family attitudes, how risk information was communicated, who they sought for support, what influenced them about decisions to undergo genetic testing and obtain their results, what their response was to their results, and how they made decisions about surveillance and prevention if the results were positive. The investigators asked the children about their beliefs and feelings on future testing, surveillance, and prevention. The investigators used nondirective prompts and clarifying questions throughout the study. All parents spoke openly about their experiences and feelings. The children initially were hesitant in interviews, but they were comfortable and had thoughtful questions and useful comments to share with their parents and the investigators during the family interviews. As a group, families were asked to address their recall and responses to key events, how they perceived and responded to each other’s concerns as a family, how they supported one another, and how they felt about the decisions that had been made.

Data Analysis

Each taped interview was transcribed and read for accuracy by an investigator. Upon verification of the transcript’s accuracy, the tapes were destroyed; the participants were identified only by family letter and role (family A, B, or C and mother, husband, daughter, or son). Each investigator individually read and coded the transcripts, then all met to code the data by group consensus. The transcripts for each member and the family interviews were analyzed by consensus before proceeding to the next family. Codes were entered into N Vivo® for ease of retrieval, comparison, and analysis. Themes derived from the interviews are listed in Figure 1.

Establishing Rigor

Sandelowski (1986) identified four aspects of rigor for qualitative studies: credibility (truth value), auditability (consistency), fitnessness (applicability), and confirmability (objectivity). Credibility was ensured by tape recording and transcribing the interviews verbatim and reviewing them for accuracy before coding. Auditability was maintained by retaining a record of the transcripts, codes, changes in codes, and memos of decisions made so another qualitative researcher could follow the reasoning. Data and codes were reviewed by a qualitative research expert and discussed by phone conference. Fitnessness was tested by inviting five counselors from other hereditary cancer centers to review the results of the study and indicate whether the results were consistent with their experiences of women with HBOC risk and their families. Three counselors from other centers read the manuscript and themes and found them consistent with their experiences; the counselors were a certified genetic counselor working in a medical genetics clinic, a nurse with a doctorate working in a university setting providing genetic counseling to patients and conducting research on families with HBOC risk, and an advanced oncology certified nurse with extensive counseling experience in HBOC. Results of the present study also are consistent with the quantitative, descriptive studies reported in the literature on this population, thus supporting the confirmability of the study.

Figure 1. Themes in Families With Hereditary Breast and Ovarian Cancer (HBOC) Risk

Family Stories

Family A

Mrs. A described a sense of inevitability from childhood that she and her sisters would die from the “Big C” (cancer) as many others had in her extended family. The belief came from hearing adult discussions during family gatherings throughout her youth. She reported that, as teenagers, the sisters taunted each other with gallows humor about who would be the first to “get it.” When Mrs. A was a young mother of three small children, her sister died of breast cancer after warning her, “You’re next.” At the urging of her mother, Mrs. A consulted a cancer specialist for testing and learned that she was at high risk, had early thickening of breast tissue, and should have mammograms at six-month intervals. However, her family physician declined to schedule mammograms because she was “too young.” About a year later, Mrs. A discovered a lump in her breast that was diagnosed as malignant. She was shocked by her diagnosis and sought for support, feeling isolated and alone because her husband was not involved in the decision-making process. She felt supported by a close friend, who helped her to voice her concerns and make decisions about her care. The friend encouraged her to seek a second opinion at a different hospital, which ultimately led to a more aggressive treatment plan.

Family B

Mrs. B described a sudden change in her family’s dynamic when her sister was diagnosed with breast cancer at a young age. The diagnosis was a shock to the entire family, and they were forced to confront the reality of their personal risk. The family was unable to come to a consensus about whether to pursue genetic testing, leading to stress and conflict within the family. Mrs. B’s daughter was particularly affected by the news, feeling overwhelmed and unsure of how to handle the information. The family eventually decided to undergo genetic testing, and the results revealed that Mrs. B herself was at a high risk for breast and ovarian cancer. This news was difficult for Mrs. B to accept, and she struggled with feelings of guilt and self-blame. The family sought support from a support group for HBOC families, which provided a sense of community and helped them to navigate the challenges of the disease.

Family C

Mrs. C described the impact of her family’s history of breast and ovarian cancer on her personal and family decision-making process. The family had a history of HBOC, with several aunts and cousins diagnosed with both breast and ovarian cancer. This knowledge was a source of anxiety and distress for Mrs. C, who was at a high risk for the disease. The family was initially hesitant to pursue genetic testing, feeling overwhelmed by the potential results. However, after consulting with her doctor and genetic counselor, the family decided to undergo testing, which revealed that Mrs. C was indeed at a high risk. The family was faced with the difficult decision of how to share this information with other family members, and they ultimately chose to disclose the results to as many relatives as possible, who were able to make informed decisions about their own health. The family’s experience highlighted the importance of open communication and support in managing the challenges of HBOC.
regretted telling her preschool-aged children too much; she let them see how sick she was during chemotherapy and how afraid she was that she would die. She told them that they must always be alert for cancer and be tested as soon as possible. The children accompanied her to chemotherapy and later reconstruction visits because of difficulty getting babysitters. At home, the children played “chemo” and “finger stick” and the youngest girl repeatedly drew suture marks like her mother’s on her own chest. The two daughters reported that they frequently claimed to be sick to stay home from school or return home early to be with their mother because of their fears for her. Later, when the older daughter began to develop “breast buds,” she told her mother she was afraid she had cancer. The younger daughter reported always leaving the room when discussions of breast cancer or risk took place. The son said he was paranoid about getting cancer himself. When her daughters and son became old enough to be tested, their mother insisted they do so, despite reluctance by the younger daughter. The older daughter wanted to know her status because she had a baby and wanted to know if she, too, was a carrier. Mrs. A persuaded all three to be tested together, repeating to them and to the interviewers that “knowledge is power” because early detection saved her life. The younger daughter said she was being tested because her sister wanted her to do it but did not plan to obtain her results; she said “[I] just didn’t want to know . . . knowing would ruin my life.” She said she kept her fears under control by not thinking about them.

Family B

Mrs. B was a housewife and Mr. B was a healthcare professional. She was in college when her mother developed cancer and had a mastectomy and chemotherapy. Years later, her mother had a recurrence and died. When her sister developed breast cancer and Mrs. B developed a benign lump, she and Mr. B decided that she needed to have a bilateral mastectomy based on the family history. Later, Mrs. B heard about genetic testing and tested positive for BRCA1. She said that although she expected positive results based on the family history, “It still was very emotional; it’s really different expecting it from knowing it.” Mrs. and Mr. B believed that the test confirmed their earlier decision and decided that she should have a prophylactic total hysterectomy and bilateral oophorectomy. Mrs. B had the procedure when her children were in elementary school; her son wanted to be home with her, and her daughter asked whether she might have to undergo the surgery. Mrs. and Mr. B protected the children by giving limited, age-appropriate information combined with reassurance to communicate what was happening. The son vaguely remembered that when his mother had her hysterectomy and bilateral oophorectomy, he was told that she was not sick and was having the surgery so she would not get sick. He said he did not know much about the hereditary cancer risk but did have concerns for his sister and might consider testing for himself if he was in a serious relationship. He did not ask his parents about his risk, and they did not tell him much. He added that he planned to ask his parents more about the risk, particularly if he were to have children. Mr. B said that he was aware of Mrs. B’s family history when they married and recognized the potential for breast cancer even though the actual genetic basis was not known. Mr. B had not talked much about the risk with either his son or daughter but expected that Mrs. B had. He had no regrets about the prophylactic surgeries and believed Mrs. B did not either because she said she “wants to be around to see the children grow up.” Their daughter reported knowing little when her aunt became ill.

I think [our parents] tried to shield us. . . . I saw [my aunt] in her weakened state, but they always told us she’d be fine and I believed them. When my mom had her surgeries, that was more of a roller coaster because I knew more of what was going on. She told us she was just having some parts taken out that she didn’t need anymore, because of my aunt, so my mom could be with us longer and not get it. My parents haven’t said too much, just that I will probably be at risk, which I have known for so long . . . . I just think “OK.” I want to get tested when I’m older so I can make sure to get it out if there is something there, just the same as my mom did. If I were my mother or aunt, I would have been more scared of cancer because their mother and grandmother died from it, but a lot more people prevent it or survive it now.

In the family interview, Mrs. and Mr. B talked about electing for prophylactic mastectomy before hearing about genetic testing because frequent screening—finding a lump and having a needle biopsy followed by lumpectomy—and seeing what her sister with cancer went through were stressful. After testing showed the gene mutation, the decision for oophorectomy was not difficult because Mrs. and Mr. B believed that they had completed their family. Mrs. B said, “[I] wanted to see my kids grow up, have grandkids, because I still think how neat it would be to have my mom around and how proud she would be of her grandkids.” Mrs. and Mr. B reported being pleased with the decisions they had made and described being open with family and friends about communicating the risk and open with the children in age-appropriate ways. Asked about when and how to tell children about risk, the parents suggested, “Whenever and whatever they are old enough to understand. . . . in bits and pieces.” In the family interview, Mrs. B reminded her daughter that she would need to begin mammograms, breast self-examinations, and Pap smears early. Her daughter responded, “When my mom started talking to me about that, I thought, ‘This is really sick,’ but it’s something that needs to be done.” Mr. B referred to his wife’s brother who refuses to be tested as an ostrich who “just sticks his head in the sand.” Mr. B encouraged making people more aware at younger ages.

Family C

Ms. C was an unemployed, single mother. She is the parent of an older daughter in her late teens who has an infant and lives with her boyfriend; Ms. C’s other daughter was too young to participate. Ms. C and her sister became aware of cancer risk at about age 12 or 13 when their mother and aunts were diagnosed with breast cancer. Ms. C said, “We always thought our mother must be very strong because she was the only one who survived cancer after she had her mastectomy.” Ms. C and her sister used to joke about “which of us would get it first.” Ms. C denied that the cancer risk influenced her life plans in any way. Ms. C’s mother told her to have someone with her when she obtains her results because hearing them can be devastating, so she and her cousin planned to go together; however, they had not obtained their results at the time of study. Ms. C and her sister did not believe that the results would be very devastating; Ms. C said, “[We] know we are at high risk.”
Ms. C said she does worry, but “that’s a bridge you cross when you come to it.” However, she tells any boyfriends at the beginning of a relationship that “[breast cancer] could happen to me and if they have any problem with that, then they better not be going out with me.” Asked about health-protective behaviors, Ms. C reported that she always has a clinical breast examination with her annual Pap test, but she said, “I don’t do breast self-exams, and I know I’m wrong.” Her last mammogram was in 2001 after her younger daughter’s birth. Ms. C said that when she obtains her genetic testing results, “If it turns out I am a carrier, I will need to look into programs for assistance because I don’t have insurance.”

Ms. C’s older daughter said that she considers her mother her best friend. The older daughter first became aware of the risk for cancer when her grandmother had surgery years before but did not know much about the disease. When her mother was tested, the daughter was older and became worried about her own risk. Ms. C told her daughter, “They can take your breasts out and replace them with something else before you get [cancer] or before it spreads,” so the older daughter does not worry about her risk. She has not thought about being tested; she said, “I’m only 19, I don’t think about that stuff.” However, she told her boyfriend about the risk because she would rather he knows at the start of the relationship instead of later when she might have to have a mastectomy. The older daughter said, “He probably thinks like I do—it may matter later on but not right now, so why worry about it?” During the family interview, the older daughter expressed interest in knowing she has cancer early rather than in 20 years. Ms. C asked what the chances were that her daughters would be positive and was told that if she was negative, her daughters would not be at high risk. After the interview, Ms. C made an appointment to obtain her results based on the knowledge that her daughters would not need to be tested if she were negative.

Family D

Mrs. and Mr. D have two young adult sons (one in college and one married and living in another state) and a 17-year-old daughter. Mrs. D became aware of her risk when her identical twin sister was diagnosed with breast cancer and said Mrs. D should undergo a mammogram. The twin sister received chemotherapy for five years, struggled with bone metastases, and died. Mrs. D said, “Cancer was constantly on my mind then, but during her illness I really didn’t think much about heredity.” After her twin died, Mrs. D’s mother and her other sister developed breast cancer; none had had genetic testing. Mrs. D said, I started an anticancer diet program, interviewed surgeons, and found one I liked. . . . I figured if I watched closely enough, I could catch it early. . . . I did breast self-exams regularly and had mammograms and a doctor’s appointment every six months. I didn’t want the risk to be all consuming, so every six months I had to think about it, needed to remember it, but then go on with my life. Given the family history, doctors recommended bilateral mastectomy, but I didn’t want to have surgery on a healthy body part before I had to.

Later, the mammography center, knowing the family history, alerted Mrs. D when they saw an initial small change. Although the change did not appear significant, Mrs. D asked the doctor to do a biopsy. Her husband later called her at work to tell her to contact the doctor.

I went home to call [the doctor] in a panic because I knew what the odds were. I cried when he told me [that the results were positive]. . . . It’s so different expecting it from actually knowing, and then I handled it. . . . We discussed the bilateral mastectomy and reconstruction options, and I called my sister and my folks and let them know it was my turn. My husband was supportive, my sister came to help, and my church members just rallied around. [They were] a real support group.

Mrs. D reported that she had been grieving and depressed about her twin’s death for almost 10 years. “I was more concerned with her death than with my own cancer.” Marital stress also occurred; six weeks after Mrs. D’s surgery, her husband had a prescheduled road trip and asked if he should cancel. Mrs. D said no, and her sister stayed with her; however, she resented that he left. Years later, Mrs. and Mr. D sought counseling to resolve the marital stress and work through her grief over her twin’s death. Mrs. D said she wishes more counseling had been available to her earlier because she did not experience positive emotions again until soon before the present study. She described her response to the prophylactic surgery: “I live with a changed body every day. . . . It took a long time to accept the implants, even after healing. There are still weak muscles, I can’t lift some things.” Mrs. D recommended intensive screening as a preventive strategy, but believes that oophorectomy is important for women with high ovarian cancer risk because of the uncertainty. She said, “The 30%–40% risk of ovarian cancer was just too much for us, and we were done having children.” Mr. D said he had not thought much about the risk to the children. He said he will be concerned for his daughter as she grows older but he does not think about his son’s risk. He said, “Maybe I don’t know enough about it to scare me, but I assume it’s just a breast cancer gene.” Mrs. D has informed her three children that they can be tested at age 18 if they wish, but she has not encouraged or discouraged them. The oldest son told his wife about the risk before their marriage and said he would consider being tested when their children are older. The younger son said he would consider testing if he was involved in a serious relationship. The daughter remembers very little about her aunt’s illness and death because she was too young, but when her mother had her biopsy, the daughter was “really scared.” The daughter said, “[My mother] sat me down and told me, ‘I am not going to die like [my sister].’ I was older and understood more, so it was OK because the cancer was so small and early. She did not remember much about her mother’s hysterectomy because “[It was] not a big deal. . . . She wanted to avoid ovarian cancer. . . . She told me about it and what was going to happen.” When asked if she thought about whether cancer would affect her, the daughter said,

Oh definitely . . . I will have to get tested to see if I have the gene or not. . . . I know it’s going to be part of my life since most of my relatives had it. . . . I’m a little worried but haven’t found out yet. I’d like to get tested early so I can start preventive measures and stuff. . . . Our parents are pretty open about it, so I knew what was going on when I was old enough to understand. . . . I know I’m going to have to fit it in. It’s going to be a part of my life for a long time. . . . I know it’s not common to have a family so at risk, but I am going to use that to take care of myself if I’m positive. It’s best
to get mammograms every six months and be prepared. That’s what helps, that’s what saved my mom.

At the family interview, Mr. and Mrs. D said that thinking about Mrs. D’s risk “almost never comes up; it’s after the fact now except for concerns about our daughter.” The daughter responded, “I would say I think about it more than they do. It’s in the past for them, but it’s in my future.” Asked if they had recommendations for others, Mrs. D said she wanted to see more counseling available in addition to genetic counseling. Mrs. D believes genetic counseling is as important as testing and therapy and would have liked to have it available to assist her family and others.

**Family E**

Mrs. E is married and has two daughters and a son. Her first awareness “came out of the blue because there was no breast cancer in the family at all.” She was age 47 when her sister was diagnosed with breast cancer, but healthcare professionals did not recommend genetic testing at that time. She said,

As a sister, you don’t think of yourself at risk, but it does raise your antenna to be thinking about something you never had to think about before. . . . My sister had radical surgery and then, two years later, she developed ovarian cancer and decided, being a health professional, that she wanted genetic testing. When it was positive, she alerted all the female members of the family that they were at 50% risk and needed to be tested. . . . I look at her as having taken the bullet for the rest of us. . . . My first thoughts were that I am lucky, I am not sick, but then my thoughts went to my daughters . . . my God, I didn’t have to go through this all my adult life. . . . I was lucky to have all my choices to make and here I am, but my daughters will have many hard choices and serious decisions to be made much earlier in their lives.

Mrs. E added that her father was very distressed because he was the carrier, with absolutely no knowledge of the disease. His daughter was extremely sick and, although no one blamed him, he felt guilty. Mrs. E said, “It hasn’t changed our relationship with him,” but the sisters are careful to shield their own pain and distress to protect him from feeling worse.

I didn’t think getting the results of my test would be such a hard thing, but it turned out to be more traumatic than I thought. The resulting prophylactic mastectomies and total hysterectomy took a year out of my life . . . took a toll on aspects of my work life. . . . I was with my sister when she had chemotherapy and [saw] what she went through. . . . She showed me the difference between her radical mastectomy scars and the later prophylactic mastectomy scar. . . . I put it in perspective for me.

Mrs. E said her husband was supportive throughout the cancer experience. She said, “If he had any personal feelings about any of it, he kept them well guarded.” Her older daughter and son came home for the surgery, but Mrs. E scheduled the procedure when her younger daughter was away for the summer; Mrs. E did not tell her younger daughter about the surgery until she returned home. Mrs. E told her older daughter about the genetic risk and the need for future testing; however, her younger daughter and son, who were not interviewed, likely have not been told. Mrs. E said that her older daughter was told because “[cancer] is in her near future, but the ramifications for adult life are such a big possibility, we need to be very careful about that.” When asked about telling her younger daughter and son about testing, Mrs. E said, “We are working on that.” Communication in the family was guarded, despite Mr. E and the older daughter’s comments that open communication would have been preferable. Mrs. E reported that many members of her extended family are resistant to being tested; she mentioned one who is “adamant that [testing for cancer] is not going to be a part of her daughters’ lives.” Mr. E said that their relationship was even better because “in small ways, you think more about each other and their well-being after a threat like this.” He added that much consideration was given toward “when to tell the children . . . when to get them worrying about it.” He said he will not be comfortable with the entire risk experience until the children are tested. The older daughter recalled her mother’s prophylactic surgery.

I really didn’t know anything about it until one day when I was home from college. She said she had this gene and had decided to have the surgery . . . it was like hitting me all at once. . . . I really hadn’t known anything about that . . . she tries to protect me. I kind of wished I had been clued in more along the way. . . . I know she didn’t want me to worry and didn’t want it to become this thing hanging over my head. . . . Her surgery seemed really radical at first, but after it sunk in, it seems like the best thing to do. . . . I was scared for her. I haven’t talked about it with my sister and don’t know how much my mom has told her.

As asked if she had made a decision about testing, the older daughter said,

I’m not freaking out yet, and when I do think about it, it’s not for long. . . . The point of not getting tested yet, I think, is so that I am not living my life with something hanging over my head if it’s positive. . . . My mom thinks in the next few years would be appropriate and I would tend to trust her judgment. . . . The thought has crossed my mind to not do [genetic testing], but I think that is unwise. . . . I probably will in five or six years and that is far enough off, I don’t really have to deal with the reality of it yet.

The older daughter said that negative consequences of knowing her genetic testing results included worrying and the possibility of sabotaging significant relationships in the future. She added, “If I were to be negative, and my sister positive, that would break my heart.” She knew that positive results were not a death sentence, but because the risk had not changed any of her plans or relationships, she was just “enjoying friends and work and being young.” She did not know if her brother knew much about the cancer risk because “it’s like a female thing.”

**Discussion**

Saturation was not achieved in this brief, descriptive study. However, the family findings were consistent with data reported from numerous quantitative studies and were validated by three genetic counselors from other centers. The purpose of the present study was to understand themes and issues in becoming aware of intergenerational vulnerability to HBOC risk. Many responses may be individualized to the participants and their families, but several themes were identified to clarify responses that initially appear ineffective, fatalistic, or nonfunctional but
are based in family history, awareness of vulnerability, and attempts to cope with painful choices.

Implications for Future Research

The investigators believe that a larger, qualitative study is needed. A grounded theory approach could provide a theoretical framework that encompasses the issues, including influential factors, decision-making and communication processes, and the outcomes of those processes on decision making about testing, adherence to surveillance or protective behaviors, and communication of risk awareness in appropriate ways to the next generation. Some of the issues typically are not addressed during counseling given at the time of genetic testing and disclosure of results. Many women who are not tested or do not receive results may not become aware of their risk until after cancer surgery and treatment. Other women may not obtain their testing results or may continue to be concerned even after receiving negative results. In addition, the best ages, timing, and approaches for communicating risk to children have not been studied. Genetic counseling usually ends for many families after disclosure of results and recommendations, but families may need additional guidance regarding decision making or emotional support. Parents have concerns about how and what to tell children at various ages (Bradbury et al., 2007), and the present study demonstrates that husbands want to understand and better support their wives. Counselors may want to test various approaches to providing anticipatory guidance for predictable stages when additional guidance may be useful and explore resources available to meet those needs.

Implications for Nursing Practice

Studies have shown that many family members at risk choose not to be tested, many of those tested do not obtain their results, many who are given negative results continue to be overly anxious and vigilant in screening, and many who receive positive results do not adhere to screening or preventive recommendations (Tinley et al., 2004). A literature review suggested that healthcare professionals should be cautious about generalizing and should tailor information based on the individual medical and emotional needs of patients and families (Hutson, 2003).

Communication of risk information is infrequent and related to emotional and behavioral factors in the identified carrier (Lansbergen, Verhaak, Kraaimaat, & Hoogerbruggen, 2005). Another qualitative study found that parents saw themselves as responsible for disclosing risk information to their children, but did so in various ways, including complete openness, limited disclosure, and complete secrecy, based on their beliefs about protecting children from anxiety versus their right to information (Hallowell et al., 2006). A survey of 267 breast cancer survivors’ attitudes about informing children about the risk found that 71% believed children should be informed before age 18 and 84% believed parents should provide the explanations, but many preferred that a health professional convey the risk information (Miesfeldt, Cohn, Jones, Ropka, & Weinstein, 2003). Most respondents reported that their children had already expressed concerns about cancer risk, suggesting that parents need support and assistance in making decisions about what, when, and how to tell their children as well as recognizing that sons and daughters should learn about risk status.

Children in the present study who were most realistic and accepting of their risk without being overwhelmed were told in small amounts in age-appropriate ways during teachable moments by their parents. Nurses can help parents discuss questions and concerns and assist them in solving issues in their approaches or refer them to counselors. Hallowell et al. (2006) noted that single parents and their children may need additional support because no neutral parent exists to act as a sounding board.

Nurses in oncology and hereditary cancer centers should be particularly aware of the needs of various family members for additional counseling that may occur at different times. Husbands of women experiencing mastectomy or total hysterectomy for cancer or prophylaxis expressed a need to talk with others about their concerns and how to be more supportive of their wives. Two of the women suggested that genetic counseling centers stress an open door policy and assure women that they can seek additional counseling at any stage in decision making or adjustment. In addition to genetic counseling received during pretesting and on disclosure of results, families with HBOC risk often need guidance at times for decision making and emotional support. By providing ongoing assessment and support, nurses can help families throughout this difficult disease experience.

Author Contact: Joan Norris, PhD, RN, FAAN, can be reached at joannorris@creighton.edu, with copy to editor at CJONEditor@ons.org.

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