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“The Cancer Bond”: Exploring the Formation of Cancer Risk Perception in Families with Lynch Syndrome

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Abstract

This study explores the social context of hereditary cancer risk perception in three families, an African-American family, a Mexican-American family, and a Caucasian family, each with Lynch Syndrome documented by a mismatch repair gene mutation. Communication network assessments measured family communication about cancer experiences and genetic testing information among a total of 26 participants. Participant narratives were evaluated to gain insight into how family cancer experiences and genetic testing information have shaped perceptions of cancer risk. Analysis of communication networks indicated that some families discussed cancer experiences to a greater extent than genetic testing information, and vice-versa. Interviews elucidated that sharing both types of health information led participants to conceptualize linkages among a strong family history of cancer, genetic testing information, and cancer prevention strategies. Understanding how different types of family communication influence the formation of perceived hereditary disease risk may enhance efforts to tailor genetic counseling services for families.

Keywords

Risk perception; Family communication; Genetic testing; Lynch Syndrome; Genetic counseling

Introduction

Prior to the advent of tests for specific genetic mutations associated with hereditary cancers, family history was the single most important indicator of hereditary cancer syndromes. Genetic testing for cancer susceptibility has transformed the nature of communication between clinicians and their patients about disease risk, screening, treatment, and prevention strategies. Effective communication with patients about disease risk is important because previous research has demonstrated that one's risk perception has the potential to positively influence screening behaviors and treatment decisions (Lipkus et al. 2000; Lucke et al. 2008), both of which may improve health outcomes. Yet, the extent to which lay theories of disease influence the interpretation of genetic information about cancer risk among patients and their families remains largely unanswered.

The analysis of family health communication provides a window into the relational processes through which disease risk is perceived, defined, and redefined (Finkler 2000). Communication within families about health history and illness experiences is an important means by which family members may begin to conceptualize risk perceptions at both individual and family levels (McAllister 2003). In the context of inherited cancer syndromes, the disclosure of personal genetic information within families has been shown to influence the risk perceptions of other family members, even those who have not received genetic testing and counseling services (Gaff et al. 2005).

The manner in which families discuss health history and illness experience in general is relevant to genetic counseling practice as it may influence the way family members share information about genetic test results and the extent to which these discussions shape risk perception (Cameron and Muller 2009; Nycum et al. 2009). Various aspects of family systems structure and functioning impact the extent to which families discuss genetic test results and with whom they are discussed (Koehly et al. 2003). Family communication about genetic test results also plays a pivotal role in influencing health behaviors such as screening for early cancer detection (McCann et al. 2009; Ersig et al. 2009a).

The aim of this investigation was to explore the familial context of risk perception formation in three families with a documented genetic susceptibility to Lynch Syndrome. Each family was from a different ethnic group. Persons with Lynch Syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC), may have up to a 70% to 80% lifetime risk of developing colorectal cancer and increased risks for developing cancers of the endometrium, stomach, ovaries, small intestine, hepatobiliary system, upper uroepithelial tract, pancreas, and brain (Lynch et al. 2009). Lynch Syndrome is attributed to germline mutations in one of four mismatch repair (MMR) genes (*MLH1*, *MSH2*, *MSH6*, and *PMS2*) (Lynch and de la Chappelle 2003), which are inherited in an autosomal dominant pattern. Approximately 3–5% of colorectal cancer cases diagnosed annually in the United States are attributed to Lynch Syndrome (Jemal et al. 2002; Yu et al. 2003). Risk for Lynch Syndrome is evaluated based on clinical presentation, pathologic criteria, and family history (Olschwang et al. 2004). Currently, mutation carriers and those at risk of carrying a Lynch Syndrome mutation are advised to have a screening colonoscopy every 1–2 years beginning at age 20–25 years, and they may be advised to undertake risk management strategies for other syndrome-related cancers (Lindor et al. 2006).

Two domains of health communication anchor the exploration of risk perception formation among the three families in this report: communication about family cancer experiences and communication about genetic testing information. Communication about family cancer experiences was selected as a research focus to explore perceptions of disease risk formulated

primarily through lived experience. Communication about genetic testing information was chosen to understand how clinical determinations of disease risk were discussed among family members. The ways in which family members conceptualized a linkage among a strong family history of cancer, genetic testing results, and cancer prevention strategies were given special attention. Because the three family groups are ethnically distinct from one another, the role of social contextual factors in explaining differences in patterns of family communication was also considered. This study contributes to a growing body of work on the effect of genetic testing information on families, perceived risk, and cancer prevention beliefs.

Methods

Study Design

Data were collected as part of a cross-sectional, qualitative study to evaluate family communication regarding Lynch Syndrome (Koehly et al. 2003; Pentz et al. 2005; Peterson et al. 2003). The qualitative study was part of a multi-phase longitudinal study of psychosocial aspects of genetic counseling and testing for Lynch Syndrome (Gritz et al. 2005; Vernon et al. 1999, 1997). Both studies were conducted concurrently with a research protocol offering free genetic counseling and testing for Lynch Syndrome. The multi-phase psychosocial study was reviewed and approved by the University of Texas M. D. Anderson Cancer Center Institutional Review Board.

Recruitment and data collection procedures have been described in detail elsewhere (Gritz et al. 2005; Koehly et al. 2003; Peterson et al. 2003). Briefly, for the multi-phase psychosocial study, colorectal cancer patients were recruited from gastrointestinal cancer clinics at the University of Texas M. D. Anderson Cancer Center, and were eligible if they had a cancer family history that met the Amsterdam II criteria for Lynch Syndrome (Lipton et al. 2004) or otherwise suggested an increased risk of carrying a MMR mutation (e.g., colorectal cancer diagnosed at age ≤ 45 years; multiple relatives and/or generations affected with syndrome-related cancers). Eligible patients were offered the opportunity to complete psychosocial questionnaires and to undergo genetic counseling and testing. Biological relatives of MMR mutation-positive patients who were at a 25% to 50% increased risk of carrying a mutation also were invited to participate in the psychosocial questionnaire study and to undergo genetic counseling and testing.

Individuals were eligible to participate in the cross-sectional, qualitative study if they belonged to a family that included at least one family member who had participated in the longitudinal psychosocial study, and who was currently undergoing genetic counseling and testing for Lynch Syndrome or had received MMR mutation-positive genetic test results. Eligible persons also were at least 18 years of age and could speak and read English. Families with at least 5 persons who were MMR mutation carriers or who were estimated to be at 50% or 25% increased risk of carrying an MMR mutation were also included to assure that an adequate number of persons was available within the family network to evaluate patterns of communication about genetic risk in a meaningful way. Participants included both biological as well as non-biological family members (e.g., spouses). Eligible individuals were invited to participate regardless of whether they had undergone genetic counseling and testing.

Letters of invitation to participate in the qualitative study were mailed to eligible persons. Study staff subsequently telephoned potential participants to provide additional information about the study and to answer questions. Family members who consented to participate in the study completed a semi-structured interview by telephone. All interviews were tape-recorded and transcribed verbatim. A total of 80 people from 15 families completed the cross-sectional qualitative study.

Sample

Of the 15 families that participated in the cross-sectional qualitative study, one was African-American, one was Mexican-American, and the rest were Caucasian. A purposive sample of three families (26 individuals) was selected from participants in the cross-sectional qualitative study for the present analysis. The families chosen for the present analysis were the African-American family, one Caucasian family, and the Mexican-American family, referred to herein as Family A, Family B, and Family C, respectively. Ethnicity for each participant was self-ascribed, and all members within each of these three families identified themselves as belonging to the same ethnic group. The rationale behind their inclusion was that family communication and illness experiences might vary with ethnicity and other socio-demographic variables, and if so, such variation would be reflected in their narratives. The families were also chosen because they had a comparable number of family members participating in the qualitative study, thus enhancing our ability to conduct comparative analysis of their communication networks.

Interview Guide

For the qualitative study, a semi-structured interview guide was developed to assess families' communication about colorectal cancer screening and Lynch Syndrome genetic counseling and testing results (Koehly et al. 2003; Pentz et al. 2005; Peterson et al. 2003). Interview questions were based on models of family functioning (Sawin and Harrigan 1994), and on the investigators' prior research findings with these families. During the interview, participants were asked to enumerate all of the people whom they considered to be part of their family. Basic demographic information for the named family members was collected. These named family members were referenced for all of the subsequent social network questions during the interview.

During the interview participants were also asked open-ended questions regarding various aspects of family communication about cancer experiences and genetic counseling and testing. For example: *Tell me about your experience with the cancer(s) that happened in your family. Who told you about the cancer(s) in your family? What kind of information did they share? How did it affect your family? Tell me about your experience with your family's genetic testing. Who in your family do you think is at high risk of cancer?*

Assessments of Communication Networks

For the present study, responses to interview questions about two types of family communication were used to create the communication networks. Participants were asked to name the family members with whom they discussed: (a) family cancer experiences, and (b) genetic testing information and results. The named family members were recorded and coded for input into a communication network dataset. Validation of the network data and resolution of any discrepancies between coders were addressed by a third party (L.K.). Two communication networks were created for each participant, one for each type of family health communication. Participants' networks were combined into a single network for each type of health communication to create three family-level network datasets.

A simple comparison of the proportion of family members who were engaged in the communication (i.e., density) for family cancer experiences and genetic testing information was conducted across the three families (*ref.* Koehly et al. 2003 for an in-depth social network analysis of family functioning and communication about genetic counseling and testing information). Additionally, the proportion of men and women engaged in communication about the two types of family health information was also evaluated. Quantitative analysis of the communication network data was conducted using SPSS 15.0 (SPSS 2007). Diagrams of the

family communication networks were obtained using NetDraw within UCINET (Borgatti et al. 2002).

Qualitative Data Analysis

The full set of interviews from the cross-sectional, qualitative study ($N=80$) were grouped by family ($N=15$) and imported into NVivo 7 (QSR International 2007) for analysis. The primary coder (A.P.) reviewed the full set of interview data to first gain familiarity with the interview data and then establish a framework within which to code data for the subset of three families (Bernard 2005; Strauss and Corbin 2007). During this initial reading of the interviews, emergent themes pertaining specifically to family cancer experiences, genetic test results, and risk perception were delineated. These themes were then used to guide the systematic coding of data for the three families ($N=26$). Interviews were coded by family group, such that individual interviews were coded within the context of other interviews from their own families.

To code the interviews, interview text that corresponded with one of the research themes was selected and then assigned to a designated theme using NVivo 7. Validation of the themes and coding strategy was performed by having one-third of these interviews double-coded (A.P. and M.S.), comparing the results, and finalizing a coding strategy. The remaining interviews were coded by the primary coder (A.P.). Interviews were carefully reviewed throughout the coding process for references to cultural norms of communication, the effect of socioeconomic issues on health, educational differences, and other social and cultural factors that might enhance the interpretation of communication variation among families. Notes on these references were recorded and maintained separately from the formal coded text.

The final integration of communication network assessments and interview data was achieved through an iterative process. For example, participant narratives about family cancer experiences revealed that such discussions were important to the formation of perceived cancer risk. The subsequent comparative social network assessments suggested potential differences in how the three families discussed family cancer experiences. This finding provided a rationale to revisit participant narratives and identify any new passages that might elucidate reasons for these differences and shed light on how, for some of the families, discussions of family cancer experiences might be more or less important to the formation of perceived risk.

Results of Communication Network Assessments

Table 1 contains demographic and other descriptive information for each family group.

Family A had 6 female and 3 male participants, Family B had 6 female and 3 participants, and Family C had 3 female, and 5 male participants. Each participant named an average of 21 people as part of their family.

A total of 516 communication dyads were enumerated by participants. Dyads refer to a communication tie between two individuals, for example, a study participant and his or her family member, herein referred to as an *alter*. Participants in Family A enumerated 200 total dyads for both types of health communication; Family B, 153 total dyads; and Family C, 163 total dyads. The gender distribution of communication dyads for study participants and their alters are summarized in Table 2.

Communication about Family Cancer Experiences

The communication network assessment for Family A revealed that 27% of all enumerated communication dyads for this family involved discussions of family cancer experiences. Similarly, 20.3% of the dyads described by members of Family B involved communications

about family cancer experiences. However, only 9.8% of the enumerated communication ties in Family C concerned discussions about family cancer experiences.

Communication about Genetic Testing Information

In Family A, 8% percent of all enumerated communication dyads were related to discussions about genetic testing. In contrast, 29.5% of dyads were named for genetic testing information in Family B. In Family C, 33.1% of dyads were named for communication about genetic testing.

Comparison of Communication Patterns

Fig. 1 illustrates the comparison of the two types of communication patterns by family group. The exploratory comparison of communication networks for each family indicated some interesting differences. First, considering the two types of communication networks within each family, there was a difference between Family A and Family C in terms of the proportion of communication ties designated for discussions of cancer experiences in the family and discussions about genetic testing. In Family A, a higher proportion of family members were engaged in discussions of family history of cancer and cancer experiences than in discussions about genetic testing. Conversely, in Family C, a relatively low proportion of members reported discussing family history and cancer experiences with other family members when compared to the proportion of members involved in discussions about genetic testing. Family B had about the same proportion of family members engaged in discussions about both types of family health information.

Family A had the highest proportion of family members engaged in communication about family history of cancer, while Family C had the lowest. Family B and C both had higher proportions of communication about genetic testing than Family A. In all families, women were dominant in exchanges of health information. Women generally discussed both family cancer experiences and genetic testing information with other women to a greater extent than men discussed the same information with other men (See Table 2). Communication between women and men was also higher than between men for both types of family health information. In Family A, only one male-male tie was named for communication about family health, and no male-male ties were designated for communication about genetic testing information. Men communicated with other men about both family cancer experiences and genetic testing information in Family B, but to a much lesser degree than women discussed such information with other women and other men. In Family C, there were no male-male ties enumerated for communication about family health, but this family had the highest rate of male-male communication about genetic testing information.

Results of Qualitative Analysis

Four major themes pertaining to disease risk guided the analysis of interview data: (1) family history and cancer experiences in the formation of risk perception; (2) pre-existing explanatory models of cancer prior to genetic counseling and testing; (3) the influence of genetic counseling and testing information on risk perceptions; and (4) the link between risk perception and cancer prevention. Each major theme is presented along with verbatim interview excerpts to illustrate key points. A notation at the end of each excerpt contains a code for the corresponding participant indicating positive mutation status (+), sex (M/F), and age at the time of the interview.

Family Cancer Experiences and the Formation of Risk Perception

Typically, narratives of family health history were embedded in participants' stories of illness experiences, including caregiving, personal disease diagnoses and treatment, and thoughts about disease risk in the family. Colorectal cancer was often a focal point of these stories;

however, many other types of cancers were mentioned. Interviews indicated that an awareness of family health history and cancer diagnoses in the family was the primary basis upon which shared perceptions of family risk of cancer were formulated. Participants from each family reflected on how the diagnosis of cancer, either colorectal or other cancers within the family, had affected them and their own ideas about hereditary cancer risk.

Family A —All participants described a link between knowing that many family members had been diagnosed with cancer and a belief that the risk of cancer was high in their family.

All the re-occurring theme was that we have known cancer runs in our family. It's like if you're going to get sick and have a serious illness, it's going to be cancer. [+F, 52]

So, you know, like I said, there's always this bond. You know, it's a kind of unknown bond that nobody talks about, but there's always this bond. [*Interviewer: The cancer bond?*] Yeah. [F, 48]

Family B —Likewise, participants in Family B expressed a shared sense that the cancer diagnoses in their family were due to an inherited predisposition to cancer.

...we have known in our own minds a long time before we had this genetic testing that there was a genetic gene that caused all this cancer. We have been well aware of that. A long time, but not any scientific proof of that. But we just known it for a fact. [+M, 82]

I probably realized it probably ran in the family when my grandfather had it. Oh, way back. I, I, I just assumed that it did and always have thought, you know, a lot of times back years ago, I think they used to say no, they don't know whether it's hereditary or not and I've always thought it was. [F, 56]

Family C —In Family C, which was the family that had the lowest proportion of family members involved in discussions of family health and cancer experiences, there was the greatest degree of variation in the perception of cancer as a familial disease. These differences were notable between generations, but it is unclear whether differences in perceptions of hereditary risk of cancer are related to significant differences in the level of cancer knowledge or the communication patterns of older and younger family members.

Younger family members tended to describe cancer as a familial disease more often than older family members.

Some time ago ...with my grandfather dying, [my mother] getting cancer, my grandfather's brother dying, his two or three children dying, his four grandchildren dying, you know, it just, it was too—it was just too much for it to be a coincidence. [+M, 21]

Older family members tended to express surprise at learning that certain cancers in their family may be hereditary.

I was surprised and I wasn't expecting this. I'm telling you....Well, because—maybe because I think it was—maybe the disease you have is a personal thing, that nobody else is going to have it. Or not because my father had it, and I had it. But it wasn't hereditary or my kids could have it. I didn't expect anything of that. [+F, 56]

When asked how other family members' cancer experiences affected them, they explained that their perceptions of their own risk were not strongly affected by the cancer experiences of their family.

...when my *tia* had it, or cousins it didn't affect me at all. I was not even thinking about that I might have it. [F, 51]

I didn't think about me getting cancer sometimes, you know, it was not on my mind. [+M, 49]

Family Explanatory Models of Cancer Prior to Genetic Testing

Many participants described having a preconceived explanatory model for the prevalence of cancers in their families prior to learning about their genetic risk for factors associated with inherited cancers. These beliefs are interesting because they provide insight into the existing conceptual frameworks that may shape how family members interpret genetic testing information (McAllister 2003) as well as elucidate potential reasons for why certain family members are more involved in communication about genetic risk information than others (MacDonald et al. 2007).

Family A —Several participants in Family A explained a family theory of inheritance in which the women in the family were considered at higher risk of cancers than the men.

...where they used to think it was just female passed to female that they are finding it can be from female to male. [+F, 45]

...there was no way to really trace it if it was an overall thing, or if it was a girl thing. 'Cause it was no girls in their family, I mean no boys [that got colon cancer]... So, you know, then we didn't know if it passed to, you know, from female to female or if it can go from female to male or male to female.... [M, 46]

Another explanation was that a family member's blood type or Rh factor could have been the culprit of disease transmission on "one side of the family." One participant questioned whether an Rh-positive or Rh-negative factor was the "bad blood" in which the genetic factor was manifest among certain family members who had been diagnosed with cancers.

Family B —Observed similarities in appearance and behavior between particular relatives in Family B were sometimes extended to explanations of disease susceptibility.

So, my brother he looks like the E's and I look exactly like the L's. And, I guess that the genetic gene goes along with the looks. [+M, 82]

A lot of my family members say that I'm a lot like my Aunt L. and she is my dad's sister who died of cancer. I have always been told that I look like her and you know, and so I just kind of had it in my mind, that you know, I probably will follow in her footsteps if I had the same lifestyle as she did. [+F, 54]

Other aspects of cancer risk related to certain factors and health behaviors, such as age, diet, exercise, and keeping up with medical appointments, in the development of disease, emerged from interviews in Family B.

Family C —Family C was divided in the extent to which they thought of cancer as a familial disease prior to genetic testing. Some felt that cancer could not be prevented, necessarily, through changing lifestyle behaviors.

Well, I've always thought that it's just one of those illnesses that if you'll get it, you get it. I mean, there really isn't too much you can do to avoid it. [F, 28]

Others had personal theories of cancer causation that involved being of a certain age and diet.

Well, first of all, she's my oldest sister and she's already 56 years old. I was just thinking that probably that's the time for us to have cancer. [+M, 49]

And, maybe all the meats, we shouldn't eat those meats. Maybe we should eat just vegetables. [+F, 56]

The Influence of Genetic Counseling and Testing Information on Risk Perceptions

Participants addressed the relationship between genetic test results and perceptions of cancer risk as well as what the potential impact of discussing this information might be on the rest of the family and their risk perceptions.

Family A —Because participants in Family A had such a strong shared belief that the risk of cancer was high in their family, learning that they or other family members had been found to carry the mutation for Lynch Syndrome seemed to fall in line with their preconceived perceptions of cancer risk.

Oh I think I probably knew I carried it because I had already had the one cancer that seems to go along with it. So, I don't think I was surprised at all. [+F, 45]

You know, whether or not we have cancer is kind of a given....It's just you know, since cancer has run in my family for so many years, that's just something that I—to me—had accepted that probably did run in our family some way or other. [F, 41]

Some family members noted that they would only share their genetic test results with relatives they perceived as being at high risk, such as their children, but not with in-laws or aunts and uncles, who many felt were not “at risk.” Unlike in the other families, participants in Family A described concern about exposure to various types of social stigma, ranging from family stigma to health insurance discrimination, associated with having a positive genetic test result and being at higher risk for cancer.

'Cause they'll look at you as the same was with cancer. You know, you've got the gene. You've got the genes. When will you come up with cancer? [F, 48]

...it kind of places a little bit of guilt on a person, I think, and I guess, well, it's hard for me to say, but—'cause I guess I'm sensing what my wife would feel—that she doesn't want to, you know, certainly a parent doesn't want to pass on anything to their offspring. [M, 54]

The possibility of creating fear and worry in other family members was another reason some people chose not to discuss genetic testing information with family members.

Well, I think it scares the poop out of my in-laws. ...I think it scares them to death. Well they know about it, but I think they're terrified to find out. So I don't really tell them that much about it. You know. ... Because I'm not sure they're ready to hear that, you know, that their grandchildren could carry this gene.

You know. [F, 42]

I don't think I would discuss it with my mother 'cause I just feel like at her age, it would just worry her. [M, 54]

Family B —Genetic testing was considered valuable by all of the family members. While it did not appear to greatly affect their preconceived notions about cancer risk in their family, they discussed the value of having this additional piece of information to help them understand the familial disease patterns. Commonly, participants described personal beliefs about their own cancer risk and the risk of their family members as a matter of fact and with a sense of acceptance.

Well, the only way I can say it is when they had known, and we heard for years that M. D. Anderson wanted to do genetic testing because of what they'd found in the

family and so forth, and so it was always a thing that, you know, they looked forward to, not negatively, but positively. [M, 71]

I already knew it before, you know, when they did the testing. I knew I would have it. So, it was not surprising, and it was not devastating. [+F, 54]

Family C —Learning about the role of genetics in the transmission of cancer risk had a profound impact on perceptions of disease risk in Family C, particularly among those who did not think cancer was hereditary prior to learning about the genetic testing.

...now that we've been educated about how the cancer can be—how do you call—passed from our parents to us, that's been kind of a, well, I wasn't expecting that. But now that I learned that that's why, or that's how we physically, we'll expect, if this is in the family. [+M, 49] You know, it's better to know than to ignore it, to be ignorant. You know it can happen to me when so many family members have died of it. [+M, 21]

Unlike in the other families, there were reports of multiple family members who denied that anyone in the family had ever been diagnosed with cancer. This denial of cancer in the family and disbelief reportedly posed some barriers to family communication about cancer as well as efforts to encourage some family members to screen.

Whenever I see them, I tell them....I tell them about what happened to me, what could happen to them. If they need some information, I can give it to them. But like I told you, I have another aunt. She's my father's oldest sister. She says, 'No, I think you're wrong. Your dad didn't have cancer! None of my sisters have cancer.' She's too, in denial. She's very old, but she's always telling me, 'No, you're wrong.' She hung up on me, too. [+F, 56].

And, you know—few years, two or three years back, and I just kept, you know, like 'aw, nothing is going to happen to me,' you know, like—but, you know, and then she [sister] said, 'Well why don't you give them a call and, you know, find out more about it.' And, you know, and like I say, you know, I got curious about it. I said, 'Well, hell, maybe, maybe she's got a point,' you know? [+M, 46]

A fear of cancer emerged in several interviews, primarily with regard to other family members who were perceived as being unwilling or disinterested in having genetic testing done or having regular screening colonoscopies. In reference to one of the two family members who is a medical doctor, one woman responded:

Like my youngest brother doesn't want to know anything about it. No, because he says, well this is a statement that he has made: that he is too young to know if he has cancer or not. He said, 'Why do I want to suffer now that I am young and then later I am going to find out that I have this'? [F, 51]

Perceptions of risk in this family were on the whole variable, both for relative and personal risk. Typically, risk perceptions were strongly influenced by whether or not a person had tested positive for a Lynch Syndrome MMR mutation.

My mother [is at high risk], because she's been through several cancers already.... You know—once I got the results—once, you know, like since I knew I had it, I would think about my uncles. For some reason I thought they would come up positive, and they have, but when I see my aunt, I don't see her coming out positive....I don't really see any of my cousins [being at risk]... [+M, 21]

And yet, after going through genetic counseling and testing one sister remarked that, even though she had tested negative and one of her siblings had tested positive for a MMR mutation,

they both had about a 50/50 chance of developing colon cancer, because they were of a similar age. Despite her recognition that cancer was common in her family, when asked about the relative risk of family members developing cancer, one of the sisters explained:

...to me, cancer is one of those by chance type of things, or at least I've always thought of it as a by chance rather than a hereditary type of disease [F, 29].

The Link Between Risk Perception and Cancer Prevention

Family A —Most family members indicated that they participated in the genetic counseling and testing study because of their family cancer history. Their interviews also reflected a belief that participating in genetic testing and sharing genetic test results with family members is important to prevent disease. Participants emphasized the future health and well-being of their children, naming this as their primary reason for wanting to undergo genetic testing. Despite a strong family history of cancer, most participants in this family described feelings of optimism and hope that they would be able to either prevent or deal with a cancer diagnosis successfully through early detection and prevention.

... for me, the testing lets you know one way or other, yes, it is there; and then it gives you a chance to do preventive measures and early detection so that there's hope. [+F, 52]

Having the genetic test results as well as being familiar with their family history gave some family members a sense of empowerment.

Our physician told me that they would not have checked [my son] if it hadn't been for me, well, my having been diagnosed with cancer. [+F, 52]

...I think it [genetic testing] is the link that will get me the proper treatment perhaps that I might not get otherwise....I don't feel like I've always gotten the best care.... [F, 42]

Participants from Family A reported discussing family health matters and family history among members openly. However personal genetic test results were primarily discussed among immediate family with the hope that they would be more aware of ways to prevent cancer.

I think maybe I probably wouldn't discuss it with anyone other than my own kids. [M, 54]

... I feel like, well, you could tell your aunts and uncles, but what good is it going to do? Because they're really not going to be concerned. They're only going to be concerned with their offspring as to whether or not it's passed on to them. [F, 48]

There was a strong emphasis on parents having a responsibility to share their personal genetic test results with their children, especially if they were positive.

Both of my sons, I do hope that sometime they decide to have the testing done for their own knowledge and so they would have that information, if they do, that they can do something about it and go through prevention so that their life is not affected by tragedy before they know tragedy. [+F, 52]

Family B —A majority of the participants in this family had reported participating in regular colon cancer screening based on their knowledge of family health history and their own efforts to discuss this history with their doctors.

Well I think all my children have known that it's absolutely compulsory that they get their checkups. And they all go. Since I've had my problem and they all—my girls are well educated and got a lot of common sense. And they know that this genetic thing in my family and they go for a check up all the time. [+M, 82]

The availability of genetic test results was described as beneficial, particularly for providing children with information about how to be proactive for their own health.

...we were just happy to find it [genetic mutation] because it would help his children later in life possibly. Yes, yes, because if, you know, if the gene could be passed on and—that way they could get something done earlier, you know. If they could watch for it rather, if they have something. [F, 70]

Family C —Participants from Family C made reference to the importance of early detection.

This is not something bad...In fact, this is a lot better since we can be aware of something that could happen in the future. [+M, 49]

The matriarch of this family, the proband's mother, began discussing cancer in the family and encouraging family members to participate in the study. Family members reported that she was the first to encourage others to have screening colonoscopies done.

You know, I think she's the one who first started the processing. And I know she—it took several years before, I think, anybody else began the study. Because she had been talking to everybody, you know, 'You need to get yourself checked because it's something that you may be carrying in your blood,' and all this and that. And, I know that—well, when my grandfather passed away, I think I was 17, and several years later, I know my grandmother had told us, the grandchildren, that we needed to get ourselves checked out by the time we turn 25. [F, 28].

Health care providers were also named as individuals who were influential in helping some family members decide to have a screening colonoscopy at an early age.

Well, I know my brother and sister, they're not too happy about having to do something like that [colonoscopy].... Both [sisters] you know, they just say that if their doctor were to tell them they have to do it, they'll do it, but if not, they won't. [F, 28]

Discussion

This exploratory study offers insight into the ways that communication patterns are implicated in the formulation of individual and family level perceptions of disease risk through the analysis of each family's communication networks and participants' interview data. Our findings draw attention to how health information gained through the context of family experience or through genetic testing may variably influence perceptions of disease risk and beliefs about cancer prevention.

In families A and B, in which discussions about family cancer experiences and family health history seemed to occur more frequently, family members shared a belief that the risk of cancer among all family members was high. Participants from both families were well-informed of their family's cancer history and spoke clearly about the relationship of family health history and their perceptions of cancer risk for themselves and their relatives. In contrast, Family C reported the least communication about family cancer experiences and family health history. Younger participants in this family tended to describe cancer as a hereditary disease more than the older participants (e.g., their parents, aunts and uncles, and grandparents), some of whom said they had never thought of cancer as a disease that ran in their family. Family health was not discussed widely among family members, to the extent that various participants noted that they were not aware that others had ever been diagnosed with cancer or that they were aware that other people in the family probably knew more about the family health history than they did. Family members of all ages often described their own risk of cancer or the risk of family

members as “average” or “low,” along with a belief that cancer is largely a disease determined by individual lifestyle behaviors.

While there are certainly factors beyond the family that influence one’s perceived risk of disease, family experiences play an important role in how people make sense of a strong family history of cancer, especially in the absence of genetic testing information (Finkler 2000). Family beliefs about the mechanisms by which cancer may have been passed on in the family were found within all families. Again, the two families with the highest proportion of communication about family cancer experiences had explanatory models of disease that implicated some form of inheritance or shared biological risk. Only a few explanations for cancer in the family were provided by participants in Family C, and these centered largely on individual behavioral factors, such as diet, alcohol consumption, and physical activity. These findings suggest the presence of explanatory models that are interesting because they may reflect beliefs that were held prior to genetic counseling about a familial versus individualistic nature of cancer. They also can provide a context within which new information about the etiology of cancer is received and interpreted (McAllister 2003).

Narratives regarding the impact of genetic testing results on perceptions of cancer risk varied across these three families. Participants in families A and B who had previously conceptualized cancer as a familial disease did not report feeling surprised at learning that they themselves, or other family members, carried a genetic mutation for Lynch Syndrome. Generally, the genetic test results seemed to reinforce long-held beliefs about the prevalence of cancers in their families. The case was different for Family C. Learning that a genetic factor could be responsible for cancers in their family had a substantial impact on the way participants conceptualized cancer as a disease and their perceptions of risk. This influence was particularly notable among those participants who had not previously invoked heredity in explanations of cancer causation and risk. Still, participants across all of the families did not espouse deterministic beliefs about genetics and cancer risk. Lifestyle factors, particularly diet and exercise, as well as participating in cancer screening were emphasized as important means to offset any genetic risk of cancer across all families.

One might anticipate that families who discuss family experiences about cancer and family health history would also discuss genetic testing results to a similar degree. Family B was the only family that followed this expected pattern. Family A discussed genetic testing information to a lesser degree than they did family experiences with cancer or family history. Family C did not report a high proportion of people in the family engaged in discussions of family health history, but the proportion of family members that discussed genetic testing information was markedly higher.

Interviews with members of Family A indicated that a fear of social stigma, feelings of guilt, and a fear of cancer were associated with communication about genetic test results with other family members. Family members varied in who they would be comfortable sharing their results with, and suggested that they would disclose this type of information to other family members that they, themselves, had decided were at high risk, regardless of their actual risk based on their biological relationships. Discussions about genetic test results among members of Family B or C were not encumbered by these same barriers, even though many members also expressed a fear of cancer. In fact, based on the network assessments and interview analysis, it is possible that in Family C discussions about family health may not have been very common due, in part, to the fact that many family members did not conceptualize cancer as a familial disease. However, it appeared that after some family members underwent genetic counseling and testing as part of the study, the importance of family communication and awareness of the possible genetic component of disease became very important. For this family, participation in the research appears to have acted as an intervention, successfully raising

awareness about the etiology of cancer and motivating family members to discuss this information with each other.

One common theme throughout all of the families' interviews was the importance of cancer prevention, namely through beginning to screen for colon cancer at an earlier age. Family members thought it extremely important to encourage other members to engage in cancer screening and participate in genetic counseling and testing (Peterson et al. 2003). The stories from these families elucidate that both an awareness of family history as well as genetic test results variably led individuals at high risk for cancer to engage in screening at an earlier age. Encouragement to participate in cancer screening was predicated by a strong family history of cancer in Families A and B, before genetic testing was available. Encouragement to screen did not happen in Family C, however, until participants completed genetic counseling and testing. Based on reports of their experiences with doctors in clinical settings, the key difference in these two types of family risk information is that physicians seemed to value genetic test results more than stories of strong family history. For example, genetic test results in Family A were a means by which one set of parents was able to advocate early screening for their children, one of whom was eventually diagnosed with colon cancer before the age of 30.

Differences in communication about either family cancer experiences or genetic testing information across these three families may reflect factors associated with ethnic/racial differences, socioeconomic differences, or education level (Royack-Schaler et al. 2004). Allusions to cultural norms about communication regarding family health experiences or genetic testing information were scarce in the interview data; however, there were no specific questions in the cross-sectional study interview guide to elicit such norms.

Some unexpected findings did emerge. Socioeconomic differences that are associated with education and access to health care may affect a family's awareness of the importance of sharing family health information or engaging in preventive health behaviors (Lipkus et al. 2000). Yet, the family with the highest mean household income (Family A) was the only one in which a family member discussed socioeconomic hardship and lack of health insurance as a barrier to seeking out screening for colorectal cancer. Low education level and health literacy may be barriers to how patients interpret health information (Peterson et al. 2007) and subsequently communicate with family members about health (Davis et al. 2002). But, Family C, which reported the lowest mean income and talked the least about family health history, had two physicians in the family. These unexpected findings may indicate that the variability observed between families is indeed cultural in nature, stemming from fundamental differences in how health information is valued, the ways in which meanings are ascribed to this information, and norms for how it is shared within families.

Study Strengths and Limitations and Research Recommendations

The importance of ethnicity and cultural norms that guide family health communication has not been well studied, particularly in the area of genetic testing for Lynch Syndrome. For this reason, along with the small sample size, it is difficult to ascribe the variations that we see in patterns of communication for these three families to ethnicity or other socio-demographic factors. The differences we see in communication patterns could be due to cultural and social differences; however, they may also speak to the fact that individual family systems have unique idiosyncrasies that need to be explored to gain an understanding of how family health communication shapes risk perceptions. More research is needed to explicate cultural norms that guide family communication and how such norms intersect with other social factors known to influence risk perception and health behavior.

Other studies based on data from the cross-sectional qualitative study that employ larger sample sizes and contain more generalizable results have been published elsewhere (see Koehly et al.

2003; Pentz et al. 2005; Peterson et al. 2003). The present study departs from this earlier work in that it is an in-depth, mixed-method exploration of the connection between communication patterns and perceptions of disease risk in three families of different racial/ethnic backgrounds. The small sample size and limited applicability of results are an obvious limitation.

Nevertheless, given that there is a dearth of research on family communication and risk perception in the context of inherited cancer among families in ethnic minority groups, the inclusion of an African-American family and Hispanic family in the present study enriches the literature. An important contribution of this study is that it lays the groundwork for further research into ethnic differences in health communication and perceptions of inherited disease risk in the context of genetic testing. An added strength of this study is that it incorporates perspectives of multiple members of a single family into the analyses, providing a richness of perspective that cannot be captured through interviewing a single family member. Finally, this study provides a model for future research in which empirical analysis of communication is combined with qualitative data analysis of social context.

Conclusion

In addition to information provided by health care providers and through public health education, people develop beliefs about disease risk based on a variety of experiences and exchanges of information. This study offers insight into how perceived risk of hereditary disease may evolve and how beliefs about the importance of cancer prevention may develop through various types of family communication. Communication between family members facilitates exchanges of important health information that may encourage those who are at increased risk for cancer to engage in appropriate screening or to seek out preventive options (Ersig et al. 2009b). Assessments of social networks along with patient interview can aid genetic counselors in identifying key persons within family systems who may be particularly helpful in promoting the diffusion of risk information within at-risk families (Koehly et al. 2009; MacDonald et al. 2007). In our study, for example, women seemed to be more engaged in communication about both family health and genetic testing information and could be integral to promoting information about cancer prevention, particularly to male family members not included in important family health communication exchanges.

The three families included in this study provide examples of how family communication dynamics and illness experiences may shape risk perception. These findings have implications for genetic counseling practice. Understanding how risk perception is embedded within lay theories of inherited disease that are situated within family health experiences is relevant to promoting health behaviors in families at high-risk of inherited cancer syndromes. Genetic counselors, physicians, other health care providers and educators must remain mindful that individuals receive and process information in the context of complex social relationships and belief systems (Etchegary et al. 2009; Kass et al. 2004; Ramsey et al. 2003). Understanding the processes by which risk perception is shaped in families can help counselors and other health care providers in personalizing the way risk information is communicated to patients and their at-risk family members.

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Family Cancer Experiences

Family A

27%

Family B

20.3%

Family C

9.8%

Genetic Testing Information

Family A

8%

Family B

29.5%

Family C

33.1%

Fig. 1.

Comparison of Communication Networks for the Three Families. This Figure Illustrates the Network Assessments for the Two Types of Communication by Family. In the Diagrams, Each Node Represents a Named Family Member and Each Line Represents a Communication Tie Between Two Family Members. The Density of Each Family's Network is Calculated as the Total Proportion of Enumerated Family Members Engaged in Communication About (a) Family Cancer Experiences, in the Left Column, and (b) Genetic Testing Information, in the Right Column. The Nodes of Interviewed Participants are Larger Than Other Nodes of Enumerated Family Members. Females are Represented by a (Circle) and Males by a

(*Square*). Mutation Positive Status Is Indicated by Grey Fill and Mutation Negative Status by No Fill. A Black Arrow Points to the Index Case in Each Network.

Table 1

Demographic Information for Study Participants by Family Group

Family ID	Family A *	Family B **	Family C
Total family members enrolled	9	9	8
Median, Age range	43, 21–63	55, 23–82	29, 21–56
Number of females	6	6	5
Number of biologically related	7	6	8
Mean household income (range), thousands of dollars	46, (15–75)	34, (15–75)	32, (<15–75)

* Missing data for 5 participants

** Missing data for 3 participants

Table 2

Distribution of Family Communication Ties by Sex for Each Family Group

	Female Alter	Male Alter
Family A		
Communication about Family Cancer Experiences:		
Female Participant	27 ties [13.5%]	21 ties [10.5%]
Male Participant	5 ties [2.5%]	1 ties [0.5%]
Communication about Genetic Testing:		
Female Participant	8 ties [4.0%]	4 ties [2.0%]
Male Participant	4 ties [2.0%]	0 ties [0%]
Family B		
Communication about Family Cancer Experiences:		
Female Participant	20 ties [13.1%]	6 ties [3.9%]
Male Participant	3 ties [2.0%]	2 ties [1.3%]
Communication about Genetic Testing:		
Female Participant	18 ties [11.8%]	14 ties [9.2%]
Male Participant	10 ties [6.5%]	3 ties [2.0%]
Family C		
Communication about Family Cancer Experiences:		
Female Participant	9 ties [5.5%]	4 ties [2.5%]
Male Participant	3 ties [1.8%]	0 ties [0%]
Communication about Genetic Testing:		
Female Participant	23 ties [14.1%]	15 ties [9.2%]
Male Participant	9 ties [5.5%]	7 ties [4.3%]