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Unpacking the Blockers: Understanding Perceptions and Social Constraints of Health Communication in Hereditary Breast Ovarian Cancer (HBOC) Susceptibility Families

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Abstract

Family communication is essential for accurate cancer risk assessment and counseling; family blockers play a role in this communication process. This qualitative analysis of social exchanges is an extension of earlier work characterizing those who are perceived by study participants as health information gatherers, disseminators, and blockers within families with Hereditary Breast and Ovarian Cancer (HBOC) susceptibility. Eighty-nine women, ages 23–56 years, enrolled in a Breast Imaging Study (BIS) and participated in a sub-study utilizing a social assessment tool known as the Colored Ecological Genetic Relational Map (CEGRM). Purposive sampling ensured that participants varied according to numbers of participating family members e.g., ranging from 1 to 6. Eighty-nine women from 42 families (1–8 relatives/family) participated. They collectively designated 65 blockers, both male and female. Situational factors, beliefs, attitudes and cultural

traditions, privacy and protectiveness comprised perceived reasons for blocking intra-family health communications. Longitudinal data collected over 4 years showed families where blocking behavior was universally recognized and stable over time, as well as other families where blocking was less consistent. Self-blocking was observed among a significant minority of participating women. Blocking of health communications among family members with HBOC was variable, complex, and multifaceted. The reasons for blocking were heterogeneous; duration of the blocking appeared to depend on the reasons for blocking. Blocking often seemed to involve bi-directional feedback loops, in keeping with Lepore's Social Constraints and Modulation Theory. Privacy and protectiveness predominated as explanations for long-term blocking.

Keywords

Health communication; Hereditary breast-ovarian cancer; Family; Social network; Social constraint; Social support

Introduction

Background

Psychological and medical consequences of Hereditary Breast Ovarian Cancer (HBOC) susceptibility due to a deleterious mutation in either the *BRCA1* or *BRCA2* gene have been well studied during the past 15 years (Lerman et al. 1998; Narod and Boyd 2002; Stratton and Rahman 2008; van Oostrom et al. 2007; Watson et al. 2004). Both men and women with inherited deleterious mutations may develop cancer (breast, ovarian, male breast, prostate, and pancreatic cancer, melanoma, perhaps others), with the risks substantially higher for women. (Gaff et al. 2006; Thompson and Easton 2001; Thompson and Easton 2002).

Prevailing standards of care include counseling mutation carriers about proactive medical management of cancer risk, as well as strongly encouraging those who test positive to notify relatives of the presence of a deleterious mutation in their family (Gaff and Bylund 2010). Since acquiring and disseminating accurate information regarding familial disease risk is a key component of the genetic counseling enterprise, intra-family communication has been investigated extensively (Kenen et al. 2004b; Peterson et al. 2003; Suthers et al. 2006; Tercyak et al. 2002; Tercyak et al. 2007; Van Riper 2005). The present study builds on this work as well as our own prior studies (Kenen et al. 2001; Kenen and Peters 2001; Koehly et al. 2009; Peters et al. 2006).

A recent review of relevant studies highlighted particular affective, cognitive and structural complexities of family health communications. (Chivers Seymour et al. 2010). These include participants' feelings about informing relatives about genetic test results and the 'closeness' of relationships within the family. Cognitive factors included deciding the right time for and level of disclosure, judging the perceived relevance of the information to family members and imagining their anticipated reactions. Important were family rules pertaining to family scripts, family membership and family health communication, e.g., who is considered "family" and best positioned to share information with whom (Chivers Seymour et al. 2010).

The ability to integrate the impact of cancer on their lives through social processing is a primary predictor of emotional adjustment in people who have cancer. Social constraints on disclosure of cancer-related thoughts and feelings can adversely affect their understanding of their illness, their coping strategies and emotional adjustment to cancer. (Lepore and Revenson 2007). It seems likely that unaffected women with strong family histories of cancer who learn that they carry a susceptibility mutation will also find that social

relationship adjustments are necessary. For example, Manne and colleagues have described emotional benefits of supportive communications and detrimental effects of unsupportive responses from spouses and relatives (Manne and Badr 2008). They also observed that people commonly process medical events by sharing their experiences with others. This phenomenon, labeled as “social modulation of cognitive processing” (Lepore 2001), was described a decade ago in the “Social Constraints and Social Modulation of Cognitive Processing Theory” (Lepore and Helgeson 1998; Lepore and Revenson 2007). This perspective considers social constraints to be a “product both of social actions of others as well as the individual’s construal of those facts.” There is evidence that notifying relatives of genetic risk is difficult for some people, and many women who undergo genetic testing and receive this guidance experience it as pressure to inform relatives of cancer risk and to act responsibly (Claes et al. 2003; Costalas et al. 2003; MacDonald et al. 2007; Patenaude et al. 2006). In other words, those with cancer or a *BRCA1/2* mutation and those around them “may be ambivalent in talking about cancer or feel uncertain about how best to respond to their emotional reactions” (Lepore and Revenson 2007, p 2).

To capture relevant social exchanges between our Breast Imaging Study participants and their relatives, friends and significant non-kin, we introduced the CEGRM, as means to obtain and present simple, concise, visual representations of 4 social interaction domains - information, services, emotional, and spiritual support - by applying color-coded symbols to the genetic pedigree (Kenen and Peters 2001) (Fig. 1). In the past decade, we have demonstrated that the CEGRM is feasible, comfortable and useful in the clinical cancer genetics research context to facilitate better understanding of the social as well as emotional sequelae of belonging to an HBOC family (Koehly et al. 2008; Peters et al. 2006; Peters et al. 2004) Driessnack utilized a modified CEGRM process with similarly positive results in a pilot study of children aimed at understanding their sources of, and perceptions about, health information (Driessnack 2009).

A social network is a social structure composed of individuals who are connected by one or more specific types of relationship such as friendship, kinship, or common interest, such as breast cancer risk (Freeman 2006). We have previously documented the presence of specific family communication roles, i.e., gatherers, disseminators and blockers of health information, within our study population using social network analysis, which statistically reveals ties among members of networks (Koehly et al. 2009).

While the social network analysis gave us a snapshot of the differing health communication roles among families, we suspected that more subtle individual differences and complex dynamic processes that regulate family conversations about genetic risk were likely to lie beneath the surface. It is our belief that both the *outcomes* of family health conversations and the related communication *processes* are important.

The purpose of the present qualitative research project was to explore individual and family ambivalence and communication difficulties that may underlie the blocking of open communication of health information within HBOC families.

Aims of this Study—The primary aims of this exploratory study were to:

1. Comprehend or “unpack” the blockers, i.e., to better understand who was perceived as blocking and identify the beliefs, personal characteristics, and situational factors that were associated with behaviors perceived as impeding intra-family communication;

2. Examine longitudinal trends over the 4-year study timeframe in which participants were enrolled in the study, e.g., was the same person consistently perceived to be blocking for all 4 years?
3. Compare agreement between various participants' impressions of the same persons, e.g., was the same person seen by two or more study participants from the same family as blocking?
4. Explore special cases, e.g., self-blocking and steadfast blockers

Methods

Study Design

This was an exploratory, qualitative, longitudinal study of health information communications problems within HBOC families as documented via repeated annual individual CEGRMs, expanding our previous report on health communications in the Breast Imaging Study families from which the present study sample was drawn (Koehly et al. 2009).

Participants and Recruitment

The participants were a sub-set drawn from the 200 women recruited between 2001 and 2007 for a 4-year, prospective, IRB-approved NCI protocol 01-C-009, Breast Imaging Study (BIS) at the NIH Clinical Center, designed primarily to evaluate novel screening and prevention strategies in women from *BRCA* mutation-positive families at high risk of breast and ovarian cancers, with secondary behavioral research aims (Loud et al. 2009). All participants had received prior genetic education, counseling, and testing and most were positive for *BRCA1/2* mutations. A small subset of non-carriers from the same families served as controls for their mutation-positive relatives. The study included psychosocial assessments at each visit through the use of standardized instruments and study-specific instruments, in addition to co-constructing a CEGRM (see Procedures).

Sampling

Two-staged sampling was used to demonstrate feasibility of the research methods, maximize family structure variability, and capture the greatest number of relevant themes and patterns about communications within the support systems of women at high genetic risk of breast and ovarian cancer without exhausting research resources.

In phase 1, the breast imaging participants were first stratified by the number of family participants and their degree of relatedness:

- a. Multiplex = three or more first, second or third-degree participants from one family;
- b. Dyads = two participants from same family, e.g., sisters or aunt-niece;
- c. one single participant from the family.

The strata of families were then sampled by random number selection within these three categories, providing 12 study participants in each of the 3 strata for a total of 36 pilot participants. CEGRM-note data from all members of each selected family and their designated blockers were included in the pilot analysis. After the phase 1 sampling was completed, the entire research team examined the preliminary data and social network diagrams of the initial participants' families and decided to over-sample additional families-of-interest until we reached data saturation with a total of 89 participants as follows:

- a. all remaining 37 members of multiplex families with 3 or more participants;
- b. 16 women from 8 additional dyadic inter-generational pairs;
- c. 10 study participants who identified themselves as self-blocking, 7 of whom were accounted for the categories (a) and (b) and 3 additional women for a total of 10 (5%) from the total 200 women.

Procedures

Data Collection: Participant and Investigator Co-constructing the CEGRM—

After consent was obtained, women were seen annually for 4 years for a physical examination, screening mammography, breast MRI, trans-vaginal ultrasound and serum CA-125, as well as completing a series of questionnaires. Annually each participant conjointly constructed the CEGRM with a researcher (JP or LH), using the participant's computerized genetic pedigree as a template as previously described (Kenen and Peters 2001). The researcher used a semi-structured script to guide the participant towards identifying, with colored symbols, the individuals who filled various social roles in their lives from within and outside the biological family – tangible, emotional, informational, spiritual.

Star symbols were used to identify relatives exemplifying the specialized family health communication roles of information gatherers (green star), disseminators (silver star), and blockers (red star). Blockers - those given red stars because they were perceived to deter conversations about health information within the family for any of a variety of reasons – were the focus of the current analysis. While the participant was constructing the CEGRM by placing the colored symbols, the investigator took detailed notes (including salient points of participants' comments and verbatim quotes whenever possible) to capture the complexity, reasoning, and fine-grained characterization of individual perceptions of health information communication. We used an iterative process of identifying and naming recurrent patterns, relationships and processes in the data (Strauss and Corbin 1998).

Coding and Analysis

This qualitative study was based on inductive reasoning and an interpretive paradigm. The latter is based on the belief that there is not one objective social reality but, rather, multiple realities that are “local temporally and historically situated, fluid, context-specific, and shaped in conjunction with the researcher” (Guba and Lincoln 1994, p. 109). All of the researchers' handwritten notes that were taken during the CEGRM construction and related to the perceived blockers were transcribed. Two researchers (RK & JP) reviewed all CEGRMs and the accompanying notes for the selected participants, using open coding to identify preliminary themes. After several re-readings by JP and RK, higher order concepts were developed. An audit trail was developed to defend the trustworthiness and creditability of the analysis (Bailey 2007).

Results

Results are organized by study aims:

- I. Unpacking the blockers
- II. Examining longitudinal trends and level of intra-familial agreement
- III. Comparing agreement about perceptions of blocking
- IV. Self-Blocking and other special issues

Unpacking the Blockers

This section includes relevant characteristics and themes concerning blocking health communications. When available, verbatim quotes from participants are noted with quotation marks followed by the participant ID number in parentheses. For easy reference regarding results, we supply a glossary of terms in an Appendix.

Characteristics of Study Participants at Baseline Assessment—The characteristics of the study participants are summarized in Table 1. All 89 participants representing 42 families were female participants in the breast imaging study, the great majority of whom were well-educated, between 30 and 50 years of age, and married/partnered. There were 1–8 participants per family, with an average of 2 per family in this study. Eighteen families had a single member and the remaining 24 families had different constellations of family participants. The majority of participants were not affected by cancer; however, most participants (80%) were mutation carriers (50% *BRCA1*; 30% *BRCA2*); (the remainder were from high risk families with *BRCA1/2* mutations but were personally untested or of unknown mutation status).

In general, participants did not display/report emotional distress; self-reports of current mood at the time of the CEGRM (objectively captured with the BSI-18) were all below the median for anxiety, depression, somatization and global distress.

Characteristics of Perceived Blockers at Baseline CEGRM—The characteristics of the blockers are also summarized in Table 1. Naturally, we have less demographic information available for them since they were not directly interviewed. Eighty-nine subjects designated 65 blockers, a slight majority of whom were male. Very few (3%) blockers had a personal history of cancer, and even fewer had breast/ovarian cancer (1.5%); the vast majority (82%) were at increased genetic risk of cancer. A variety of family relationships were represented among blockers, as follows: nearly half (43%) were siblings or half siblings; 17% biological parents or step-parents; 8% spouse; 6% in-law or family through marriage; a variety of other second and third-degree relatives and 2% friends.

While some blockers seemed cut off from a variety of family interactions, many were very much socially engaged with study-participating relatives in other ways, e.g., 45% of blockers had some form of information exchanges with the participants; 19% provided tangible exchanges; 22% had emotionally supportive relationships; 17% of those on whom we had this data provided spiritual support; and 12% provided both emotional and tangible support. As expected, very few blockers (1%) engaged in information dissemination.

Characteristics of Study Participants' Social Networks—We observed extreme variability of social network relative to size of network, density, cohesiveness, direction, reciprocity, multiplicity, and shared supports within the research families, which were predominantly large and extended. Study participants enumerated an average of 25 (SD=15) unique family members, ranging from 10 to 97. There was significant variability in the number of family members with whom participants discussed their genetic risk of cancer; on average, participants engaged 43% of their enumerated family in such conversations. Figures 2a–b illustrate the social networks of two diverse families with multiple study participants.

Themes Regarding Perceived Reasons for Blocking—We grouped the variety of issues that participants discussed in terms of perceived reasons why some relatives were identified as blockers into the following themes:

1. Social context: Salient situational factors

2. Beliefs, attitudes, knowledge, family traditions
3. Protectiveness and Privacy

Social Context: Salient Situational Factors—Multiple study participants reported instances of powerful prior emotional experiences with lingering emotional and communication effects. One poignant example included curtailed communication about cancer risk by father and daughter due to the elderly father's unresolved grieving the unspeakably painful losses of his wife and daughter. (134) While it is often assumed in psychosocial oncology research designs that only the cancer losses are relevant, we found that any prior loss of a loved one due to any cause has the potential ability to color their subsequent health discussions and shape their behavior by avoiding current topics that might become emotionally painful reminders. (24)

Other participants reported current or recent situations that were believed to significantly impact certain family members and disrupted health communications, e.g., "My sister is in bad financial shape and doesn't have any insurance for screening so why talk about genetic testing?" (146) Some daughters who subsequently avoided health discussions had a history of being prematurely pushed by early-onset cancer diagnosis, or death of a parent (usually the mother) into highly-responsible family roles ("parentification") for which they felt unprepared and inadequate. One participant reported that her sister still has unresolved feelings about being their mother's caretaker many years ago, during her cancer diagnosis, treatment and death. In this case, there were additional communication barriers related to fears of discrimination by health insurers. (146)

Competing concerns about other health issues also interfered with HBOC-related communications. Two participants from the same family each reported that their brother avoided discussing the family's mutation because he was more concerned with managing his diabetes and mental health issues. (226 & 227)

At times communications were difficult in certain settings due to certain family communication rules. Some women agonized over whether family reunions or holidays were an appropriate setting in which to raise issues about the family's shared genetic risk. These women were reluctant to raise issues of cancer and genetic testing in an effort to keep the holidays "pure and uncontaminated," and to avoid damaging the memories of good times. (20) In other cases, they used their social intelligence to skillfully navigate emotionally difficult scenarios, e.g., "He listens but doesn't talk; he looked scared and worried." (215)

Those who did not see the utility of talking about genetic information were primarily men, often unmarried and/or with no daughters, and whose sisters sometimes colluded with their silence. One woman reported that, "I don't bother talking any more to my brother since he has low motivation for genetic testing because he has three sons and no daughters." (54)

We also heard about circumstances, such as membership in the non-mutation side of the family, that curtailed communications. While mutation-negative relatives may correctly perceive their risk of developing cancer as lower than mutation carriers, some seemed (to certain participants) to be oblivious to the stress that mutation carriers experience and the mutation carriers' needs to discuss their high risk situation. Thus, some participants felt misunderstood and hurt: "Paternal relatives (non-mutation side of the family) are not at high risk so they don't get it about me." (46) and "They just don't care." (31)

In some situations communication restraint proved functional. For example, strict communication boundaries permitted some people with unresolved grief or competing social

issues the opportunity to resolve their issues before tackling genetic counseling/testing decisions.

Selected Beliefs, Attitudes, Knowledge and Family Cultures—The second thematic category related more fully to the interaction between social context and individual characteristics and coping styles, including personal, familial and cultural beliefs or values. For example, a number of blockers were described as not accepting medical explanations of disease or as having a more generalized distrust of the healthcare industry. One subject reported that her husband didn't believe in genetic testing or hereditary predisposition, saying, "It's all BS." He just doesn't go to doctors (83). Another described her mother saying "Doctors are butchers," (26) and the father-in-law who says, "It's all a big hunk of baloney." (215)

Strongly held but erroneous beliefs may preclude unfettered cancer risk communications, such as the woman who reported that her mother-in-law never had a mammogram, saying, "I'll know when I have cancer." (107)

In other cases, the beliefs had more religious, spiritual, or fatalistic content, e.g., "There's nothing to prevent it [cancer]" (31). One participant's sister was very religious and believed in myths- "If you say it out loud, then it's gonna happen." The participant reported that her sister had "passive unacceptance" of medical procedures due to religious beliefs – "She doesn't do anything that God doesn't tell her to do." (120)

There were a number of social and cultural norms that were cited as reasons for blocking by a variety of relatives. One such notion had its basis in traditional gender roles of the "uncommunicative male" or what is proper for men and women. Others talked about family traditions of constrained communications. The following illustrate this theme:

- My brother's uncomfortable talking about breast cancer, nervous about saying the actual words "breast" and "cancer". (336)
- My husband's family has traditions of secrecy. (20)

Protectiveness and Privacy—Because protectiveness and privacy were frequently reported themes among participants, we classified them as a separate category melding situational concerns, family traditions, beliefs, attitudes and rules about interpersonal boundaries.

Study participants used the term "protector" in regard to emotionally protecting themselves or others. Family members who blocked health communications to protect themselves emotionally included those who: (a) were uncomfortable talking or thinking about death, (b) avoided unpleasant topics; or (c) did not want health information that might disrupt their sense of well-being. For example, one woman's father was phobic about death, cemeteries, and hearses and her paternal grandmother believes that chemotherapy killed her husband. (117). Another woman reported that her brother said "I don't want to know," (54)

There were numerous examples of people who did not want to burden others with genetic information that might upset them. Some of the expressions of this sentiment were:

- "Why worry them when they have their own troubles?" (38)
- "Mom says, 'Everything will be alright. She sometimes distributes health news but stops herself if it's bad news; e.g., tells about cancer diagnosis but not poor prognosis.'" (24)

This protectiveness was often in response to perceived vulnerability of the blocker, e.g.:

- “Sis is still very nervous and ready to break down, but she gets through it and it makes her stronger.” (98)
- A blocking participant said of herself, “It’s easier not to dwell.” (99)
- Another woman felt emotionally wounded and subsequently withdrew from family health conversations when her sister pointedly asked, “Where were you when our sister was dying?” (60)

Sometimes participants reported spirals of increasing communication constraints in which they and the blockers mutually withdrew from contact as the results of prior misunderstandings or non-supportive responses, e.g.:

- “When I raised the [genetic testing] topic they panicked; now I don’t even bother.” (194)

Self Blocking: Ten of the 89 CEGRM study participants (7 in the original sampling frame of 86 and 3 additional ones found among the 200 BIS participants for a total of 10 self-blockers) placed a red star on themselves at least once during the study. Privacy and protection of self and others were common themes among self-blockers. One woman became a blocker after a relative was denied insurance due to the family’s cancer susceptibility; she and her sisters made a pact not to tell others out of fear of being similarly treated. (44) Another woman said that she “puts a limit on it [communicating]” because “It feels private,” and “I don’t like to think about it in the first place.” (11) In her case, family dynamics were important; she explained that she “doesn’t like to be crowded” [emotionally], and she backs off from family members whose behavior feels too intrusive. A desire for independence was offered as a rationale for self-blocking by one woman (35) who said, “I don’t want to hear it from them. I’m independent.. I don’t need or want any help.”

After protectiveness, privacy was the second most common theme underlying blocking behavior. We used Cho & LaRose’s definitions of psychological privacy as “the control over release or retention of personal information to guard one’s cognitions and affects” and informational privacy as “the desire to have control over the conditions under which personal data are released” (Cho and LaRose 1999, p. 422). We heard of direct expression of blocking due to privacy, e.g., “My sister is private, especially about her body.” (26); and, “Father just doesn’t talk; he’s a very private person” (107)

Duration of Perceived Blocking Behavior

Participants were invited to complete CEGRMs on each of their annual visits for breast and ovarian screening, providing the research team an opportunity to evaluate trends in perceived communication blocking over time. We found several patterns related to duration of the blocking behaviors. Table 2 provides examples of temporal trends in blocking.

- Permanent Blockers were named 100% of the time by at least one family member in multiple years, i.e., 2/2 (two respondents, 2 years’ reports), 3/3, 4/4. The 13 family members in this category included: fathers, husband sisters, self, brothers, and uncles. The reasons for their blocking as reported by study participants varied widely, e.g., family culture of low emotional expressivity; private personality, values and beliefs; unresolved grieving; or taking a male gender role.
- Intermediate Blockers were so classified if blocking behavior was reported at least half of the time, with a minimum of twice, e.g., 2/4, 2/3, 3/4. There were 18 families with 28 blockers of intermediate duration by a wide variety of relatives. Participants’ perceptions of reasons for intermediate levels of blocking included:

privacy, self-protection, grieving, emotional lability, values, mutual restraint, situation factors, financial constraints, and competing health concerns.

- Transient blockers were individuals only occasionally designated as blockers, with no specific pattern. This was the largest blocker subgroup, with large and small families represented.

Intra-Familial Agreement on the Blocker Designation

Agreement was defined as multiple family members in the multiplex families selecting the same person as a blocker; excluding study participants who were the only representative of their families, making it was impossible to study family agreement of their views about family communication and blocking. We hypothesize that concordance, i.e., independent triangulation on the same person by multiple participants, might be a surrogate validation of true blocking behavior.

We found that the multiplex families with blockers best fit into 3 patterns in terms of agreement about who blocked.

- Unanimous Agreement about particular blockers existed when every member of 11 multiplex families chose the same person at least once during the course of the study. Participants identified siblings (both brothers and sisters), more so than other relatives, as unanimously endorsed blockers. Study participants reported protection of vulnerable relatives and privacy were the most common bases for universally acknowledged blocking behavior.
- Partially Agreed upon blockers were designated by 2 but not all participants in 4 families. We arbitrarily decided that this classification could occur within the same year or cumulatively over several years. In one family, three of four sisters (including the designated blockers) saw the blocker as passive, vulnerable and information-avoidant. In another case, family culture seemed to play a part; the in-laws were perceived as having multiple family secrets. In a third family, different relatives were chosen by different participants.
- Sporadic Blockers – Most designated blocking was sporadic. In one family with three participants, two sisters each named a different, single blocker. There were multiplex families with few blockers, presumably due to family culture playing a positive role, “A red star person would not fit in our family.” (7)

Additional Findings

Steadfast Blockers—Certain families appeared to include what we might call “steadfast” blockers, i.e., persons who consistently were perceived as blockers by many family members over multiple years. In some cases, these were very private people, often men in families where men were expected to display low emotional expressivity. Other steadfast blockers were described as expressing vehement anti-healthcare system attitudes, having mental health issues or unresolved grieving. These special situations are more fully addressed in the Discussion section.

Social Network Variability—In all aspects of the analysis, we found a great deal of inter- and intra- familial variability. More specifically, there was variability in social network patterns, themes, congruence and longitudinal trends associated with perceived blocking of health information.

Very Sparse and Very Numerous Blocking: Three of the 65 families had very sparse blockers, even though these were multiplex families with multiple participants who might

have generated considerable number of blockers. One such family had only 2 blockers, once each; another family had only 1 blocker who was actively grieving. In contrast, there were 3 other families with numerous sporadic blockers, e. g., two different participants in different families identified 9 blockers total apiece, but not the same people in succeeding years. The third such participant listed miscellaneous cousins throughout the world with whom she was intermittently in contact.

Discussion

Our current analysis capitalizes on several unique features of the CEGRM study design, namely: 1) Participants were seen annually for up to 4 years allowing us to assess blocking duration; 2) a subset of families were represented by multiple family members allowing for multiple perspectives, i.e., triangulation on certain relatives; and 3) investigators' handwritten notes taken during the CEGRM interaction which were suitable for qualitative analysis were available to supplement the CEGRMs, which previously formed the basis for two social network analyses (Koehly et al. 2009; Koehly et al. 2008), which initiated our exploration of family conversations regarding genetic risk of breast and ovarian cancer.

We strongly concur with other investigators who found that health communication is a complex process that appears to evolve over time (Chivers Seymour, et al. 2010; Forrest et al. 2003; Wilson et al. 2004). Blocking occurs within the wider context of intra-familial communication. Among our participants, blocking was reported to have its origins among blockers' (1) desires to avoid creating and being entangled in upsetting social situations; (2) adhering to a set of strong beliefs, attitudes and/or family communication styles; (3) preferring personal privacy; and (4) believing that family members or they themselves needed to be protected from emotional problems or fears created by cancer risk-related information (Forrest et al. 2007).

Our premise is that, in general, families benefit in many ways from open communication about health issues that threaten them as a group, allowing them to employ "communal coping", i.e., collective coping with what is seen as a collective stressor (Koehly et al. 2008). If healthcare professionals are to facilitate effective, personalized family communication strategies, we need to understand in greater detail what actually happens in families, as they cope with their increased genetic risk (K. Forrest et al. 2003). With the introduction of widespread genetic testing in the past few decades, a number of professional health organizations and genetic advocacy groups from six countries have issued guidelines regarding the communication of genetic information in families, which can be summarized as follows: (1) individuals have a moral obligation to communicate genetic information to their family members; (2) genetic health professionals should encourage individuals to communicate this information to their family members; and (3) providers should support these individual family members throughout the communication process. However, healthcare professionals do not agree among themselves where it is ethical to break confidentiality in order to identify and inform the at-risk relatives. (Forrest et al. 2010; Loud et al. 2006). Furthermore, in selected families, declining to inform relatives for the sake of preserving fragile social bonds may warrant consideration (K. Forrest et al. 2003).

In our study, we found that communication blocking or silence were common in some families with HBOC, with great inter-familial variability in prevalence and motivation. We found great differences in the levels of agreement among members of each multiplex family regarding who was blocking at any particular point in time, and how their behavior did/did not change over time. Blocking ranged from a permanent, universally agreed upon behavior by those we have come to label "steadfast blockers" to blocking behavior that was more transient and based upon upsetting situations, e.g., divorce, lack of insurance, other health

problems and chronic unresolved grief. All of these sources and levels of variability make fine-tuned and longitudinal social assessment important in cancer-prone families so that healthcare providers know the family's current communication status and preferences to guide communication interventions accordingly.

Our participants provided evidence to support social modulation of cognitive processing of health information which posits that past experiences in which a family member was unreceptive to health conversations, or responded negatively with criticism, denial, defensiveness, anger or withdrawal were likely to inhibit a person from sharing feelings in the future. Behavioral, cognitive and emotional factors of both of the conversants become entwined in complex transactional patterns rather than discrete "acts" of communication (Gaff and Bylund 2010). These mutually off-putting reactions might occur either acutely, in response to a single unsympathetic incident, or gradually over time with increasing avoidance of certain topics, distancing from the person trying to communicate, or even estrangement.

The comments provided by participants to investigators about how blocking occurred highlighted that many conversational impasses were bi-directional, the products of feedback loops of social actions of others as well as each individual's interpretation of those actions. When participants interpreted relatives' non-communicative behavior as uncaring, the resulting hurt and diminishment often deterred further conversational effort.

It has been noted that the family is a primary source of gender role socialization, with women typically assigned health related responsibilities in general and as gatekeepers of genetic information in general (Gaff and Bylund 2010). While we found a number of instances where these patterns were born out, we also found exceptions. While a slightly greater proportion of blockers (55%) were men, significant numbers of women also avoided genetic health communications. Furthermore, women sometimes colluded with their male relatives' blocking by restricting the flow of genetic information to these men, in bi-directional processes as described above. Thus, participants described interplay between men's and women's health communication roles that were more complex than the existing genetic literature in which men are more commonly reported to have communication difficulties (Daly 2009; Hallowell et al. 2006; Kenen et al. 2004b; Stromsvik et al. 2009).

We know from prior research that women often take the lead communication roles in HBOC families, that communications sometimes breaks down between the women and men in the family, and that many mutation-positive men express a desire to keep their genetic information private, perhaps due to strong emotional reactions, traditional male gender identity and communication roles, or fear of stigmatization (Daly 2009; Forrest et al. 2003; Stromsvik et al. 2009). However, many men also have a sense of family duty, and are concerned about their children (d'Agincourt-Canning 2001; Hallowell et al. 2005; Liede et al. 2000; Lodder et al. 2001), which may lead them to behave in a more open, non-traditional manner. For some men, the responsibility of fatherhood may create real tension with their innate reticence, producing a phenomenon that Forrest and colleagues call "disclosure dilemmas" (Forrest et al. 2003).

We described some blocking behavior as fundamentally ideological, i.e., participants described relatives who expressed strong beliefs and opinions opposed to discussing genetic information within the family. In addition, some relatives were known for their strong dislike and distrust of health professionals and medical technology. Such intense expressions as "It's all BS!" or the belief that chemotherapy killed a relative reflected this perspective. For this sub-group of blockers, there was a strong distrust of doctors, and a de-valuing of both genetic testing and more traditional medicine. This facile dismissal of genetic

information's value has been interpreted as a manifestation of psychological resistance, a strategy intended to limit full emotional engagement in the counseling and testing processes as a means of emotional self-protection (Weil 2010).

Some participants also reported that social and/or cultural norms, e.g., family traditions of secrecy, or the impropriety of speaking the words "breast" or "cancer", were reasons for vague or passive communication styles in their families. Religious or spiritual reservations comprised an additional albeit infrequent stream of beliefs which formed the basis for blocking, e.g., "only if God tells me to test".

We were impressed with the frequency with which we encountered privacy and emotional protectiveness as reasons for constrained communications. Privacy concerns were heterogeneous, being reported as due to both social norms and personality characteristics, e.g., some people were described as very private; they rarely shared inner thoughts and feelings with other, while for others it was more of a family tradition.

The women in this study cited many examples of protectiveness as the source of blocked communication interactions, often in response to perceived emotional vulnerability of oneself or others. Gaff and colleagues defined emotional vulnerability as characterized by the potential of being emotionally harmed by the reaction of the other person (Gaff et al. 2007). This protectiveness might take the form of "I don't want to go there," or "she is anxious already, so I don't want to talk to her about it anymore."

In particular, the participants who designated themselves as self-blockers offered privacy, protectiveness and avoidance of unpleasant family dynamics as their main rationales, although at times the distinction between them was blurred. Our examples of self-blocking seemed similar to the "self censoring" that Kenen and colleagues observed among women who had chosen not to pursue conversations that they expected would be difficult and which might cause anxiety (Kenen et al. 2004b).

We heard multiple examples of relatives' desire to protect other family members, e.g., "Why worry them when they have their own troubles?" This may reflect their perception that a loved one is vulnerable and their desire to limit potentially upsetting discussions about genetic risk. Literature reports describe both vulnerability and protectiveness as the basis for self-limiting communications with children, spouses and parents (Kenen et al. 2004a). Our results are similar to those of Hamilton's (Hamilton et al. 2005, p. 20). A recent publication using a new mixed methodology approach (in ways similar to the CEGRM) for examining the processes of family communication of genetic test results despite different data collection and analysis techniques (Smith et al. 2010).

Interestingly, we frequently found that blocking was reported for relatives who were supportive in other ways, e. g., the majority of designated blockers in the CEGRM were also labeled as exchanging tangible and emotional supports with study participants. Among the 65 blockers, almost half were involved at baseline in other forms of information exchange; significant minorities provided tangible or emotional support; and a few offered both emotional and tangible support (Koehly et al. 2009). We interpret this to mean that different types of social exchanges may act semi-independently and would be obscured by global questions about the adequacy of social support in general.

Anecdotally, we found that some women in the study developed appreciation of their blocker relatives' communication challenges regarding genetic risk information, e.g., "looking at the CEGRM brings back sad memories and recognition of difficult family dynamics" (16).

We also found a sub-group that we labeled “steadfast” blockers. They were perceived within multiplex families as blocking by multiple participants consistently and frequently over several years, i.e., what we would consider unambiguous blocking. Permanent/steadfast blockers, often the brother, sister or parent of a participant were more likely to have private personalities, mental or physical health issues, a family culture of low emotional expressivity, or strong anti-biomedical/technology attitudes. Privacy and protectiveness were prevalent explanatory themes among these steadfast blockers.

We are aware of multiple study limitations. Our study population is largely white, middle class, self-selected, and research-savvy; therefore, findings are not entirely generalizable to non-clinical, non-research populations. Data were available only from women who participated in the larger Breast Imaging/CEGRM study, undoubtedly leading to an undetermined amount of recruitment bias. Some relatives were ineligible to participate, including men as well as women with recent cancer diagnoses. Furthermore, the sessions were not audio-taped as the CEGRM method was not originally designed for analyzing notes of conversations occurring during CEGRM construction, nor for detailed, targeted probing about communication blocking. Definitions of blocking and the willingness or reluctance to label someone a blocker differed among participants. This was demonstrated by occasional instances of a participant describing a relative’s various blocking behaviors without giving that person a red star because it felt disloyal to that person to label him or her in this way. It is also possible that bias could have been introduced due to subtle differences in administration of CEGRM, although this potential confounder was minimized as much as possible by extensive CEGRM training, use of a standardized protocol and CEGRM script to guide the process. Finally and importantly, we have attempted to study participants’ perceptions of who blocks family health communications without access to views obtained directly from the designated blockers. This one-sided data collection precluded deeper analysis of the bi-directionality transactions of interpersonal communication processes in which both participants and the designated blockers contribute to breaches in the flow of health conversations.

The underlying themes re: blocking behaviors and motivations were diverse, overlapping, complex and often ambiguous. From a data coding perspective, the ambiguous situations were difficult to resolve and required adjudication between coders to reach a consensus. The themes presented represent our best clinical judgment regarding the primary reasons that an individual was perceived to be a blocker by the participant, given that we could not hear directly from those considered to be blocking.

Potential Clinical Applications

We believe that our findings add to a body of evidence that supports the following recommendations:

- Discuss genetic risk and its social implications in multiple visits within a supportive framework, perhaps by multiple healthcare providers
- Involve primary care practitioners, genetics professionals and perhaps family therapists in the process of family risk communications
- Include exploration of family health communication styles, experiences and concerns
- Embed communication discussions in fine-grained assessment of social context and supports
- Coach families on how to approach disclosure of cancer genetic information

- Become more aware of the two-way flow of communications, i.e., interactions between social actions of others and the individual's interpretation of them
- Balance “the right to tell” and “not to tell” with consideration of “the right time, place, circumstances to tell”
- Encourage patience among family members and their providers regarding communication constraints due to situational difficulties, which may ultimately resolve
- Work around steadfast blockers or refer for therapy to resolve long-standing issues
- Promote public health messages that support personalized *familial* genetic risk assessment and health communication.

Discussions of genetic risk should be seen as an evolving, long-term process rather than a discrete, time-limited act (K. Forrest et al. 2003). A genetic counselor or primary care nurse might open the inquiry about family communication patterns with one counselee and then continue the conversation as various relatives from the same family are counseled. Alternatively, guidance about family genetic health communications may eventually evolve into a task for primary healthcare providers, who are seeing people longitudinally and can ask periodically about family communications, along with updating pedigrees to incorporate changes in relatives' medical status.

As others have observed, emotional closeness may be more salient than genetic relatedness when it comes to communicating about familial genetic risk (Chivers Seymour et al. 2010). While it is generally assumed in medical practice, and especially genetic counseling, that people “should” act on information they have, (i.e., that it is “good” to talk with relatives about genetic risk, and that those relatives “should” follow preventive health advice), there is less recognition of the harm that may occur from inopportune or clumsy attempts to talk about difficult topics with people who currently do not want to know about their risk. For example, “forcing” unwanted knowledge on a person via a well-meaning but poorly-received conversation might disrupt normal family communications, trigger psychological harm, color planning for the future, or threaten social bonds and relationships by the interpersonal tension or rifts that follow. Too often forgotten is the awareness that social constraints are transactional, a “product both of social actions of others as well as the individual's construal of those facts.” (Gaff and Bylund 2010; Lepore and Helgeson 1998; Lepore and Revenson 2007) Thus, each member of an interaction subjectively interprets the other member's un/willingness to discuss genetic information and incorporates these emotionally-valenced impressions into decisions about proceeding or withdrawing from present and future discussions. It is essential for genetic and other health care professionals to take these issues into account.

Timing of these genetic health conversations is essential because, at certain times, blockers may become more open to discussions about genetic risk. Our data about longitudinal timing for discussions of genetic risk have been emphasized by other authors as well, such as waiting until “the time is right” (K. Forrest et al. 2003, p. 322) and “old enough to know but not ready to hear it yet” (Hamilton et al. 2005, p. 20). Many of the problems we recorded can be traced to miscalculated timing related to anticipating when relatives actually need the information to modify health behaviors and risk management. Using family history and social exchange information (obtained from the pedigree and CEGRM) could lead to personalized health messages, which are potentially more effective than standardized prevention messages. However, we also see a need to extend beyond the individual to family level communication. Therefore, we recommend that the general genomic trend toward

“personalized medicine” be explicit in incorporating the whole family, by including “personalized *familial* genetic health communication”.

By taking careful social histories that include in-depth exploration of family communication patterns, genetic counselors and other healthcare providers may be able to distinguish “steadfast blockers,” who may not be amenable to change or who require highly-tailored interventions, from those with transient emotional or social situations (e.g., unresolved grief) that may be modified with support, time and/or counseling. Alternatively, we could help families work around steadfast blockers who hold consistent and long term ideological opposition to genetic testing and health information. To maximize efficient use of resources, effort should be focused in directions that offer a genuine prospect for change and improvement.

Psychosocial approaches may be helpful in certain situations in which health information blocking threatens family genetic health. Various counseling programs and techniques have been introduced to facilitate giving bad news and initiating difficult conversations (Back et al. 2009; Buckman 1992; Costalas et al. 2003; Daly et al. 2001). With active prospective genetic follow-up, there is opportunity for apparent disinterest to evolve into keen interest in receiving and discussing salient genetic information.

Future Research Directions

Privacy norms may be eroding (or evolving, depending on your viewpoint) in western culture. As mentioned in the results section, one person blocked further genetic health communications after a relative gave a media interview about their family mutation status. Almost certainly, younger generations will have very different views of privacy, given the flood of electronic social networking tools such as Facebook or Twitter, to which they are exposed. Future studies may capitalize on use of these new media as study methods or data sources. In the interim, there may be clashes between the privacy views of different generations of family members as well as researchers and clinicians. The observation that many men may be late adopters of genetic testing could be attributed in part due to traditional gender role socialization with women as the primary “kin-keepers” (Kenen et al. 2004b; Richards et al. 1996). For generations, it was tacitly assumed that the boys and men would not participate fully in healthcare discussions, especially about women’s health issues. This dynamic may be changing as younger men who are more technologically adept with electronic information-seeking may enter the genomic age.

We agree with calls for further investigations of male emotional reactions to genetic information and on the impacts of genetic status on male social networks, using both qualitative and quantitative study designs (Strømshvik et al. 2010). It is essential that we hear from the men directly, rather than hearing about them from reports by the women. An ongoing study about social exchanges and communication patterns of men from testicular cancer families will hopefully aid in clarifying male perspectives (unpublished data), as will studies of inherited prostate cancer and men in HBOC families (Moynihan 2002; Moynihan et al. 2003).

In summary, blocking of health communications among family members with HBOC is fluid, complex, variable, multifaceted and involving series of two-way communication interactions that mutually impact each participant and create a context for future interactions. For the most part, our results confirm and extend findings from other hereditary cancer family health communication studies during the past decade, which involve study participants from several continents and data collected with different methodologies. Further research targeted on understanding and perhaps modifying the social and familial contexts of genetic testing is warranted.

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Appendix 1- Glossary of Terminology

CEGRM – Colored Eco-Genetic Relationship Map	a method introduced in 2001 to present simple, concise, visual representation of the social interaction domains of health information exchange, tangible, emotional, and spiritual support through the application of color-coded symbols to the genetic pedigree.
Participant or study participant	woman participating in CEGRM study portion of the Breast Imaging Study
Blocker	Relative identified by study participant as impeding the flow of genetic health information in the family.
Themes	the primary reasons that an individual was perceived to be a blocker by the participant. <i>Salient Situational Factors-</i> The effects of particular social, medical, financial or emotional situations that affect genetic health communications; may be chronic or acute <i>Beliefs and Attitudes-</i> concerned with personal and cultural ideology and values. <i>Protectiveness-</i> protect self or others from emotional or social discomfort <i>Privacy-</i> the desire to have control over the conditions under which personal data are released.
Agreement about blocking behavior	the extent to which the participating women in a given family identify the same person as blocking communication.
Unanimous agreement	about particular blockers existed when every member of multiplex families with multiple participants chose the same person at least once.
Partially agreed-upon blockers	were chosen by at least two participants, but not every participant. This agreement could occur within the same year or cumulatively over several years.
Sporadic blockers	were those designated by a single person

Duration of blocking behavior	the number of years during which a relative was considered to be a blocker
Permanent Duration	Relative identified as blocking every year of study by at least one study participant
Intermediate Duration	the blocker was chosen at least half the time.
Transient Duration	Most individuals who were given a red star were given them sporadically, with no specific pattern over time
Steadfast blockers	persons who consistently were perceived as impeding health communications by many family members over multiple years, i.e., a combination of high agreement and long duration over several years
Self-blockers	placed a red star on themselves at least 1 year and sometimes multiple years.
Social Network Variability	variability in social network patterns, themes, congruence and longitudinal trends associated with perceived blocking of health information

Fig. 1.
Hypothetical CEGRM. Arrow indicates the proband, Jane. Note red stars indicating communication blocking by proband's mother and paternal aunt
Blue circles=information; Green circle =tangible support; Yellow circle = emotional support
Red circle= spiritual exchange; Silver star= information-gatherer Green star= information disseminator; Red star= blocker, C= Cancer

Variability of HBOC Communication Networks

Fig. 2.

Variability of HBOC Communication Networks. Shown are two social networks of HBOC families with different patterns of social networks among multiple family participants. Network 2a. A well connected family with widespread intra-familial connections and information dissemination to many relatives in common. Only one participant named a blocker (red star); this blocker does not share communication lines with any other relatives. Network 2b. Five participants from this family have extensive but independent networks, each with her own constellation of connections with few overlaps. One participant at the top of the figure does not network with any other participating relatives and thus appears isolated from the rest of the family. The other four participants in this family have designated 1–2 blockers apiece

Arrows = study participants; Red stars = reported blockers; Red lines = blocked communication; Green lines = information gatherers and/or disseminators; Blue lines = information exchanges.

Table 1

Study participant and family blocker characteristics

	Participants	Blockers
Number	89	65
Female gender	89 (100%)	29 (45%)
Age, Mean (SD)	40 year (+/- 9)	N/A
Partnered/Married, yes	62 (72%)	N/A
Education, college	62 (72%)	N/A
Number families participating	42	N/A
Number per family, mean (range)	2 (1–8) participants/family	1.5 blocker/family
Number of families with 1 Participant	18 (20%)	N/A
Cancer status = unaffected	58 (71%)	63 (97%)
Mutation status	48 (80%) carriers	53 (82%) at risk
Anxiety, T score on BSI-18 (SD)	48 (+/- 8)	N/A
Somatization, T score (SD)	44 (+/- 6)	N/A
Depression, T score (SD)	46 (+/- 8)	N/A
Global distress, T score (SD)	45 (+/- 9)	N/A

Table 2

Blocking duration and agreement

Duration	Year 1	Year 2	Year 3	Year 4
Permanent	X	X	X	X
Intermediate	X	–	X	–
Transient	–	X	–	–
Intra-familial agreement	Participant 1	Participant 2	Participant 3	Participant 4
Unanimous	X	X	X	X
Partial	X	–	X	–
Sporadic	X	–	–	–