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Perceived Intra-Family Melanoma Risk Communication

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Abstract

Melanoma is a skin cancer that can be deadly. Members of families with a strong history of melanoma have a high risk of melanoma occurrence or recurrence. Enhanced survival in these family members could be influenced by their knowledge of melanoma risk and by simple behaviors to decrease their risk or detect melanoma in its early, most curable, stage. Yet, there is minimal exploration on communication of risk or risk-modifying behaviors in melanoma at-risk families. In this study we described perceived intra-family communication of melanoma risk. Using a qualitative descriptive approach, we examined in-depth interviews with 22 members of eight families having two or more cases of melanoma. We identified four major themes: (1) Awareness and understanding of risk, (2) Families facilitate and hinder communication, (3) Promoting melanoma prevention and detection in the family, and (4) An obligation to tell others. We discuss these findings in the context of extant knowledge of cancer risk communication in families at high risk for other cancers, impediments to cancer risk communication, remaining gaps in knowledge of this phenomenon, suggestions for hypothesis-driven research, and clinical implications that are applicable to these and other at-risk families.

Introduction

Communicating about melanoma risk is an important task for families with a history of melanoma. About 5% to 12% of melanoma patients report that one or more first-degree relatives (FDR) are affected with the disease.^{1, 2} Members of melanoma-prone families have a 35-fold to 70-fold risk of melanoma.³ A personal history of melanoma confers a 9-fold risk of further disease.² Increased risk, coupled with the fact that melanoma diagnosed early has a better prognosis,⁴ underscores the importance of family communication concerning risk and detection and prevention behaviors. Early detection behaviors with known efficacy include regular clinical skin examinations⁵ and skin self-examination (SSE).⁶ Primary preventive behaviors include reducing ultraviolet radiation exposure by avoiding the sun and artificial tanning, wearing sun protective clothing, and applying sunscreen.⁷ Clearly, families with a history of melanoma may benefit from knowing about their disease risk and behaviors to modify that risk. However, little is known about intra-family communication of melanoma risk, i.e., messages about that are exchanged within the family. The purposes of this study, therefore, were to (1) describe patients' and family members'

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perceptions of intra-family melanoma risk communication and (2) generate hypotheses for future research.

Risk communication consists of messages that describe or typify hazards, risks, or risk-reducing actions.⁸ These messages are interactive exchanges of information and opinions that occur among individuals, groups and institutions.⁹ If recipients of these messages assimilate the information, then this new or “re-framed” knowledge may have a direct effect on their beliefs and influence their use of health-promoting behaviors.¹⁰ However, the complexity of risk communication may result in uncertainty or worry, which potentially interferes with receivers’ processing of the information¹¹ and prevails in their perceptions of risk for a health condition.¹²

Intra-family risk communication is important in at-risk families because cancer risk is shared genetically, emotionally, and socially within the family.¹³ Additionally, family communication of cancer risk is likely to influence family members’ disease-related decisions and coping strategies.¹³ Families exhibit different communication patterns that could play a role in intra-family communication of risk. For example, families using frequent and open interactions and unrestrained thoughts and feelings concerning a wide array of topics likely would openly discuss risk-modifying actions or activities that affect the family as a unit and together would make family decisions concerning risk.¹⁴ Other families may prefer communications emphasizing family homogeneity, conformity, conflict avoidance and interdependence; electively closing off certain topics from discussion.^{14, 15} Either of these patterns may represent the norm in a specific family or vary within different generations or branches of that family, adding to the complexity of communications.¹⁴

Few studies have explored family communication of cancer risk; most of these address communication in the context of hereditary breast/ovarian cancer (HBOC) and/or disclosure of *BRCA* predisposition genetic test results. Key findings pertaining to these topics were summarized in a recent systematic review of communication of genetic information.¹⁶ Fewer studies have addressed family communication pertaining to hereditary colorectal cancer.^{17–19} Viewed collectively, existing studies reveal that risk communication in cancer at-risk families is complex and displays a diversity of patterns; i.e., open and supportive, blocked, self-censored, using intermediaries to present information.^{15, 17, 20, 21} Communication in these families is affected by contextual factors such as social role, gender, and age,²¹ emotional factors such as worry, guilt, uncertainty, and tension,^{21, 22} feelings of respect and isolation,²¹ and a sense of responsibility.²³ In cancer at-risk families, open cancer communication has been associated with lower intra-family levels of anxiety and depression²⁴ and enhanced emotional and social support.²⁵ Even fewer studies of melanoma risk communication have focused on discussions from patients to family members²⁶ and rules that guide family melanoma discussions.²⁷ Several authors have noted the need for further family studies of cancer risk communication,^{28–30} and Marcus²⁹ (p. 36) stated, “the focus on the family represents an exceptionally fertile ground for research” of cancer risk communication.

Methods

Design

This study used a qualitative descriptive design. According to Sandelowski,³¹ qualitative description is the optimal choice for viewing straight descriptions of the basic nature and shape of events or experiences such as family members’ perceptions of melanoma communications. Additionally, a qualitative descriptive design is minimally encumbered by pre-existing theoretical and philosophical commitments, and facilitates the gathering of minimally theorized answers to questions of special relevance to practitioners. Knowing

how at-risk family members communicate melanoma information should be of interest to practitioners. Furthermore, qualitative description produces a useful end-product consisting of a “comprehensive summary of those events in the everyday terms of those events.”³¹ (p. 336) Enhanced knowledge of at-risk family members’ perceptions of melanoma risk communications is useful information for practitioners and families, alike. A qualitative descriptive design contrasts with other qualitative approaches such as grounded theory, phenomenology, or ethnography that are based on specific methodological frameworks emanating from distinct philosophical perspectives and for which description comprises only an initial analytic step. We view this research as an initial step in discovering more about intra-family melanoma risk communication.

Sample and Setting

We used purposive sampling to recruit the target group for this study, specifically melanoma patients reporting a family history of melanoma (at least two affected FDR in the family) and having at least one FDR (with or without a personal history of melanoma) that was willing to participate. Although the index patient’s melanoma diagnosis was confirmed histologically, melanoma in FDR was known only through self-report. Although genetic predisposition testing is an option for persons with a strong family history of melanoma,^{1, 32} none of the patients enrolled in this study elected to have genetic testing.

After receiving institutional review board approval, we recruited patient participants from the Cutaneous Oncology Program (COP) at the Arizona Cancer Center’s, Arizona Skin Cancer Institute. The COP is a clinic that provides comprehensive care using a multidisciplinary approach to risk management and treatment. Participating in the COP are experts in dermatology; medical, surgical, and radiation oncology; pathology; radiology; genetics; and behavioral science. For this study, the medical specialists identified patients with a family history of melanoma and then referred them to the principal investigator (PI). The PI is an experienced melanoma researcher in the COP but is not directly involved in patient care or clinical decision making. The PI obtained a more detailed melanoma family history and then informed eligible patients of the rationale, risks, and benefits of the study. If patients chose to participate, they signed the consent at that time and then agreed to a single interview at a later date. Using the process of primary selection,³³ the PI asked patients to identify at least one FDR (with or without a personal history of melanoma) that also would be willing to participate. The FDR signed consent prior to the interview. Three patients declined participation because they did not want to contact FDR regarding the study. All first-contacted FDR agreed to participate.

The sample consisted of 22 individuals in eight at-risk families (Table 1). Eleven persons had melanoma (8 women and 3 men); all but two women had early-stage disease. Ten FDR did not have melanoma (4 women and 6 men). Participants were all non-Hispanic white, of European ancestry, and with an age range of 18 to 65 years.

Procedures and Data Analysis

The PI conducted individual in-person interviews with each patient and family member and asked two minimally structured questions (an acceptable strategy for qualitative description):³¹ *Please tell me about (a) typical discussions your family members have about the risk of melanoma occurrence or recurrence among family members; and (b) the discussions your family members have about ways to control their risk of melanoma.* The PI used minimal prompts aimed at enhancing description of communication, examples of which included, *Give examples of words family members share with each other about the risk of developing melanoma, and What information about melanoma prevention and detection behaviors do family members share with each other?* All interviews were audio

recorded and lasted approximately one hour. We did not pre-determine the numbers of interviews, which continued until data saturation was achieved.³³

The PI verified the interview transcriptions by checking them against the recorded interviews. Qualitative content analysis is the strategy of choice in qualitative descriptive studies,³¹ and to facilitate this analysis, we used ATLAS.ti 5.2³⁴ software to manage the data. The PI first assigned codes to the data by using the following schema: (a) risk communications encompass the risk of developing melanoma or melanoma recurrence; (b) risk communications also include risk-modifying communications, which address melanoma prevention, early detection, and screening; and (c) “intra-family” refers to communications among or between family members. Then using a technique acceptable for qualitative description, the PI and a second investigator reached consensus on modified codes as new information emerged from the data.³¹⁻³⁵ Words and phrases from the data constituted units of coding.³¹ For easy accessibility and intra-coder reliability, we defined each code. For example, preventive communication codes included shielding (encouraging use of any type of barrier between skin and sun), avoiding (messages to keep away, prevent contact/exposure to the sun’s rays, collaborating (working together to prevent/avoid exposure). This process continued until codes became redundant.

The same two investigators organized codes into themes, created by linking the codes to form meaningful relationships³⁶ and labeling these relationships with a more abstract description. The third investigator independently verified the codes and themes, supporting dependability of findings.³⁷ Finally, three participants read summary statements (not the quotes) and concurred that the statements summarized the essence of their perceptions.³⁷

Findings

We identified four major themes: (1) Awareness and understanding of risk, (2) Families facilitate and hinder communication, (3) Promoting melanoma prevention and detection in the family, and (4) An obligation to tell others.

Awareness and Understanding of Risk

Participants had high awareness of melanoma risk within the family. All were able to describe their family history of melanoma in first- and second-degree relatives but had more limited knowledge of more distant relatives. Although all participants were at actual high risk of melanoma occurrence or recurrence, they had varied perceptions of the family’s melanoma risk, including overestimation and underestimation of risk. Participants’ comments also suggested that family members did not fully understand the meaning of being at risk of melanoma. For example, one male patient participant stated,

“It’s hard for some of my family to understand their chances of getting this. We all pretty much think it will happen to us. I know about it [risk], but what does it mean?”

A sister of another patient offered an opposing view: *“I don’t think that there is anyone who feels like they will get melanoma, they probably feel that they won’t, that they’ll beat the odds by luck.”* When describing her mother’s melanoma, an affected daughter stated:

“[Her brothers and sisters] know that she has melanoma. They know that it has re-occurred, but whether or not they fully understand it is another thing. But I talked with my oldest aunt she remarked that she figured [patient] is on a death bed. The chances of surviving were out. She has no understanding of melanoma, what it is, or anything like that.”

Most participants perceived that discussions of melanoma within the family enhanced personal awareness of risk. For example, an unaffected brother stated:

“I think talking about it has made me more aware of melanoma, and [sister] has it, and going through what she is going through, I think it’s come close to home.”

Another female patient participant voiced that having melanoma in the family “*definitely has increased our discussions about the chances of getting it.*”

In summary, family members at risk of melanoma aware of that risk, and this awareness is enhanced through intra-family discussions. The meaning of being at risk is less tangible.

Families Facilitate and Hinder Communication

Participants’ comments reflected the use of open communication for delivery of melanoma information in some families and more selective communication strategies in others. A female patient participant offered:

“Whenever any of us hears anything about it [melanoma] we share, we do a lot of emailing, and we talk on the phone a lot. I think any time any of us hears anything new; we are always sharing it with everybody else in the family.”

In some families, certain family members took charge of delivering melanoma information to other family members. The person in charge typically either was the patient or FDR. A female patient participant voiced:

“I get the information, but if I want it spread I tell my younger sister. She is the one who gets on that phone and emails and sends everything out.”

In contrast other participants described a variety of impediments to communication. One patient commented that

“I’ve talked to my daughters about my melanoma, but I really have not sat down and talked to [my son] as much as I should about it. But I am going to. We both seem to have so little time to talk.”

An unaffected brother of another patient revealed,

“I don’t ever discuss my sister’s risk of re-occurrence with her, because I figure that whatever happens, it’s up to the good Lord now. He has a reason.”

Yet another female patient participant shared:

“I have decided not to tell my mother about my melanoma. She is just too old and has too many health problems herself. It would be cruel to tell her about this new one. She would just fall apart if she knew.”

Being so selective with sharing information sometimes generated conflict within the family, in that some family members wanted melanoma information shared and others did not. For example, an unaffected son noted that:

“I know it’ll [information about melanoma] bring them closer together, that’s one reason I’d like to see her share it more with her family, you know, her nieces and nephew, but I am not going to say anything, I’ll get in trouble.”

Geographic distance also affected the sharing of information. Family members that lived closer together tended to have more frequent communication. One male patient participant stated that he had fewer discussions with his brother and dad, because

“I don’t see them as much, mostly it’s geographic, and when I was living close to them, we probably spoke about it more.”

In some cases, family members with classic melanoma phenotype (light-colored or red hair, light eyes, skin that easily burns or freckles) tended to communicate more with each other about melanoma risk than with other family members that did not exhibit this phenotype. For example, an unaffected sister noted that, *“between the redheads in my family, we talk about it [getting melanoma] more than with anybody else. We have more of the same genes”*

Several participants shared that melanoma risk communication among melanoma survivors in the family had special meaning. For example, one female patient participant shared that,

“[My sister] and I have more of a special talk about melanoma, because we’ve both been there, and we have always been pretty close. She and I talk about it a lot. We talk about all of it.”

In summary family members typically shared information freely; sometimes one person “took charge” of communications using various strategies. Barriers to communication were elucidated. Family members that shared certain characteristics communicated with each other about melanoma.

Promoting Melanoma Prevention and Detection in the Family

All the participants perceived that it was easier for their family members to talk about specific melanoma risk-modifying actions than it was to discuss chances of developing melanoma. Some participants perceived that family members had frank discussions about melanoma prevention and detection activities. For example, family members persistently reminded each other about sun safety in discussions of sun avoidance and shielding (e.g., sunscreen application and use of sun-protective clothing). One unaffected sister noted that,

“We talk endlessly about making sure that we are all wearing our sunscreen whether it’s really sunny out or not, whether it’s summertime or not, making sure that we all have our sunglasses whether we want to wear them or not, hats, and just the importance of wearing those things and trying to stay of sun when it’s the hottest, trying to plan activities before and after that really intense sun period, and just if at all possible, stay out of sun if you can. That’s one of my biggest things.”

Participants also discussed collaborating for surveillance in that family members were vigilant in encouraging each other to have regular visits to a dermatologist and having suspicious skin lesions removed quickly. In particular, family members that had not had melanoma tended to scrutinize the skin of family members who were melanoma survivors. Another unaffected sister stated:

“If anybody says anything about having something unusual, we always say, Go get it taken off right now, don’t hang out and wait around.’ I think we all bug [sister with melanoma] a lot more.”

However, some participants perceived less extensive discussion about prevention and detection; for example, one male FDR mentioned

“We leave it up to the individual. It’s their business, but if we think about it, we will remind about sunscreen.”

An Obligation to Tell Others

All participants perceived that it was important for them and other family members to talk to others outside the family about melanoma risk-modifying behaviors, particularly in regard to ultraviolet radiation exposure. Participants perceived a strong sense of responsibility to share this information with others. An affected sister recounted,

“I started to be very vocal, you know, and I will tell people I work with, ‘quit going to that stupid tanning bed, because this is what’s going to happen’, so I am pretty verbal about it. My family knows several people who died of melanoma, so we mention it to everyone.”

A female patient participant commented: *“Our friends all know that they can’t go anywhere outside with me unless they have put on sunscreen. We [family] are responsible for spreading the word. We owe this to ourselves and to others”*

Summary and Discussion

To our knowledge, this study is one of few focusing specifically on family communication of melanoma risk in at-risk families. Our intent was to summarize perceptions of intra-family melanoma risk communication. In general, participants’ perceptions illustrated open patterns of risk communication; however, there were also examples of blocked (hindered) communication, providing further support for the complexity of these interactions in at-risk families.

Similar to other family studies of cancer risk,^{38, 39} our participants had high awareness of their melanoma family history. They perceived that discussions of melanoma within the family also enhanced other family members’ awareness of melanoma; however, many of them did not fully understand melanoma as a disease. This insufficient understanding contributed to melanoma risk perceptions. For example, based on their understanding of melanoma, some participants were overly optimistic about their chances not of getting melanoma, or getting it again; e.g., “beating the odds;” whereas others were more pessimistic in that they thought they definitely would get melanoma (again). Findings of another qualitative study that included melanoma patients and others (not necessarily family members) indicated that participants with a family history of the disease tended to have slightly less variable comparative risk perceptions ranging from melanoma risk being the “same” to “much greater” than that of their peers.⁴⁰ There is evidence that persons in families with a history of chronic illnesses, including cancer, use heuristics that incorporate notions of bad luck, chance, and fate in regard to risk of disease,⁴¹ and we noted some of these among our participants. The diffusion of inaccurate risk perceptions throughout the family has potential for increasing worry or cancer-specific distress among family members.¹³ These findings highlight the importance of risk communication for forming more accurate risk perceptions.

Further illustrating the complexity of risk communication were the various communication strategies used by at-risk families. In some families, certain family members took charge of information. Other authors have described the concept of “kin keepers” or persons who have a prominent role in maintaining family communication.²¹ Findings from HBOC family research denote mothers as typical kin keepers; however in our study, the patient (who was not always a mother) frequently took charge of initial communication to other family members. These pivotal persons feel a sense of duty or responsibility to communicate this information,^{17, 18} but they also should be informed and prepared to discuss their cancer with relatives.²⁵ Some participants indicated that their family used existing networks dedicated to transmitting information, many of which involved emailing or telephoning family members. What is not known is whether these networks existed for other important communication within the family. Unlike findings in some HBOC communication studies,^{21, 22} the male participants in our sample were willing to be a part of those networks and discuss melanoma risk and risk-modifying behaviors with other family members.

Other participants revealed specific impediments or “blocks” to communication. The impediment of time (taking time to discuss melanoma risk) has not been identified in other

studies of family cancer risk communication, although timing of communication delivery has been well described.¹⁶ The impediment of geographic distance (fewer discussions with family members geographically distant from family members with melanoma) has been noted in several studies of inherited cancer risk.^{22, 42} Emotional barriers such as anxiety or concern stemming from the perceived stressful effect of discussions on family members are not uncommon in other cancer at-risk families.^{25, 42} Kasparian and colleagues⁴⁰ (p. 276) described family members' perceptions of "rippling emotional effects" of a melanoma diagnosis. There were concerns about conflict if a family member (source) disclosed melanoma information about the family member patient to another family member (recipient) against the patient's wishes. In cancer at-risk families, such a conflict has been identified in the context of disclosure of genetic information,¹⁶ whereas the diagnosis of cancer in the family usually is common knowledge. Finally, a few of our participants identified a sense of fatalism (i.e., no discussion because it's "up to the good Lord"). This finding has not been elucidated in other studies of risk communication in cancer at-risk families.

In our study, there appeared to be a special communication bond, or homophily, between family members with a melanoma high-risk phenotype (i.e., light hair, light eyes, fair skin) and between melanoma survivors in the family. A parallel finding has been reported in communication studies of women in HBOC families who preferred to talk with female relatives.^{21, 22, 42} Authors of another study that included minimal findings pertaining to melanoma risk communication, did not specify homophily *per se*, but did report that the psychological impact of a melanoma diagnosis was closely associated with factors such as the specific family member affected, or members who had survived or died.⁴⁰ Although we did not find any studies or findings regarding survivor-to-survivor communication in cancer at-risk families; there is evidence that survivor communication to unaffected family members may influence perceived risk of cancer, family coping, and quality of life of both survivors and family members.^{43, 44} The bonds between these similar family members reflect not only social comparison processes, wherein people evaluate their opinions and abilities against similar others,⁴⁵ but also the sharing of similar genes and cancers when considering their familial risk. Opinions formed based on homophily are less subject to change⁴⁵ and represent an important focus in future studies of intra-family cancer risk communication.

Further reflecting open communication, many participants perceived that their families had expansive discussions of prevention and early detection behaviors, which are paramount to modifying melanoma risk and potentially improving melanoma survival. Engaging in risk-modifying behaviors gave family members a sense of control over their risk. Members of these families had a "watch dog" approach to monitoring sun protection and skin lesions, making sure that family members used sunscreen and had suspicious lesions checked by a dermatologist. Other investigators of melanoma at-risk families have reported similar results.⁴⁰ Collectively, these findings exemplify the notion that the family as a unit can play a vital role in risk communication, especially in terms of promoting and sustaining healthy behavior.²⁹

All the participants indicated that family members felt an obligation to talk to persons outside the family about melanoma. Messages from at-risk families with melanoma could affect the attitudes, strength of beliefs, and perceived norms held by others outside the family in regard to performing (or not performing) skin cancer prevention and/or early detection behaviors. At-risk family members may be viewed by others as trustworthy and considered as "experts" because of their experience with melanoma. Nevertheless, some family members may not have an adequate understanding of melanoma, which renders them less credible as a message source.¹⁰

Limitations

According to Sandelowski,³⁴ the use of purposeful sampling was appropriate because our informants were articulate, reflective, and willing to share information. However, maximum variation sampling, which in qualitative research allows investigators to explore the common and unique manifestations of a target phenomenon across a broader range of varied cases,⁴⁶ may have added further to the rich information contributed by our participants. We did not ask about underlying family communication patterns, which could add to the interpretation of risk communication. Additionally, specific queries about contextual factors that affected risk communication (although some of these did emerge as barriers) or cognitive or emotional outcomes of communication, might have strengthened the findings.

Research Implications

Future research can build on our preliminary findings. Such research could target (1) testing of interventions that are used by providers to promote accurate understanding of cancer and perceptions of risk within high-risk families; (2) comparisons of “kin keepers” or similar family members’ (e.g., melanoma survivors) effectiveness in promoting risk communication; (3) testing of alternative methods of intra-family risk communication, e.g., family blogs or emails to enhance inclusion of family members that are geographically distant or reduce family conflict; and (4) techniques to promote the use of at-risk families as credible sources of prevention and early detection messages.

Clinical Implications

Only a small percentage of patients with melanoma have a family history,⁴⁷ so providers typically may see few families like those in our study. Nevertheless, there are clinical implications for the findings. First and foremost, providers must query patients about a family history of melanoma (or any cancer),⁴⁸ because patients may not think to volunteer this important information to providers.¹⁶ Providing patients with a family history diagram will enable them to visually explain risk to other family members.⁴⁸ Providers should be assessing both patients’ and family members’ understanding of melanoma in order to clarify information, allay fears, and promote more accurate risk perceptions.⁴¹ Providers might consider using a two-pronged approach to delivery of risk communication by (1) providing risk information tailored to individual patients, and (2) providing family-focused information to relatives of the patient. We agree with Marcus²⁹ that targeting risk communication to families’ outcomes, particularly to families at high risk of cancer, may elevate the significance of the message for the family (e.g., “By examining your skin carefully, you may find melanoma early, increase your chances for survival, and protect your family from the possible consequences of this disease”). Our findings indicated that at-risk families are “ambassadors” for providing melanoma prevention and detection information to others. Providers, therefore, need to ensure that these patients and family members have accurate information to disseminate.

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Table 1

Family Participants (n = 22 participants)

	Index Patient (all had melanoma)	First-Degree Relative
Family 1	Female	Female ¹ (daughter); Female ² (sister)
Family 2	Male	Male ² (father); Female ² (sister)
Family 3	Male	Male ² (brother); Female ¹ (sister)
Family 4	Female	Female ¹ ; (sister) Female ² (sister)
Family 5	Female	Male ² (brother); Male ² (father)
Family 6	Male	Male ² (brother)
Family 7	Female	Male ² (son); Female ¹ (sister)
Family 8	Female	Female ² (mother)

¹ Melanoma history² Did not have melanoma