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# All in the family? Communication of cancer survivors with their families

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## Abstract

**Purpose—**Families often bear the burden of communication about cancer risk, as well as support during and after treatment for cancer in family members. These activities are left up to survivors and their families, with little support or knowledge of useful methods. We present data on aspects of family that are most relevant to risk of cancer-related communication and health promotion among family members.

**Methods—**Families (a survivor, one first-degree relative and one parent; n=313 families) were enrolled in the survey-based study. We assessed multiple aspects of family communication about risk for melanoma among family participants.

**Results—**Families communicate less frequently than desired about cancer risk. Most families do identify a “Family Health Provider” who keeps family data and serves a resource for family members. The reasons given for lack of family communication are diverse but many can be addressed as part of a family communication intervention.

**Conclusion—**Families are poised to improve their family communication about cancer risk and so can play a role in increasing the health of their members.

### Keywords

Melanoma; Prevention; Family communication

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## Introduction

Melanoma is the most severe form of skin cancer, with rates increasing dramatically since the 1970s. In 2016, The American Cancer Society anticipates 76,380 individuals in the United States will be diagnosed with melanoma, and 10,130 will die from melanoma [1]. Fortunately many people survive with melanoma, as in 2010 there were 453,000 men and 469,000 women living with a history of melanoma in the United States [2]. New immune therapies are anticipated to further increase the number of individuals living with melanoma in coming years [3]. Survivors of melanoma carry increased risk of additional melanoma diagnosis[4], and first-degree relative (FDRs) carry increased familial risk for a primary diagnosis of melanoma [5]. Communicating this risk among FDR's is often left to the survivor and family members, with little guidance as to how to do it or what to communicate.

Family history of cancer is a common risk factor for most cancers, specifically in melanoma, the diagnosis in one family member has implications for the health and potential risk for other family members [6,7]. The construct of "family" a critical one in health communication and cancer prevention research for a number of reasons. First, a family cancer history could lead to discussion among family members about cancer and cancer risk. The diagnosis of melanoma in family members could lead to discussion and awareness of risk within families, and this could help the survivor and family members make risk reduction choices. Second, family members serve a source of support if one family member is diagnosed with an illness [8]. Third, the family is arguably the most important social and cultural context for the development and establishment of most health risk behaviors, such as smoking, dietary habits, as well as sun exposure patterns [9] that might prevent cancer. In the absence of intervention, dissemination of information about melanoma risk may be based on misconceptions about family melanoma risk or poor communication among family members about familial risk [10].

Previous research in cancer has identified lack of communication among family members about genetic risk [11–12]. Research on high risk breast and colon cancer probands and their first-degree relatives (FDRs) has found that communication about risk does not flow seamlessly among family members (13, 14) and often does not motivate clinical screening or genetic testing (15). However, in high risk families communication might be more common [18–17]. A retrospective study of cascade counseling and testing in hypertrophic cardiomyopathy showed that only 39% of family members participated (18). Best practices for communication of genetic test results may also depend on cultural or social context. For example, studies have found that uptake of *BRCA1/2* tests to identify inherited risk for breast/ovarian cancer was lower among AA compared to EA (19,20). At present, the process of communicating genetic risk from probands to family members, its dynamics, and differences across cultures have not been studied.

Accordingly, these extant connections within families are potential untapped avenues for disseminating information to the entire family, including the survivor, but also to multiple generations and parents of younger family members, in particular, given that the entire family represents an important intervention target, particularly for family members who may

be at risk for developing disease. Research in the health field has generally emphasized a conceptualization of family that highlights the traditional nuclear family, characterized by clear, first-degree biological connections. However, in many health intervention studies there might be great utility in examining a broadened conceptualization of family. For example, research has identified the importance of cancer survivor discussion among siblings, parents or children [17]. Approaches that conceptualize families as including multiple generations and multiple adult members within each generation will be useful as we move forward to intervene more effectively to promote health and reduce disease outcomes for survivors. This paper presents data on the communication behaviors and perspectives of melanoma survivors and their first degree relatives. We hope that these data will be useful for health promotion and can guide us as we plan interventions to work more directly with families to improve health.

## Methods

### Study sample

The data for these analyses are from the Suntalk Study, a randomized controlled trial of a web-based communication and support intervention funded by the National Cancer Institute [21–23]. Families (including melanoma Case, first-degree family member, and adult Parent) with at least one case of melanoma were recruited and assessed via a telephone survey at baseline, and then randomized to either an immediate intervention or a delayed comparison group. Intervention families received access to the study website, which was an interactive communication-oriented system, for approximately one year, based on our previous research with breast cancer families [24–25]. Enrolled family members completed a follow-up survey one year later, and then the comparison families received access to the study website.

We used two sources for recruitment of families: 1) the Northwest Cancer Genetics Network (NWCGN) a regional site of the Cancer Genetics Network [26] and 2) The SEER registry (Cancer Surveillance System or CSS) at the Fred Hutchinson Cancer Research Center. Recruitment is described in detail in a previous manuscript [23]. Melanoma Cases diagnosed with a first primary melanoma between April 1$^{st}$ 1998 and October 1$^{st}$ 2001 were recruited from the registries. We recruited a family for this study as the combination of: the Case of melanoma (Case), a first degree relative (FDR) of the Case, and a relative who was a Parent of a 0–18 year old child (Parent). The eligibility criteria for Cases diagnosed with melanoma, aged 18 years or older. All participants had to have access to the Internet from a place that would be comfortable for accessing the study website.

### Recruitment Procedures

Recruitment and informed consent for each family consisted of three stages: physician, Case, and relative as previously reported (23). The IRB at the Fred Hutchinson Cancer Research Center reviewed and approved this study's procedures. Prior to approaching the patient, his/her physician of record was contacted by mail with a letter explaining the study. If there was no response from the physician after three weeks, the physician's permission to contact the patient was assumed. Each Case with physician consent was mailed a letter and study brochure briefly describing the Suntalk Study and offering the opportunity to

participate. The Case passive consent letter, like the physician mailing, included the project's phone number for anyone wanting to decline or refuse participation. Study staff contacted Cases by telephone to screen for eligibility and interest. If the Case was eligible and interested, project staff then collected the names, relationships, and contact information of all possible FDRs and Parents. We enumerated the family with each Case, and permission for staff to directly contact was documented for each relative. Study staff directly contacted and recruited FDRs and Parents. If a Case refused to give permission for study staff to contact relatives or did not have any FDRs, no further contact was made with that Case and they were not eligible. Finally, all participants were asked to complete a baseline survey over the telephone, either immediately following the screening survey or at a later time. All of the Case's FDR and Parent relatives provided by the Case were then approached using the same methods used to approach Cases for participation. We have previously reported baseline values for the survivors' outcomes (27). Once all three family members (Case, FDR, Parent) completed the baseline survey, families were randomized to receive either the immediate web-based intervention (50%) or to participate in the delayed intervention group that had access to the intervention only after final outcome assessments (50%). Study outcomes of this intervention were reported in separate papers [21].

## Measures

Each participant completed a telephone survey asking about melanoma prevention behaviors, family communication, and background and demographic data. \One item read, "People have different definitions of "family." For this question, please define family in whatever way makes sense to you. Tell me about those individuals, that you consider to be part of your family. First, who would you consider to be part of your family? Respondents checked boxes beside multiple family member types (eg, brother) and could complete blanks with family members not listed. Next we asked about the existence and identity of a Family Health Informant. We asked, "Different people in extended families have different roles or activities. Sometimes a family member takes the lead in dealing with health issues. Is there a person or persons in your family who has the job of dealing with health issues?". People checked yes or no to the first question and then if yes, were asked to provide the name and relationship of that person.

Communication about family cancer history was measured with a previously used scale [16]. We asked participants to indicate how comfortable they would feel communicating with each of the following family members about melanoma risk (mother, father, sister, brother, children, grandchildren) and then how frequently in the past year they did communicate with each of the same family members. Communication was rated on a 4-point Likert scale, from 1 (not at all) to 4 (alot). An option for "I do not have a family member of this type or they are not living" was provided. The average response over all living relatives was the outcome measure. Finally, we asked about the people that the participant did not speak with using "Now I'd like you to think about those family members you said you didn't speak with about melanoma risk in the past year. People have many different reasons for speaking with their family members and for not speaking with their family members." The interviewer read a list of 8 questions each asking about a different reason as to why they did not speak with their family member about melanoma risk. There was also an open-ended option for

participants to write in reasons for not speaking with a relative. These items were developed from a previously conducted study on communication patterns among cancer families [28].

## Results

### Who are the respondents?

Table 1 presents the demographic data for the three groups of participants who responded to this study. As seen in this table, the sample (313 families) represents a cross section of adult melanoma Cases from the Pacific Northwest. Cases were primarily Caucasian, almost sixty years old, and roughly evenly split between genders. There was some variability in socioeconomic status, as represented by education and income, although the sample was reasonably educated. There were significant differences among the three family member types in only two demographic variables: age and gender. Parents were younger than either Cases or FDRs and Parents were more likely to be women (both at the $p<0.05$ level).

### Who's in the family?

Table 2 presents the endorsement of multiple types of people as "family" by Cases, FDRs and Parents. As seen in this table, there is diversity within family member type and across the three family member type. The majority of participants of all family member types included their mothers, their children, and their siblings in their definition of family. Fathers were included by FDRs and Parents, as were aunts/uncles and to a lesser extent extended relatives (relatives of one's spouse or partner) and spouses. Between a third and a half of participants included friends among their family group. A surprising number of people included pets (8–21%) and dead people (8–14%) as family members.

### Who is the family health informant?

Participants reported whether or not they had a family health informant, a person in the family who keep track of family information about health. A total of 71% of all participants (60% of Cases, 74% of FDRs, and 78% of Parents) reported having a family health informant in their family, with 76% of identified Family Health Informants being women. Table 3 presents the identity of the family health informant for each family member type. As see seen in this table, there were multiple family members named as Family Health Informants by participants in each of the three family types. Siblings, Parents, and spouses were the most commonly identified family health informants.

### Who communicates about melanoma risk?

We first calculated a score that indicated the comfort with communicating about melanoma risk and, separately, frequency of communication about melanoma risk over the past year. In general, participants reported reasonably comfort communicating about melanoma risk with their family The average comfort score was 3.1 with specific values of 3.9 for Cases, 2.9 for FDRs and 3.3 for Parents. Overall, a total of 70% of Cases, 60% of FDRs, and 72% of Parents had communicated about melanoma risk with family members in the past year. The frequency scores of communication with family members by each family member type were lower than the comfort scores, with an overall score of 2.5 for overall communication and scores of 2.8 for Cases, 2.4 for FDRs, and 2.2 for Parents.

Table 4 presents the demographic associations with communication frequency among each family member type. As seen in this table, the only two demographic variables to consistently be associated with communication frequency were gender and education. Being female was associated with higher communication frequency compared to being male. Lower education was associated with communication frequency inversely (ie, lower) compared with higher education frequency. No other demographic variables were associated with communication frequency.

### Reasons for lack of communication

All participants indicated at least one family member that they were no longer in contact with. We asked participants for the reasons that they did not communicate about melanoma with these family members, and Table 5 contains the reasons checked by participants for their lack of communication about melanoma risk. There were many reasons checked by participants for not communicating about melanoma risk with family members. Sometimes the lack of communication was attributed to lack of connection or closeness between family members. But, in other cases participants indicated that the family members would not be interested, were not at risk, would be upset, or were too young. Other family members indicated that the participants indicated that they felt uncomfortable with communicating about melanoma risk.

## Discussion

Family communication about cancer risk does occur, but it is not very frequent nor is it directed to all family members or present in all families. As a result, it makes a limited contribution to health promotion efforts. But, the communication that occurs creates a foundation for future health promotion efforts. We propose that because conversations do exist within families and exist without the cues from an intervention project, an intervention could improve or add to the focus of these conversations. People identify dedicated persons in the family who serve as a family communicant, for example, and if these communicants can be supported to communicate about a health behavior, we may be able to increase the frequency of constructive conversations about health and health behaviors.

Our data could help guide future research efforts and health promotion efforts in other ways [eg, 29]. We found that the definition of family is quite diverse and does not fit the clinical genetics definition of family. In fact, many people include individuals who are not genetically related. This finding emphasizes that family is a social construct that overlaps but is not congruent with the biological relationships that are the focus of shared familial risk. This finding is common in social science approaches to the study of family, but differs from a more biomedical definition of family, based in biology.

This framing is important and can be used in health promotion paradigms to promote health behavior. Not everyone is equally up to the task of communicating about cancer risk in families. In fact, the person in the family who has cancer is not likely to be identified as the main communicator. Over half of the cancer Cases identified someone other than themselves as the main communicant in families. This finding suggests that asking that the cancer Case be the main communicator of health information in families might be nonproductive, as this

was typically not their role in the family before the cancer diagnosis. This is an important, actionable finding as physicians and interventions may need to identify the family health informant to encourage communication, rather than just talking to the survivor and expecting them to carry through. Identification of the family health communicator and providing them with information and a mission might be a more effective strategy for increasing communication within families. Instead, identifying the health communicator and engaging them in the process of gathering and disseminating health information might make sense.

The reasons for lack of communication about cancer risk within families are quite diverse and have to do with both the person in the family who has information to communicate and the perceived relevance of the information. A person who was not communicating before the cancer diagnosis is unlikely to take on communication tasks later. For these people it may make more sense to identify other means of communication, including an email or mailed letter, to prompt family discussion. Some communication issues seem to arise because of the perception that the information is not important to the person or not relevant to them. This is easily corrected through accessible information about genetic risk. Some respondents said that they did not know what to say, and for these people providing scripts or suggestions may help. Many of these communication blocks are likely to be addressed in the context of good intervention components and comprise a testable series of hypotheses which will lead to future research.

In some families, people actually reported good reasons for non-communication. Such as being too young to understand or not feeling close enough. Some of the barriers to communication can be surmounted by intervention, but some perhaps need to be respected and not addressed, For example, some barriers (such as, my family member is not at risk) may be misconceptions and thus require intervention to correct. Splitting out barriers to communication and working to change those that seem like misperceptions could result in increases in communication.

It was surprising that a measurable proportion of family members included pets and the deceased people as family members. It is not clear from this inclusion as to whether pets and dead people also serve as communication targets. However the lack of inclusion of obvious biological relatives in some Cases is troubling. For example, 50% of Cases and 20% of FDRs did not consider their mother to be part of their family. If these people are accurately reporting, this might definitely lead to missed opportunities for communication. Perhaps a simple reminder to communicate with all biological relatives might improve this behavior.

Several elements of this study limit the generalizability of the findings. These families were primarily Caucasian and therefore generalizing to culturally different groups is problematic. The types of family members were preselected for their genetic relevance, and so we may have missed measuring communication patterns among preferred family members. Finally the quantitative nature of the data collection limits the complexity that can be studied. Perhaps a more mixed methods approach would have provided more richness to the data set.

Possible future research to be conducted based on these findings include both observational studies and interventional studies. Further observational studies could include pursuit of

these findings in a broader and a Case-selected set of family members. We also could gather actual communication behaviors, by electronically recording interactions or at least by asking more questions on communication patterns. Intervention studies could focus on the Family Health Informant as a good way to distribute information in a family, instead of relying on the Case to communicate. These natural supporters might do a better job, compared to someone who is not comfortable with communication. All of these could be research targets.

In conclusion, these data can guide the design and implementation of interventions to improve family communication among families with increased risk for cancer. Both the frequency and the content of communication among family members has considerable room for improvement. Also, the ways in which families are encouraged to communicate (e.g., through the family health communicator) could be explored further. These data suggest that families are an underutilized conduit for communication of valuable risk information and health improvement opportunities.

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**Table 1**

Demographic Characteristics of Cases (n=313)

| Variable | Categories | Cases | | First degree relatives | | Parents | |
|---|---|---|---|---|---|---|---|
| Age | – | X=56.11 (12.33) | – | X=51.6(15.6) (19–91) | | | |
| | [Range] | [20–89] | – | | | | |
| **Variable** | **Categories** | **N** | **%** | **N** | **%** | **N** | **%** |
| Gender | Female | 175 | 56 | | 64 | | 69 |
| | Male | 138 | 44 | | 46 | | 31 |
| Race | White | 311 | 99 | | 95 | | 96 |
| | Non-white | 2 | 0.6 | | 5 | | 4 |
| Education | ≤ High school degree | 39 | 12 | 35 | 11 | | 14 |
| | College/technical school | 78 | 25 | 102 | 33 | | 32 |
| | ≥ College degree | 195 | 63 | 195 | 62 | | 54 |
| Marital status | Never married | 19 | 6 | | 4 | | 7 |
| | Married or living as married | 253 | 81 | 225 | 72 | | 81 |
| | Separated/Divorced | 33 | 11 | | 21 | | 22 |
| | Widowed | 8 | 2 | | 4 | | 0 |
| Income | ≤ 50K | 51 | 16 | 96 | 31 | | 39 |
| | 51–70K | 85 | 28 | 55 | 18 | | 13 |
| | ≥ 70K | 150 | 47 | 137 | 44 | | 48 |
| | Refused/did not know | 27 | 9 | 25 | 8 | | == |
| Stage at diagnosis | In situ | 38 | 12 | – | – | | – |
| | Localized | 247 | 79 | | | | |
| | Regional, direct extension only | 2 | 1 | | | | |
| | Regional, regional lymph nodes only | 17 | 5 | | | | |
| | Distant | 1 | 1 | | | | |
| | Unstaged | 2 | 1 | | | | |
| | Other | 6 | 1 | | | | |

## Table 2

Participants' definitions of their "family"

| Included family members [1]: | % named by Case (n=313) | % named by FDR (n=313) | % named by Parent (n=313) |
|---|---|---|---|
| Mother* | 51 | 79 | 89 |
| Father* | 37 | 71 | 81 |
| Children | 85 | 79 | 92 |
| Sisters | 70 | 88 | 86 |
| Brothers* | 58 | 81 | 86 |
| In-Laws | 26 | 32 | 41 |
| Aunts/Uncles* | 31 | 77 | 76 |
| Grandchildren* | 37 | 61 | 58 |
| Grandparents* | 11 | 28 | 43 |
| Extended relatives | 45 | 56 | 51 |
| Spouses | 38 | 46 | 63 |
| Friends | 46 | 31 | 57 |
| Pets | 8 | 12 | 21 |
| Deceased people | 14 | 8 | 10 |

[1] Includes step and half relatives

* Significant difference in distribution across family member types; $p<0.05$

**Table 3**

Do you have a family health informant?

| One exists? | Cases (%) | FDRs | Parents |
|---|---|---|---|
| No * | 40 | 26% | 22% |
| Yes and it is: | 60 | 74% | 78$ |
| Self | 11 | 21 | 8 |
| Spouse or partner | 13 | 19 | 10 |
| Sibling | 33 | 38 | 19 |
| Parent | 17 | 5 | 28 |
| Children | 21 | 10 | 8 |
| Grandparent | 2 | 4 | 23 |
| Other | 3 | 3 | 5 |

* Significant difference in agreement with overall question; $p<0.05$

**Table 4**

Demographic associations with communication frequency among Cases, FDRs, and Parents in the Suntalk Study.

| Variable | Categories | Cases | | First degree relative | | Parents | |
|---|---|---|---|---|---|---|---|
| | | B | P | B | P | B | P |
| Age | Under 50<br>Compared to 50 and over | .01 | – | .04 | – | .17 | – |
| Gender | Female<br>Compared to Male | 1.15 | .02 | .89 | .05 | 1.01 | .05 |
| Education | ≤ High school degree/some college<br>Compared to ≥ College degree | −.54 | .04 | −.03 | – | −.69 | .04 |
| Marital status | Not married<br>Compared to Married/living as married | .23 | – | .04– | | .16 | – |
| Income | < 70K<br>Compared to ≥ 70K | .29 | – | .18– | | .29 | – |

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## Table 5

Reasons participants give for not communicating with family members about melanoma

| Reason [1] | % Case says applicable | %FDR says applicable | % Parent says applicable |
|---|---|---|---|
| Not in contact | 74 | 60 | 72 |
| Not close | 67 | 53 | 54 |
| Family member would not care | 35 | 50 | 33 |
| Don't want to upset family member | 67 | 43 | 39 |
| Not at risk for melanoma | 67 | 65 | 71 |
| Don't know what to say | 63 | 55 | 62 |
| Difficulty coping with own risk | 53 | 42 | 21 |
| Too young to understand | 85 | 59 | 32 |
| Other | 10 | 18 | 15 |

[1] Could mark all that apply to this question