Communication Among Melanoma Family Members

Deborah J Bowen,
Department of Bioethics and Humanities, University of Washington, Seattle, Washington, USA

Terrance Albrecht,
Department of Communication and Behavioral Oncology, Karamos Cancer Institute, Wayne State University, Detroit, Michigan, USA

Jennifer Hay,
Memorial Sloan Kettering Cancer Center, New York, New York, USA

Susan Eggly,
Department of Communication and Behavioral Oncology, Karamos Cancer Institute, Wayne State University, Detroit, Michigan, USA Wayne State University

Julie Harris-Wei,
Institute for Public Health Genetics, University of California San Francisco, San Francisco, California, USA

Hendrika Meischke, and
University of Washington, Seattle, Washington, USA

Wylie Burke
University of Washington, Seattle, Washington, USA

Abstract

Interventions to improve communication among family members may facilitate information flow about familial risk and preventive health behaviors. This is a secondary analysis of the effects of an interactive website intervention aimed at increasing communication frequency and agreement about health risk among melanoma families. Participants were family units, consisting of one family member with melanoma identified from a previous research study (the case) and an additional first degree relative and a parent of a child 0–17. Family triads were randomized to receive access to the website intervention or to serve as control families. Family communication frequency and agreement about melanoma prevention behaviors and beliefs were measured at baseline and again at one year post randomization. Intervention participants of all three types significantly increased the frequency of communication to their first degree relatives (Parents, siblings, children; range =14–18 percentage points; all p<0.05). At baseline approximately two-thirds of all three family members talked with at least some member of the family about cancer risk. Agreement between Cases and First Degree Relatives and between Cases and Parents increased from pre to post intervention in the intervention participants compared to the control

Address correspondence to Deborah Bowen, Department of Bioethics and Humanities, University of Washington, 1107 NE 45th Street, Seattle, WA 98105, USA. dbowen@uw.edu.

participants (p<0.05). These findings provide support for interventions to improve family communication about cancer risk.

Melanoma is a lethal disease, but risk of death can be reduced by certain behaviors, including reducing sun exposure and careful screening by providers (Ford et al, 1995). These behaviors are of particular importance for individuals with a family history of melanoma in a first degree relative, because they have who have an elevated risk of melanoma as well as other types of cancer. In fact, family health history is an important topic for familial interactions ranging from interpretation of genetic testing results, discussing risk, to discussing the need for proactive health behaviors and screening (Yoon, Schooner, Gwinn et al, 2004; Berg, Baird, Botkin et al, 2009; Koehly, Peters, Kenen et al, 2009; Khoury, Feero, & Valdez, 2010).

In addition to elevating risk, a a family history of cancer may inform decision-making about the timing and type of cancer screening (Acheson, 2011; Chowdhury, Dent, Pasavan, et al, 2011). Knowing one's family history of cancer can increase cancer-screening rates (Khoury, Feero, & Vladez, 2010; FH01 Collaborative Teams, 2010; Mesher, Dove-Edwin, Sasiemi, et al, 2014), and might improve other preventive behaviors. Often a diagnosis of cancer in the family can stimulate intrafamilial discussions of familial risk and precautionary behaviors that can have long ranging consequences for preventing cancers such as melanoma (Hay, Shuk, Brady, Berwick, Ostroff, & Halpern, 2009). Therefore knowing one's family history and understanding its importance could be an important step in motivating behaviors to reduce the risk of developing melanoma.

Despite the potential utility of family history, the frequency with which families share information about cancer and cancer risk is variable, potentially leading to lost opportunities to use risk-based prevention and screening strategies based on family history. For example, previous research indicates that only 20% to 50% of individuals with a cancer diagnosis discussed their risks with relatives (Oliveria, Shuk, Hay, Heneghan, Goulart, Panageas, Geller, & Halpern, 2013; Bowen, Jabson, Haddock, Hay, & Edwards, 2011; Pitcearthly, Maguire, 2003; Novilla, Barnes, Williams, Rogers, 2006) In general, the family is understudied and under used as a source of health information. Family members are a valued source of health information (Hesse, Nelson, Creps, et al, 2005)) yet reviews of patients report that discussions of familial risk and risk behaviors are relatively infrequent (Edwards et al, 2013) Although it is common for clinicians to ask affected individuals to convey information to their relatives, there is often no accompanying assistance or support. Several tools have been developed to help families collect family history of health issues, (Wang, Gallo, Fleischer, & Miller, 2011) but their general use is relatively low in the general population.

Frequency is only one aspect of communication among family members. Content of the communication might be important as well. One promising model of communication focuses on the process of convergence. Convergence has been defined as shared understanding and beliefs about a topic (Albrecht, Penner, Cline, Eggly, & Ruckdeschel 2009; Rogers & Kincaid, 2005). Convergence can vary in two important ways, agreement and accuracy. Part of convergence is the degree to which two people are in agreement about

their beliefs, knowledge, or understanding (agreement), Another component of convergence is the degree to which two people are accurate in the content of their communication (accuracy) Each of these two elements, agreement and accuracy can be studied and are potentially modifiable and ach of the elements of convergence might also be important in shaping individuals' health behavior. For example, convergence is when two people have the same belief about what might cause cancer (agreement) and might both believe that sun exposure is a main cause of melanoma (accuracy) Improving either aspect of convergence could be a target for communication intervention to improve desired behaviors.

Agreement and accuracy mostly been studied in patterns of communication between clinical provider and patient (Albrecht, et al, 2009; Eggly & Penner, 2013). However, one might consider that agreement and accuracy of shared beliefs regarding two or more family members might also be important to preventive behavior choices. For example, family members who agree on foods that they will eat together might be more likely to consume them. Also both members might believe those foods to be more healthy and therefore might consume them more frequently. Of course, agreement without accuracy between two people could actually be harmful, as when two people agree that tanning beds are a good preventive strategy. Therefore, it seems important to separate the elements of convergence into their component parts of agreement and accuracy; here we evaluated agreement on preventive beliefs among family members.

Taken together, communication about cancer prevention strategies has not been well studied among family members. A diagnosis of cancer in a family provides an opportunity to identify agreement in beliefs about cancer prevention among family members regarding cancer risk. As a secondary analysis of data from an existing randomized trial to improve melanoma prevention among family members, we were able to study changes in communication frequency and agreement about melanoma beliefs. The present study identified frequency of communication and agreement among family members recruited to participate in a web-based melanoma prevention intervention. We predicted that frequency of communication would increase as a result of the intervention and that family member pairs in the intervention arm would report more agreement in key prevention-oriented beliefs after the intervention, compared to before intervention exposure.

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. Families (including melanoma Case, first-degree relative or FDR, and 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 website with information about melanoma, for approximately one year. Enrolled family members completed a follow-up survey one year later, and then the comparison families received access to the study website. Previously published papers presented the baseline data for survivors and FDRs (Bowen, Hay, Mayer, et al., 2012) A manuscript under review has

presented the positive effects of the intervention on survivor sun protection behaviors and skin examination (Bowen, Hay, Burke et al, 2014).

We used two sources for recruitment of families in Suntalk: 1) the Northwest Cancer Genetics Network (NWCGN) a regional site of the Cancer Genetics Network (Anton-Culver et al, 2003) and 2) The SEER registry (Cancer Surveillance System or CSS) at the Fred Hutchinson Cancer Research Center. Recruitment and reasons for attrition during the screening process are described in detail in a previous manuscript (Bowen et al, 2012); a total of 28% of entire families that were initially approached were randomized to the intervention or control condition of this study. Melanoma cases diagnosed with a first primary melanoma 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 stages: physician, case, FDR, and Parent. 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 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 asked the case to identify their family members,, and permission to contact was documented for each relative. We collected all names and contact information for all FDR's and for Parents before randomly selecting one of each to contact for study participation. Finally, participants were asked to complete a baseline survey asking about baseline levels of sun protection behaviors and screening behaviors over the telephone, either immediately following the initial survey. The Case's FDRs were then approached using the same methods used to approach cases for participation. After an FDR was recruited we approached a Parent. Because of this, FDRs could be Parents and Parents could be FDRs. Once all three family members (Case, FDR, Parent) completed the baseline survey, families were randomized to receive either the immediate intervention (50%) or to participate in the delayed intervention group that had access to the intervention only after final outcome assessments (50%).

Intervention

All family members were provided with multiple links to the study website designed specifically for melanoma survivors and their family members, described more fully in the main outcome paper for survivors (Bowen et al, 2014). The website consisted of a home page, with constantly changing messages about prevention, similar to our breast cancer

interventions (Bowen et al, 1998; Bowen, DJ, Christensen, CL, Powers, Graves, & Anderson, 1999 Bowen, Powers, and Greenlee, 2004). Viewers were directed to a page with their own personal risk for melanoma, using the model developed by colleagues at Harvard University (Disease risk Index) called "your chronic disease risk" and used baseline data to complete the risk algorithm. The risk graphic included a thermometer shaped risk tool that provided an indication of the likelihood of future melanoma tailored to the individuals' risk status and risk factors. The study website linked to specific sites with more information. Additional sections from which the viewer could choose included how to reduce risk, how to prevent sun exposure, how to self-screen, how to get a screening from a provider, how to talk to a provider, how to talk to cases and other family members about risk, how to help children protected from sun exposure, and a chat room and interactive section for family members. Viewers could select any or all pages and could view them as much as they desired to during the one year study period. Every three months prompts would be sent by the study team via email to check the website and check a new previously unviewed page.

A labelled section of the website was focused on helping families communicate about cancer risk and communication, based on an NCI publication "Taking time: Support for people with cancer". Separate sections for cases and family members provided advice on how to initiate discussions of cancer risk, what family members need, and should know about their cancer risk, and how to talk with children and adolescents about cancer. Also discussed were methods of talking with difficult family members and how to communicate with family members that are not in close proximity or contact. Participants in the study were cued to use the website sections on communication, like other sections, by email and home page messages. The website is described in detail in a previous paper (Bowen, Burke, Hay, et al, 2014)

Measures for the present study

Frequency of communication about family cancer history was measured for all three family types by asking a previously used set of items starting with "How much have you spoken about melanoma risk with each of the following family members in the past year? (. Frequency of communication with all listed 1st degree relatives was rated on a 4-point Likert scale ranging from 1 (*not at all*) to 4 (*a lot*). An option for "I do not have a member of this type or they are not living" was provided (Bowen, 1999; Bodurtha, et al 2014). For each family member, the response was dichotomized into "somewhat or a lot" (frequent) versus "not at all or a little" (infrequent). The response of frequent communication was the communication frequency measure.

Agreement was measured by first asking all three family member types to respond to a series of six questions asking about family beliefs regarding melanoma risk (Harris et al, 2010). For each of six questions, participants were asked "In general, people in my family generally believe that:" and the six questions focused on tanning, risk for melanoma, and screening for melanoma (all relevant to the intervention content). An example of a single item included "In my family, people generally believe that having melanoma is a serious threat to their health" Responses were provided on a 1–4 scale, where 1 was strongly agree and 4 was strongly disagree. Agreement was calculated by identifying the response as

agreement (both family members giving the same answer) between members of a pair of family members (case-FDR and case-Parent) to each of the items. If the pair had different scores, the pair was recorded as No agreement. We were not able to measure accuracy because we did not include beliefs that were clearly accurate for all versus inaccurate.

Background variables—Other relevant measures included standard demographic measures (sex, race/ethnicity, income, education), family size in number, and a single item measuring how close each of the relative types (FDR, Parent) felt to the case, with a response category of 1=not at all close to 5=very close.

Analyses

We first described the frequency of communication about cancer risk for relevant family members. We then examined agreement between Case-FDR and Case-Parent pairs before and after intervention exposure in the intervention and control groups. We looked at predictors of agreement in these two pairs of family members from among baseline demographic variables (eg, Case age, family size, perceived closeness to case). All comparisons between relatives were analyzed using chi-square tests with a significance level of p<0.05.

Results

Table 1 presents the background data on all recruited participants (n = 313 families). As seen in this table, survivors were middle aged, included both women and men, and varied in educational and income levels. Stage of diagnosis was mostly localized melanoma, with small percentages in other stages. The demographic pattern of FDRs was similar to the pattern in cases, in terms of age, and socioeconomic factors, as seen in Table 1.

In general, Intervention cases signed into the website a total of 1.9 times during the intervention period, with a range of 0–15 times during that 12 month period. Study website usage is described more fully in a previous manuscript (Bowen Burke, Hay et al, 2012)

Table 2 presents the frequency of communication for each family member type for several categories of relatives in this present study. In this stable the cell sample sizes vary widely (from 117–313) because not all family member types had all kinds of relatives in the table. Overall, all family member types had communicated about melanoma risk in the past year with family members. This table shows that, for cases, children were most frequently communication family member types, followed by brothers and sisters, and then parents. A different pattern emerged for FDRs, for whom communication frequency for all measured family members was roughly equal. Parents communicated most frequently with their children, followed by their mother and father, and then their siblings.

Table 3 presents the overall frequency of communication score measured before and after Suntalk intervention exposure for each type of family member. This communication variable represents communication with any first degree family member, including parents, siblings, and children. As seen in this table, at baseline about two-thirds of all three family member types (ie, case, FDR, Parent) communicated frequently with at least some member of the

family about melanoma risk. For the comparison group this frequency did not significantly change from baseline to 12 month follow up. However, for intervention families communication frequency increased significantly from baseline to 12 month follow up.

Table 4 presents the frequency of agreement about various aspects of skin protection for each pair of family member types from before to after Suntalk intervention exposure. Agreement was measured as having the same rating between each family member type pair, at each measurement time point on a series of family belief items as listed. As seen in this table, agreement was relatively low at baseline and similar for intervention and comparison participant pairs. At the 12 month follow-up, agreement significantly increased for 5 of the six family beliefs (all p's<.05). The only belief that did not increase in agreement between case and FDR was the belief that "tanned skin is healthy skin". For case-Parent pairs, agreement increased in three of the six family beliefs significantly (p"s<.05). The beliefs that increased in agreement were mainly those having to do with sun exposure, while agreement about screening did not consistently increase between Cases and Parents.

We evaluated the effects of baseline demographic predictors of agreement change for each family member type. Baseline predictors included (sex of each family member type, race/ethnicity, income, education), family size (#), rated closeness to Case of each family member type, and Case's stage of melanoma. No effects of any baseline demographics tested were significantly related to agreement at 12 month follow up (data not shown).

Discussion

This study identified changes in communication patterns following exposure to a web-delivered communication intervention for melanoma families. As seen in these data, the intervention changed communication patterns for multiple family members. The frequency of communication increased for all three index family members: Cases, FDRs, and parents. The baseline communication frequencies were comparable to what little data we have for other cancer sites (Valdez et al, 2010) and also comparable to communication frequency among other melanoma families (edwards et al, 2013). Specifically, we now understand from these data that agreement about beliefs is not something that families generally report before intervention, but intervention to shape beliefs can improve agreement. We hypothesize that agreeing on beliefs is one goal of communication, and will be able in our next research project to further explore this idea.

These finding are very encouraging for future research, as these changes in communication patterns mean that we can consider changing the ways that families communicate about a range of health issues. Other studies have certainly included communication among the changes they supported during intervention, such as those of Geller (Geller, Emmons, Brooks, et al 2006) and Manne (Manne, Jacobsen, Ming et al, 2010). Perhaps interventions can be efficacious in increasing focus on appropriate health communication in families when family is the main or the only mechanism we have to identify risk, like family history and diagnosis of other diseases. Certainly for genetic risk, family members are the main method of communication at this point in time and therefore, we rely on family to communicate about increased risk with a family diagnosis of chronic disease. Families communicate about

multiple health-related issues, and we might consider the use of increased family communication as a vehicle for changing behaviors. Indeed, our group has published the effects of this intervention on melanoma-related behavioral outcomes, like sun protection behaviors and skin examination, with positive results (Bowen et al 2014). We propose that these communication differences are one mechanism by which the intervention was efficacious in changing behaviors.

The frequency measures used in this study did not assess type of, or content of communication among family members. Supplementing the big picture measures obtained here with more detailed communication measures might provide more insight into the patterns of communication on a specific topic, such as chronic disease risk or implementation of preventive behaviors. Future research should include more fine grained measure of communication patterns, including frequency, content, and styles of communication. Each of these might be relevant to further understanding of the role of communication in health behavior change.

Similarly, our data indicate whether or not participants agreed with their family members in key beliefs about melanoma risk, but we were not able to assess accuracy in beliefs about melanoma risk and therefore were not able to assess convergence in communication between case and relative, because convergence includes both agreement and accuracy. This would be important in future research, as it may be that we can encourage families to agree with each other but if they agree on a misconception about cancer, this could present problems for increasing a health-oriented behavior. Therefore, agreement and accuracy could be measured separately and combined for a convergence score or index. This could be the topic of future research. Because of the way we recruited the family members, FDRs could be Parents and Parents could be FDRs. We did not have a sample size to disentangle these relationships and communication patterns. One other limitation of these data is that the measures of agreement were all self report and not observational. In other words, participants responded with self-reports of communication frequency; we did not videotape or audiotape the conversations. Other convergence studies have been conducted using recording s between physician and patients; these interactions were taped and rated by independent observers (eg., Albrecht et al, 2009). It is likely that observational measures of communication carry less social desirability biases and fewer errors in judgment and memory on the part of participant. These limitations are critically important and have not been evaluated in studies such as ours. However, it would be possible to record interactions between family members in either laboratory or field settings, and evaluate them for agreement or other communication elements. Future research should consider these methods carefully.

These findings are encouraging to future intervention research that targets communication improvement among family members. However there is still room for improvement in increasing communication among family members. The manner in which FDR's and parents were selected left some room for potential bias, in that it relied on the case reporting accurately all contact information and identity of these groups. In the next study we will build in checks with other relatives as to all family history information collected from the initial case interview. The intervention did not increase communication among all relatives, nor did the intervention increase communication about all relevant topics. Increasing the

intensity of the intervention might be one method for increasing intervention effect. Perhaps using more flexible means of electronic communication, such as texting or other automatic proactive message delivery, might help remind people to talk to their relatives or help them during difficult times/ Perhaps immediately after diagnosis there is a teachable moment (McBride, Emmons, & Lipkus, 2003) and family communication might be even more malleable and open to change at that point. These ideas can be incorporated into future research designs.

Another limitation relates to the sample recruited for the present study. Due to the nature of melanoma and the geographic area of the study, the sample was almost completely Caucasian. We do not know how members of other cultural or ethnic groups would respond to an intervention like this one. This is a critical need for future research: to test communication interventions in other cultural groups where different disease patterns and family communication styles might occur. Different groups might have different styles of communications, and these might work more easily or more difficultly in communicating about personal risk. We have no knowledge of this type of work and we need it, before proceeding with population wide dissemination of these types of interventions.

The final limitation is inherent in the nature of the intervention under evaluation. We chose a website intervention because of the flexibility and portability of the intervention as well as the ease of dissemination to a larger sample. However, the digital divide still exists across the US, where nonwhite ethnic groups have less home Internet access and therefore would not have direct access to this intervention. This essentially reduces the ability of this intervention to be implemented on a population basis. We need to consider other means of delivering the content of the intervention, such as through telephone or print media, in order to make it accessible to individuals with limited internet access.

Acknowledgments

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Table 1

Demographic Characteristics of Family member types s (n=313 families)

Variable and categories	Cases	FDR's	Parents
Age			
Mean (SD)	56.1 (13.3)	51 (15.6)	37.1
Range	20–89	19–91	21–48)
Gender, n (%)			
Female	175 (56%)	(63.6)	205
Male	138 (44%)	(46.4)	(65.6)
Race, n (%)			
White	309 (99.7%)	297 (95%)	297 (95%)
Non-white	2 (.7)	(5%)	16 (5%)
Education, n (%)			
High school degree	39 (12.4)	35 (11.2%)	17 (4.5%)
Some college or technical school	78 (24.9%)	102(32.6%)	88 (32%)
College degree	195 (62.3%)	176(56.2%)	208(65.6)
Marital status, n (%)			
Never married	19 (6.1%)	19(6.1%)	6 (1.9%)
Married or living as married	253 (80.8%)	225(71.9%)	286(93.4%)
Separated/Divorcd	33 (10.5%)	59 (18%)	4 (1.3%)
Widowed	8 (2.6%)	10 (3%)	28 (8.9%)
Income, n (%)			
50K	51(16.3%)	96(30.7%)	19 (4.6%)
51–70K	85 (27.2%)	55(17.6%)	91 (29%)
70K	150 (47.9%)	137(43.6%)	135 (66%)
Missing	27 (8.6%)	25(8%)	28 (8.9%)
Stage at diagnosis, n (%)			
In situ	38 (12.1%)	—	—
Localized	247 (78.9%)	–	–

Variable and categories	Cases	FDR's	Parents
Regional, direct extension only	2 (.6%)	–	–
Regional, regional lymph nodes only	17 (5.4%)	–	–
Distant	1(3%)	–	–
Unstaged	2 (.6%)	–	–
Other	6 (2%)	–	–

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Table 2

Frequency of baseline communication in past year about melanoma risk for each family member type with other relatives[*]

% frequently comm.in past year (n=313)	Case	FDR	Parent
Mother	41.4	49.7	70.5
Father	28.7	34.4	67.5
Sisters	68.4	40.6	46.1
Brothers	62.0	33.9	42.4
Children	71.8	44.4	72.2

[*]Ns vary from 117–313 due to missing relatives

Table 3

Frequency of overall communication frequency about cancer risk for each family member type before and after Suntalk intervention exposure.

% communicated in past year about melanoma risk	Case	FDR	Parent
Intervention at baseline	70	59	73
Comparison at baseline	69	60	71
Intervention at 12 months	84*	77*	88*
Comparison at 12 months	76	63	75

*
Change score significant P<0.05

Table 4

Agreement in family-related beliefs among family member pairs before and after Suntalk intervention

		Percent agree						
		Case/FDR (n=305 pairs)			Case/Parent (n=300 pairs)			
In general, people in my family generally believe that:		Baseline	Followup	Sig*	Baseline	Followup	Sig*	
tanned skin is healthy skin	I	25	34	.14	28	63	.008	
	C	24	21		27	28		
having melanoma is serious threat	I	21	49	.04	24	34	/19	
	C	26	21		30	39		
There is little they can do to protect themselves from getting cancer	I	30	66	.01	22	59	.03	
	C	27	31		25	26		
It is important to check their skin for signs of melanoma	I	30	78	.001	28	27	.31	
	C				30	34		
important to visit their doctor to screen for melanoma	I	23	69	.03	24	30	.47	
	C	25	23		21	24		
Tanning lamps are good way to get tan	I	20	65	.01	24	81	.001	
	C	24	20		27	28		

*
significance of chi square tests on intervention and control frequencies from baseline to followup