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Melanoma High-Risk Families' Perceived Health Care Provider Risk Communication

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Abstract

Background.—Families with a melanoma history are at risk of melanoma. Melanoma survival improves when people are aware of their risk and ways to modify it. We explored at-risk families' perceived risk communication from healthcare providers.

Methods.—Qualitative description.

Results.—Participants perceived: (1) few provider discussions of melanoma risk or riskmodifying behaviors; (2) a desire to trust information from providers; (3) the healthcare system constrains communication; and (4) concerns about provider competence and caring regarding worrisome lesions.

Conclusions.—Providers should provide clear, comprehensive, accurate, and consistent messages about melanoma to persons at high risk; messages also convey competence and caring.

Cutaneous melanoma ranks among the top 10 cancers diagnosed in American men and women, with 60,000 new cases occurring in the United States and 8000 deaths each year.¹ Personal or family history is a high risk factor. From 5% to 12% of melanoma patients report a positive family history (one or more affected firstdegree relatives [FDR]).^{2,3} Members of melanoma-prone families have a relative risk ranging from 35- to 70-fold, compared to the general population, whereas a personal history confers about a 9-fold risk.^{3,4} Five-year survival associated with nonulcerated melanomas less than 1 mm thick is 95%, and the comparable survival rate for ulcerated melanomas greater than 4 mm is 45%.⁵ Thus, early removal of suspicious lesions is important and depends on detection via regular skin examinations.⁶

Types of skin examinations include clinical evaluation by a dermatologist or other provider, inspection by family members, and skin self-examination (SSE). Clinicians are more likely to detect thin lesions,^{7,8} but SSE may also reduce risk.⁹ Primary prevention behaviors include decreasing ultraviolet light exposure by seeking shade, covering skin with sun-protective clothing, and applying sunscreen as recommended.¹⁰

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For high-risk melanoma families, communication from health care providers about risk and risk-modifying behaviors can potentially extend survival. Yet, there is sparse research concerning this communication. The purposes of this study were to (1) describe high-risk family members' perceptions of health care provider communication regarding risk and risk modifying behaviors and (2) explore recommendations for enhancing such communication.

Cancer Risk Communication

Risk communication consists of messages that describe or characterize hazards, risks, or risk-reducing actions and can be considered an interactive exchange of information and opinion among individuals, groups, and institutions.^{11,12} Risk communication targeting individuals or groups likely influences the strength of their health beliefs and use of health-promoting behaviors and should be a two way process for exchange of information and opinions.¹³ Many times, however, it is one-way communication from experts.^[11] The complexity of risk communication may also convey a level of uncertainty that potentially interferes with information processing¹⁴ and promotes inaccurate perceptions.¹⁵

The few studies of risk communication in cancerhigh-risk families generally have looked at presentation of risk estimates to high-risk individuals^{16,17} or the risks and benefits of genetic susceptibility testing.¹⁸ In the context of high melanoma risk, research has focused on siblings of melanoma patients and their communication of family diagnosis of melanoma to health care providers, friends, and family members,¹⁹ and communication from newly diagnosed melanoma patients to family members.²⁰ Although most physicians believe they should provide skin cancer prevention messages, the rate of physician counseling is low (eg, 20% counsel for sunscreen use, 6% counsel for other sun protection measures).²¹ However, persons with known chronic sun exposure indicated that risk communication from health care providers positively shaped their skin cancer knowledge and practices, detection, and self-efficacy.²² Despite their conclusion that health care providers caring for these patients were cognizant of melanoma risk and communicated appropriate messages to specific family members, Robinson and colleagues²² observed that studies of health care provider risk communication is “strikingly absent” in the literature.

METHODS

This study was guided by a qualitative descriptive design. According to Sandelowski,²³ qualitative description is the optimal choice for viewing straight descriptions of the basic nature and shape of events or experiences, “the least encumbered by pre-existing theoretical and philosophical commitments,” and facilitates the gathering of minimally theorized answers to questions of special relevance. Other qualitative approaches such as grounded theory, phenomenology, or ethnography are based on specific methodological frameworks emanating from distinct philosophical perspectives and for which description comprises only an initial analytic step.²³

Eligible were newly diagnosed melanoma patients, having a family history of melanoma (2 or more affected FDR) and at least 1 FDR (affected or unaffected) willing to participate.

After receiving institutional review board approval, we recruited patient participants from the Cutaneous Oncology Program (COP) at the University of Arizona, Skin Cancer Institute, Arizona Cancer Center. The COP provides a comprehensive multidisciplinary approach to risk management and treatment and includes experts in dermatology; medical, surgical, and radiation oncology; pathology; genetics; behavioral science; and health education. All patients with melanoma are seen in the COP; approximately 12% have a significant family history.

For this study, we used purposeful sampling, which is appropriate for qualitative description, in that the ultimate goal is to obtain cases that provide rich information to fulfill the purpose of the study.^{23–25} COP physicians identified eligible participants and referred them to the principal investigator (PI) who performed a comprehensive family history. This exchange also allowed the PI to assess patients' abilities to provide forthright information and willingness to critically examine their communication experiences with other providers.²⁴ The PI subsequently informed patients²⁴ of the rationale, risks, and benefits of the study. Patients who consented to participate agreed to in-depth interview on another day. Patients were informed that they and their family members would be able to meet with the COP health educator (typical care in the COP) after the interview. Using the process of nominated sampling,²⁴ the PI asked patients to select a FDR that similarly could articulate their perceptions of health care provider melanoma risk communication and be willing to participate. The FDR signed consent prior to their interview. The interviews were conducted in a conference room at the Arizona Cancer Center from November 2005 through May 2007.

The sample consisted of 20 individuals in 7 families. Eleven had melanoma (8 women and 3 men): all but two had early-stage disease. Nine family members did not have melanoma (3 women and 6 men). Participants were all white, of European ancestry, and with an age range of 18 to 65 years.

The PI interviewed each patient and family member separately, structuring each interview with the following questions:

1. What discussions have your health care providers (for example, physicians, nurses, nurse practitioners, physician assistants) had with you regarding your risk of melanoma and risk for other family members? Please talk about providers you saw prior to coming to the COP.
2. What do these health care providers tell you about possible ways to control or modify your risk of melanoma occurrence or recurrence?

The audio-recorded interviews lasted approximately 1 hour. The number of interviews was not predetermined, but continued until informational adequacy was achieved.²⁴

Interviews were transcribed verbatim; transcripts were checked against the recorded interviews. We used content analysis of participants' descriptions (phrases) to identify patterns, then themes that brought meaning and identity to perceived risk communication from providers.²⁶ Because the intent was to describe communication perceived by family members (all being at high risk), interviews were analyzed together. To manage the data, we

used ATLAS.ti 5.2²⁷ qualitative analysis software. A coinvestigator with expertise in qualitative methods independently reviewed the transcripts and verified the themes.²⁸

RESULTS

There were 4 major themes describing perceptions of health care provider risk communication (Table 1).

“A Passing Interest”: Not Much Talk About Risk

The high-risk participants in this study perceived that general discussions of melanoma risk from health care providers typically were few or none, and were poor in quality:

“Nobody has told me anything about my risk, except that one time I went to a dermatologist . . . I saw a physician’s assistant who told me that I should skin check annually. My personal primary care physician has never gone into any discussion about it.” [Unaffected brother]

“There is not much messaging regarding melanoma, because I had a doctor and he says, ‘you are just routine.’ Every year it was the same thing.” [Female patient]

Regarding targeted discussions of melanoma recurrence risk, participants reported limited discussions. The presentation format of this information was limited and not always helpful:

“About my recurrence, they gave me percentages; anyway it was kind of alarming. Wasn’t sure what it meant” [Male patient]

Recurrence risk sometimes was presented as all (will recur) or none (will not recur) phenomena.

“[Doctor] just said, ‘this is most likely to recur,’ and that it did!” [Female patient]

Some patients were never told about recurrence risk:

“I got my first melanoma 23 years ago. No one ever told me then that it could come back.” [Male patient]

Despite the high-risk status of all our participants, they indicated that provider discussions of potential genetic risk or family history were almost nonexistent. This was perceived as an oversight:

“They should [discuss it] because it’s in the family history forms I fill out, so it’s there.” [Unaffected father]

“The fact that it might run in families, the fact that perhaps at some point genetic testing could be done, you may not be able to prevent it but you can certainly know ahead of time and you can start your risk behaviors even earlier.” [Affected sister]

However, some participants were not overly concerned about this lack because they were confident in their own knowledge of melanoma risk:

“I haven’t really approached the subject with [physician] either, because I have educated myself so much about it, that I probably know more about it than he does.” [Affected father]

When nondermatologist health care providers see patients, melanoma may “take a back seat” to other medical problems:

“. . . it’s not like osteoarthritis, where you are in great pain, and they can give you a tablet for that. So, sometimes things that don’t bother you take a back seat to what they perceive as more pressing.” [Affected sister]

“The Health Care System Gets in the Way”: System-Based Constraints on Communication

Participants perceived that the health care system sometimes gets in the way of risk communication. For example, individuals having an appointment with a dermatologist may not be seen by one:

“I never really see the dermatologist. . . . I can’t see the doctor. I end up with somebody who is a nurse practitioner or somebody else.” [Unaffected brother]

There were concerns about the care at health maintenance—type organizations:

“I have found since we moved into HMO-type deals, I know they are—but they don’t come across as—very informed. Seems like in the health system you go into a doctor’s office and they are worried about pushing out numbers and they tell you very little.” [Male patient]

Other perceptions were that the system allowed inadequate time for communication:

“Just not talking about [melanoma] may be a problem of not being able to look at individual patients’ records before they see them because they see such a high volume.” [Male patient]

Participants valued provider-to-provider networks for professional management of melanoma risk:

“It helps me that once the dermatologist finds [melanoma] and notifies the internist, and then together they work as a team. Otherwise, I’m lost.” [Female patient]

Another participant stated his provider’s advice: “I want you to go to the [melanoma high-risk clinic] because they are up on the latest and know things I don’t know.” [Unaffected sister]

“I Trust Them To Give Me Knowledge”: Wanting Accurate and Understandable Melanoma Information

Participants commented on paying attention to and trusting messages delivered by providers.

“I probably pay the most attention to what they are basing the information on that they are telling me, what they are telling me, and realizing that they work with this every single day.” [Unaffected brother]

“Knowing what I know now about melanoma . . . I was actually poorly informed as to what to expect in probably 90% of the visits. I trust [providers] to give me the knowledge that they have . . . even though I sometimes get inaccurate information.” [Affected sister]

When providers presented information, patients and family members did not always clearly understand it. For example, one participant commented on presentations of risk information:

“... they could probably explain to you that you are at risk ... I think patients say, ‘Well, what does that mean? Do I have a 50% chance of getting it? Do I have a 100% chance?’ I don’t think that people understand. They know that risk means you could get it, but they want to know what are the odds, or how careful should I be? People don’t always walk out with a clear understanding of what the word risk means ...” [Unaffectedsister]

Participants suggested that to easily understand risk information, it must be straightforward and they should be able to clarify it as necessary:

“I think the thing that I listen to the most, and I like to hear the most, is for the provider to tell me, if you are at risk, here are the ways you can avoid it, here are the ways you can prevent it, here are the ways you can control it if you do have it.” [Unaffected father]

Participants strove to apply information to their personal situation:

“I personally try to grasp as much of that knowledge as I can from that doctor or to take that with me when I leave his office so I can apply that to my own personal life and minimize any chances I might have.” [Unaffected son]

Participants indicated that specific behavioral messages focused on using sunscreen and wearing hats. Participants did not mention messages about reapplication of sunscreen, avoiding the sun, and covering susceptible skin with sun protective clothing. Additionally, they had few comments about health care providers’ discussions of skin examination:

“the [dermatologist] keeps pretty close watch ... he wants to know how things [skin examination and sunscreen use] are going. I think he is aware that over an extended time I am doing them.” [Female patient]

“My doctor asks me if I look at my skin. That’s all.”

In general, participants received the information directly from in verbal or print formats:

“I have never seen a video. I honestly don’t think I’ve ever gotten information about melanoma from the doctor just giving something.” [Unaffected sister]

“Is It Cancer?”: Desiring Competent and Caring Communication

Some participants perceived passive and uncaring communication from providers:

“I don’t want the comments anymore, if I have another medical student who says, ‘Oh my gosh, you really had five melanomas. ‘I don’t want that anymore.” [Female patient]

Such communication could influence patients’ decisions for follow-up care:

“... he [dermatologist] always would tell people that, ‘I am sure it’s cancer’ before they got the results back, and then it wasn’t and they’ve worried themselves sick. I

have kind of a negative experience with dermatologists, and I don't go."

[Unaffected sister]

"If I hadn't taken it upon myself to make sure I go [for a checkup] every six months, and make sure I look at my moles . . . I am not satisfied that [providers] would have done it on their own." [Unaffected brother]

Participants perceived that providers need to trust patients' instincts about suspicious lesions:

"My second melanoma was a spot and my dermatologist said, 'You don't need to take that one off.' I said, 'Yeah, we do', and that was my second melanoma."

[Affected sister]

"If anybody says 'something has changed,' [doctors] shouldn't be saying 'let's wait,' or 'you are too vain,' or 'that's going to leave a scar'. It may be too late."

[Female patient]

Participants perceived that they needed to feel comfortable talking with providers:

"There's a very valid lack of communication in the whole process, because lots of people are intimidated and they won't ask the doctor, 'What did you say, what does this mean, what can I do to correct this?'" [Male patient]

"If I bring [concerns about melanoma] up [providers] will respond professionally and give me all the information that I need and will give me any tests I've requested." [Female patient]

DISCUSSION

Participants in this study—all at high risk for melanoma occurrence or recurrence by virtue of family history—perceived that their health care providers could do a better job of communicating information about melanoma risk. Participants perceived 4 communication issues: (1) communication is absent or inconsistent; (2) communication is constrained by the health care system; (3) messages need to be clear, accurate, and understandable; and (4) messages should be conveyed with competence and caring.

Our high-risk participants perceived that risk communication was absent or inconsistent at best. These findings are not unusual. In a study of primary care physicians' use of verbal compliance-gaining communication in medical interviews, most communication was indirect and incomplete.²⁹ Similarly, other authors also have found communication to high-risk groups to be generally lacking in occurrence, quality, and consistency.^{30,31} But if individuals at highest risk for melanoma are not receiving risk communication, then it is almost certain that persons at general population risk are not receiving risk messages.

Our findings also suggest that family history was not adequately addressed. Family history of cancer is important information that members of any cancer-high-risk family should communicate to providers,^{21,32} but patients and family members cannot communicate this information if they do not know its importance. Providers can inform patients that family

history of a condition is considered one of the highest risk factors for any disease,³² and routinely query about it.

Several participants perceived that one reason communication was deficient was that the health care system sometimes interferes with these practices. Other authors have described that risk messages are often at the mercy of competing clinical demands and in many cases involve additional time, materials, and paperwork beyond that required by health care agencies for treatment.^{29,33} With such constraints, providers may be unable or unwilling to add comprehensive risk messaging.³⁰ Alternatively, health care has become so specialized that some providers (including some dermatologists) may not be fully knowledgeable about melanoma and appropriate monitoring.^{30,33} Yet another explanation is deficient communication skills training.³⁴ Our findings reflect the US health care system; future research should explore risk communication in other countries with high melanoma incidence.

The participants perceived some problems with the messages received from providers. For example, risk estimates can be confusing, and not easily understood. Misunderstanding can lead to alterations of perceived risk (pessimistically high or optimistically low), a recurrent finding in reports of risk communication for high-risk conditions.^{13,15–17} Alterations in perceived risk may influence decisions to engage in risk modifying behaviors.^{15,35}

The actual risk-modifying messages received by our participants focused solely on using sunscreen and wearing a hat, and not other well-described important behaviors such as reapplying sunscreen, seeking shade, wearing clothing with ultraviolet protection factor, and avoiding the sun.^{10,36} The lack of comprehensive messages to high-risk families is troubling in that these families should have prescribed riskmodifying behaviors and these should be monitored regularly. Comments suggested that some providers are underdiscussing skin examination, the most critical behavior for increasing melanoma survival.⁶ We contend that information about skin examinations should *always* be given to persons at high risk. We agree with Robinson and Rigel³⁷ that more research is required to elucidate types of messages used by providers to persuade their patients to engage in protective behaviors.

The findings of this study revealed that for messages to be seriously considered, provider communication should reflect competence^{38,39} and patients must perceive that providers are approachable and willing to engage in conversation. Furthermore, trust in provider risk communication could increase patients' acceptance of messages.⁴⁰ Our participants described passive and sometimes negative communication that occurred. Similar perceptions have been reported in a study of physician communication problems in patients with hepatitis.³¹ Health care provider–patient communication in ideal cases is a partnership, which involves a professional, yet caring, attitude.⁴¹

Recommendations for Health Care Providers

Training of any provider should include development of skills for effectively communicating with patients. Equally as important is a working knowledge of theories that can be helpful in framing risk information; eg, theories of persuasion if they are interested in persuading a patient to engage in sun protection or theories of health behavior change if the goal is to

have patients perform appropriate SSE.⁴² This would require collecting information on patients' behavioral predictors or antecedents (eg, beliefs, values, skills, attitudes), and current behaviors.⁴³ Such preparation, however, may not be feasible in that it would add time to the encounter, which is on average about 20 minutes for primary care.⁴⁴

Providing effective risk communication in the face of decreasing clinical time might be better achieved by considering additional channels for providing information. The interpersonal channels described by our participants are most commonly used⁴³; however, these channels are labor and time intensive.⁴⁵ Other channels include technologies that have been successfully used in other high-risk settings such as digital video disks and the Internet.⁴⁶ Nevertheless, even technology channels require reinforcement.⁴⁶ In that regard, information provided by these formats could be supplemented by more tailored information for each individual case.⁴⁷ Other underaddressed channels could be mass-mediated communication within the health care system that is then reinforced on an interpersonal level by individual providers.^{43,45}

Many authors have suggested specific strategies and messages for enhancing cancer risk communication,^{30,48,49} some of which use frameworks that have been successful for smoking and alcohol cessation.^{22,48} In our COP, we use an interdisciplinary approach to communicate risk. Risk estimates for melanoma recurrence are provided by the physicians, and estimates for genetic risk are provided by the physicians or the genetic risk specialist. Family history of melanoma and other cancers is assessed for every patient. Additionally, every patient receives information about melanoma risk-modifying behaviors from a health educator, who spends an average of 20 minutes delivering this information. During this encounter, patients receive a broad overview of sun protection and SSE information, along with information tailored to their specific needs. However, despite this comprehensive approach, there is currently little evidence of how such messages influence beliefs about risk and actual risk-modifying behaviors,¹⁰ particularly in high-risk individuals.

Limitations and Future Research

According to Sandelowski,²³ our strategy of using purposeful sampling was appropriate in that our participants 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 broad range of varied cases,²⁵ may have added further to the rich information contributed by our participants. We relied on participants' recollections about discussions with providers, and did not query the time since those discussions had occurred, so there was possibility for recall bias.

Future research can build upon the findings of this study. For example, in primary care settings, patients and family members could be surveyed regarding deficiencies in provider risk communication, and communication needs. This approach would allow the analysis of a greater number of patients and family members and comparisons between the two groups. Alternatively, in a comprehensive clinic setting, such as our COP, it is possible to prospectively monitor risk communication, design communication-enhancing interventions, and assess their impact on behaviors. These strategies may also be used as frameworks in the

study of other types of cancer, thus having an even broader impact. Future research should address the potential roots of the problem in greater detail, ie, time constraints, deficient provider communication skills, and the role of competency and caring. Exploring risk communication given by different types of providers may further delineate barriers to, and comprehensiveness of, this communication. Equally as important are studies targeting alternative channels to supplement information from providers. Not relying on providers to provide all information through interpersonal channels may be a wave of the future.

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Table 1.

Themes of Perceived Health Care Provider Risk Communication

•"A Passing Interest": Not Much Talk About Risk
•"The Health Care System Gets in the Way": System-Based Constraints on Communication
•"I Trust Them to Give Me Knowledge": Wanting Accurate and Understandable Melanoma Information
•"Is It Cancer?": Desiring Competent and Caring Communication

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