



Published in final edited form as:

Arch Dermatol. 2008 April ; 144(4): 553–554. doi:10.1001/archderm.144.4.553.

Family Communication After Melanoma Diagnosis

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Physicians often recommend that melanoma survivors discuss family-wide physician skin screening and sun protection.¹ Family discussions about melanoma are prevalent² and can potentiate screening and sun protection.^{3,4} The goals of the current study are to examine processes that enhance or discourage communication about melanoma in affected families.

Methods

We recruited patients with melanoma at surgical follow-up 3 to 18 months after diagnosis of the disease. Eligible patients (English proficient; age 18 years; non-stage IV; with at least 1 child age 18 years) were approached by their surgeon and a research study assistant. Interested patients attended the study interview with one of their adult children. Nineteen family pairs (adult child and patient with melanoma) were accrued from 74 eligible families approached (Table). Patients reported choosing the child they did because the child lived locally, was seen as being at risk, or followed a health-oriented lifestyle. The qualitative study procedure involved 4 steps. Step 1 was a 5-minute, unstructured conversation to examine family health communication processes. This was followed by a semistructured interview to determine family melanoma communication processes with both the patient (step 2) and adult child (step 3), and an interview including both family members (step 4) to assess consensus on family communication about melanoma (exact questions available from J. H.). Interviews lasted 2 hours and were videotaped and audiotaped and transcribed. Guided by Grounded Theory, a common approach to developing novel social science theory from narrative data,⁵ we analyzed 4 interview transcripts per family (76 transcripts). We first developed a codebook through consensus coding (4 raters) of the first 12 transcripts; individual raters coded subsequent transcripts, and revisions to the codebook were resolved by team consensus.

Results

Our findings reveal that family discussions about melanoma are guided by an implicit set of rules that determine what is discussed, when the conversations occur, as well as who is engaged.

Initiators of Family Discussions

Women tend to be the primary initiators of discussions about melanoma diagnosis, treatment, and prevention. Accordingly, the patient's spouse, daughter, or female patients themselves often take the lead in discussing melanoma topics in the family. As such, women are likely to spread the word through the family system that there has been a melanoma

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Financial Disclosure: None reported.

diagnosis, and they are also most likely to follow through with recommending sun protection and physician screening to children, siblings, and other family members.

Facilitators and Barriers of Discussions

Disease, individual, and family-specific factors play a role in shaping discussions about melanoma. Patients who do not believe that their melanoma was caused by sun exposure or genetic factors see less of a need to discuss it.¹ Patients who developed melanoma on a non-sun-exposed body site shared less about their disease and prevention, and discussions were more likely to occur when melanoma is perceived to “run in the family.” Those families who describe themselves as health conscious engage in more discussions. Patients often avoid discussions out of a desire to minimize fear about the disease occurring in the family and if they perceive that it is “not their place” to discuss prevention. Degree of closeness—emotional or geographical—also dictates whether and when discussions occur.

Content of Discussions

Families report that their discussions about melanoma evolve across time. At first, family conversations typically focus primarily on the patient, including diagnosis and the treatment planned. Family members often turn to the Internet during this time to supplement information learned from the patient or their physician; this is especially true when patients or family members have a desire to obtain information that is potentially upsetting. After the resolution of this acute treatment phase, conversations about family risk and prevention predominate. Discussion goals become firmly centered on avoiding recurrence in the patient or avoiding the illness in unaffected family members, particularly children. Discussion content included scare tactics as well as daily in-the-moment reminders about sun protection.

Targets of Melanoma Discussions

Family members report extensive deliberation concerning which family members are most at risk for melanoma, and these family members are singled out for more intensive family conversations about prevention. Discussion targets include blood relatives, relatives with stronger perceived genetic susceptibility, those with lighter skin, those whose severe sunburns are vividly remembered, and those who currently sunbathe and use tanning salons.

Comment

Understanding how discussion rules operate within families may help guide physicians' recommendations to families with melanoma and shape physicians' expectations for what these recommendations may accomplish. Physicians should consider asking their patients to identify a “family initiator” to take responsibility for conveying melanoma risk information and to aid in family follow-through with screening appointments and sun protection. Factors such as lesion site, family perceptions of genetic susceptibility, and family health orientation and degree of closeness may be important to consider as physicians discuss the importance of family prevention and early detection strategies. Identifying patients' beliefs and misconceptions concerning the causes of their disease may open lines of family communication considerably. Physicians may want to consider family receptivity and appropriate timing for recommendations about prevention and early detection and to elicit family reports concerning types of discussions that have or have not occurred already in the family. Finally, physicians may want to elicit family-specific ways of targeting family members to assess any needs for families to broaden their communication reach. Certainly, the results presented herein should be interpreted with caution given the small sample size assessed and the lack of demographic background data. Likely response biases include the fact that participating families tended to be communicative; even so, we document many

factors related to communication avoidance. In melanoma and other cancers, families are a key venue for dissemination of risk and prevention information.⁶ Given the fact that first-degree relatives of patients with melanoma are not highly adherent to prevention and early detection behaviors,^{7–9} these rules warrant consideration by physicians as well as intervention researchers.

Acknowledgments

Funding/Support: This study was supported in part by National Institutes of Health grant K07 CA98106.

Role of the Sponsors: The sponsors had no role in the design and conduct of the study, in the collection, analysis, and interpretation of data, or in the preparation, review, or approval of the manuscript.

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Table

Participant Characteristics

Characteristic	Mean (Range)	No. (%)
Patients (n=19)		
Sex		
Male		11 (58)
Female		8 (42)
Race		
White		19 (100)
Extent of disease		
Clinically localized		16 (84)
Locally advanced		3 (16)
Breslow depths, mm		
0–0.75		7 (37)
0.75–1.5		4 (21)
1.5–4.0		5 (27)
>4.0		2 (10)
Missing information		1 (5)
Age, y	64 (53–85)	
Adult children (n=19)		
Sex		
Male		9 (47)
Female		10 (53)
Age, y	33 (18–54)	
Families (n=19)		
Constellation ^a		
Patients with >1 child		13 (68)
Patients with grandchildren		11 (58)
Sex		
Male patient and male adult child		5 (26)
Male patient and female adult child		6 (32)
Female patient and male adult child		4 (21)
Female patient and female adult child		4 (21)

^aConstellation categories are not mutually exclusive.