ONLINE FIRST

Communication About Family Members' Risk of Melanoma

Self-reported Practices of Dermatologists in the United States

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Objectives: To assess current self-reported communication and screening practices of dermatologists to their patients with melanoma about family members' risk of melanoma at the time of diagnosis and to understand the barriers that dermatologists encounter in communicating risk to patients.

Design: Descriptive survey study.

Setting: Office-based practicing physicians in the United States.

Participants: One thousand dermatologists.

Main Outcome Measure: Melanoma risk communication practices.

Results: Of 974 eligible dermatologists, 406 completed the survey (response rate, 41.7%). Almost 85% of dermatologists reported that they often or always communicate risk to patients with melanoma about their first-degree relatives, and almost 80% reported that they often or always advise their patients with melanoma that their older children (≥18 years) may be at greater risk of skin cancer. However, less than 50% of dermatologists routinely offered to screen first-degree relatives who live nearby, while only 19.7% used medical record reminders to note communication of melanoma risk to family members. Most dermatologists reported no major barriers to melanoma risk communication. However, the presence of "any risk communication barrier" (time constraints, absence of guidelines, or lack of written material) was associated with reduced melanoma risk communication practices by dermatologists.

Conclusions: The observed high rates of self-reported risk communication by dermatologists to patients with melanoma about their first-degree family members are encouraging. However, the reported low rates of actual screening of first-degree relatives warrant easy-to-administer office-based medical record reminders to facilitate and optimize screening of at-risk relatives.

Arch Dermatol. 2012;148(5):621-627.
Published online January 16, 2012.
doi:10.1001/archdermatol.2011.2515

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In 2011, an estimated 70 230 persons in the United States were diagnosed as having invasive melanoma, and there were 8790 associated deaths.[1] An individual with a first-degree relative diagnosed as having melanoma has a greater likelihood of developing melanoma than an individual with no family history. It has been estimated that 5% to 12% of patients with melanoma have a family history of the disease.[2-4] The National Institutes of Health recommend that patients with atypical moles and a positive family history of melanoma (≥1 other affected family member) should be closely followed up by a physician owing to their unusually high risk of developing melanoma.[5-7] The National Institutes of Health also advise an initial screening of first-degree family members for all patients with melanoma[8,9] because thorough skin cancer screening by dermatologists has resulted in the detection of thinner melanomas among individuals who are being observed because of increased risk as family members.[5,8-12] Early identification of melanoma while the lesion is still thin is key in reducing mortality because lesion thickness is an important prognostic factor for melanoma[13] and because patients who have thinner lesions have a better chance of surviving the disease.[14]

Dermatologists can potentially have a crucial role during the "teachable moment" in communicating melanoma risk to their patients, but little is known about skin cancer risk communication practices among dermatologists. When the initial diagnosis of melanoma is made, dermatologists can take this opportunity to educate patients about skin cancer risk

Table 1. Demographic, Practice, and Clinical Characteristics of Responding Dermatologists

Characteristic	Value (n = 406)
Age, mean (SD), y	50.4 (10.6)
Sex, No. (%)	
Male	233 (57.4)
Female	173 (42.6)
Physician type, No. (%)	
Doctor of medicine	391 (96.3)
Doctor of osteopathy	15 (3.7)
Teaching responsibilities, No. (%)	
Residents	185 (45.6)
Medical students	129 (31.8)
Unknown	92 (22.7)
Health care provider in the practice who communicates skin cancer risk to family members of patients, No. (%)	
Physician	378 (93.1)
Nurse	73 (18.0)
Medical assistant	69 (17.0)
Physician assistant	58 (14.3)
Resident	19 (4.7)
Medical student	6 (1.5)
Nurse practitioner	5 (1.2)
Use of medical record reminders to communicate risk, No. (%)	
No	302 (74.4)
Yes	80 (19.7)
Unknown	24 (5.9)
Melanomas diagnosed per year, mean (SD), median, No.	20.5 (24.7) 15

based on family history and to recommend that family members should be screened.[15,16] This survey of US dermatologists sought to assess current self-reported communication and screening practices of dermatologists to their patients with melanoma about family members' risk of melanoma at the time of diagnosis and to understand the barriers that dermatologists encounter in communicating risk to patients.

METHODS

SURVEY SAMPLE

The American Medical Association's Medical Marketing Service, Inc[14] database contains a representative sample of office-based practicing physicians by specialty and by US state. A random sample of 1000 board-certified US dermatologists was selected from this database. The use of the sampling contact information was approved by the Medical Marketing Service, Inc. The study was approved by the institutional review board at Memorial Sloan-Kettering Cancer Center. Eligibility for inclusion in the study sample required that the physician was practicing and had a valid postal mailing address.

SURVEY INSTRUMENT AND ADMINISTRATION

The survey instrument was developed by experts in dermatology (A.C.H.), skin cancer screening (S.A.O., A.C.H., and A.C.G.), epidemiology (S.A.O., J.L.H., and A.C.G.), and survey design (S.A.O. and J.L.H.). The 12-question survey instrument assessed self-reported risk communication practices of dermatologists to their patients at the time of skin cancer diagnosis. Specifically, questions were asked about whether physicians taught a patient how to perform a full-body skin self-examination, advised patients about increased risk of skin cancer in their first-degree relatives and children, offered to screen patients' first-degree relatives who live nearby, or advised the use of sun protection for their children. Responses were elicited by asking physicians to categorize their answers as never, rarely, sometimes, often, or always (reported as routinely). Information on barriers to communicating melanoma risk to family members was assessed by asking physicians to indicate if the proposed example was a minor, moderate, or major barrier. Specific barriers included time constraints, absence of standardized guidelines, difficulty in translating scientific information, lack of confidence in the ability to communicate risk, lack of patient demand for risk information, nonresponsibility for communication, and hesitancy to cause the patient worry. Clinical practice characteristics were obtained on the physician's demographics (age and sex), his or her teaching responsibilities, the number of melanoma cases diagnosed per year, and the person in the office who communicates risk to patients. Because it was of interest to determine how dermatologists communicate melanoma risk in families to patients who may have young and adolescent children, the questions were limited to the following 2 specific patient age categories: 25 to 44 years and 45 to 64 years. Furthermore, based on existing communication literature,[17-21] dermatologists may be communicating differently to female vs male patients. Therefore, sex categories specific to each question were included. An initial questionnaire and 2 follow-up mailings were sent via postal mail between March 1 and May 31, 2008.

DATA ANALYSIS

Descriptive statistics were calculated to report dermatologists' demographics, practice characteristics, survey response rates, communication practices, and barriers to risk communication. To assess potential differences between responders and nonresponders, *t* test was used for continuous variables, such as age, and χ^2 test was used for categorical variables, such as sex and physician type (doctor of medicine vs doctor of osteopathy). Univariate logistic regression analyses were conducted to explore the relationship between each outcome of interest related to risk communication practices and selected covariates. Odds ratios (95% CIs) are presented. For the variables of age and the number of melanoma cases diagnosed per year, categories were created based on quartile distributions to allow for statistical robustness and the estimation of odds ratio variables. The interpretation of the odds ratio for the outcome of interest is the odds of reporting "often or always" to communication of these practices to patients.

RESULTS

PARTICIPANT CHARACTERISTICS

Of 1000 dermatologists who were contacted, 26 were ineligible because of the following reasons: the survey was returned to the sender with no forwarding address (n=17), the dermatologist was no longer practicing or was retired (n=8), or the dermatologist was deceased (n=1). Therefore, there were 974 eligible dermatologists; of these, 406 completed the survey (response rate, 41.7%). Characteristics of the responding dermatologists are summarized in **Table 1**.

Differences between 594 dermatologists who did not respond and 406 dermatologists who completed the survey

Table 2. Melanoma Risk Communication Practices by Responding Dermatologists[a]

Soon After Patients Are Diagnosed as Having Their First Melanoma, Do You or a Member of Your Health Care Team	No. (%) (n = 406)		
	Never or Rarely	Sometimes	Often or Always
Teach the patient how to perform a full-body skin self-examination?			
25-44 y, Female	39 (9.6)	33 (8.1)	333 (82.0)
25-44 y, Male	39 (9.6)	34 (8.4)	330 (81.3)
45-64 y, Female	38 (9.4)	35 (8.6)	330 (81.3)
45-64 y, Male	39 (9.6)	37 (9.1)	327 (80.5)
Ask if the patient has first-degree relatives?			
25-44 y, Female	27 (6.7)	31 (7.6)	348 (85.7)
25-44 y, Male	27 (6.7)	30 (7.4)	347 (85.5)
45-64 y, Female	27 (6.7)	32 (7.9)	345 (85.0)
45-64 y, Male	28 (6.9)	32 (7.9)	344 (84.7)
Advise the patient that his or her first-degree relatives may be at greater risk of skin cancer?			
25-44 y, Female	22 (5.4)	40 (9.9)	342 (84.2)
25-44 y, Male	22 (5.4)	40 (9.9)	342 (84.2)
45-64 y, Female	24 (5.9)	44 (10.8)	335 (82.5)
45-64 y, Male	26 (6.4)	43 (10.6)	334 (82.3)
Offer to screen the patient's first-degree relatives who live nearby?			
25-44 y, Female	98 (24.1)	112 (27.6)	192 (47.3)
25-44 y, Male	98 (24.1)	112 (27.6)	190 (46.8)
45-64 y, Female	104 (25.6)	112 (27.6)	184 (45.3)
45-64 y, Male	104 (25.6)	113 (27.8)	183 (45.1)
Ask if the patient has children?			
25-44 y, Female	33 (8.1)	69 (17.0)	303 (74.6)
25-44 y, Male	36 (8.9)	68 (16.7)	299 (73.6)
45-64 y, Female	32 (7.9)	69 (17.0)	302 (74.4)
45-64 y, Male	36 (8.9)	71 (17.5)	296 (72.9)
Advise the patient that he or she should make special effort to use sun protection for his or her children who are <18 y?			
25-44 y, Female	17 (4.2)	20 (4.9)	368 (90.6)
25-44 y, Male	21 (5.2)	24 (5.9)	358 (88.2)
45-64 y, Female	36 (8.9)	25 (6.2)	342 (84.2)
45-64 y, Male	41 (10.1)	29 (7.1)	333 (82.0)
Advise the patient that his or her children who are ≥18 y may be at greater risk of skin cancer?			
25-44 y, Female	25 (6.2)	45 (11.0)	332 (81.8)
25-44 y, Male	24 (5.9)	46 (11.3)	329 (81.0)
45-64 y, Female	25 (6.2)	49 (12.1)	325 (80.0)
45-64 y, Male	27 (6.7)	51 (12.6)	321 (79.1)
Advise the patient that his or her children who are ≥18 y should be making special efforts to use sun protection?			
25-44 y, Female	31 (7.6)	32 (7.9)	339 (83.5)
25-44 y, Male	29 (7.1)	37 (9.1)	334 (82.3)
45-64 y, Female	33 (8.1)	39 (9.6)	327 (80.5)
45-64 y, Male	35 (8.6)	43 (10.6)	321 (79.1)

[a]Some categories do not total 100% because of missing or incomplete responses.

were explored. A higher proportion of female physicians responded compared with male physicians (42.6% vs 35.5%, $P = .02$). No important differences were noted between responders and nonresponders for age or physician type.

COMMUNICATION ABOUT FAMILY MEMBERS' RISK TO PATIENTS WITH MELANOMA

Self-reported melanoma risk communication practices by responding dermatologists are summarized in **Table 2**. Between 82.3% and 84.2% of dermatologists reported that they often or always communicate risk to patients with melanoma about their first-degree relatives. Almost 80% of dermatologists routinely advised their patients with melanoma that their older children (≥18 years) may be at greater risk of skin cancer. However, only 45.1% to 47.3% of dermatologists routinely offered to screen first-degree family members who live nearby. Risk communication practices to patients with melanoma about their first-degree relatives and older children did not differ systematically by patient age or sex.

About 82% of dermatologists reported routinely teaching their patients with melanoma at the time of melanoma diagnosis how to perform a full-body skin self-

Table 3. Barriers to Melanoma Risk Communication by Responding Dermatologists[a]

Barrier	No. (%) (n = 406)			
	Not a Barrier	Minor Barrier	Moderate Barrier	Major Barrier
Time constraints, no time to follow up with first-degree relatives	190 (46.8)	92 (22.7)	84 (20.7)	28 (6.9)
Absence of standardized guidelines	183 (45.1)	127 (31.3)	70 (17.2)	18 (4.4)
Lack of written material	208 (51.2)	114 (28.1)	60 (14.8)	17 (4.2)
Time constraints, no time to talk about risk	227 (55.9)	107 (26.3)	50 (12.3)	16 (3.9)
Difficulty in translating scientific information	311 (76.6)	64 (15.8)	16 (3.9)	8 (2.0)
Lack of confidence in ability to communicate risk	343 (84.5)	45 (11.1)	8 (2.0)	4 (1.0)
Lack of patient demand for risk information	310 (76.3)	62 (15.3)	21 (5.2)	4 (1.0)
Unsure at which patient visit to raise risk issue	317 (78.1)	64 (15.8)	15 (3.7)	2 (0.5)
Not my responsibility to advise sun protection for patients' children	375 (92.4)	16 (3.9)	2 (0.5)	2 (0.5)
Not my responsibility to communicate risk	380 (93.6)	12 (3.0)	2 (0.5)	2 (0.5)
Do not want to cause undo worry to patients	322 (79.3)	54 (13.3)	20 (4.9)	2 (0.5)

[a]Some categories do not total 100% because of missing or incomplete responses.

examination. Less than 10% stated that they did this never or rarely.

Sun protection advice to patients with melanoma having young children (<18 years) was routinely communicated by almost 80% of dermatologists. Communication did not vary significantly by patient age or sex.

BARRIERS TO MELANOMA RISK COMMUNICATION FOR FAMILY MEMBERS

Barriers to melanoma risk communication are summarized in **Table 3**. Overall, 309 dermatologists (76.1%) reported no major barriers to risk communication for family members (data not shown). Dermatologists identified moderate barriers. Seven percent of respondents cited time constraints to follow up with first-degree relatives as a major barrier. Four other barriers, including absence of standardized guidelines and lack of written material, were ranked as moderate barriers by at least 12% of respondents.

VARIABLES RELATED TO MELANOMA RISK COMMUNICATION PRACTICES

Table 4 gives univariate logistic regression analysis estimates for melanoma risk communication practices and important covariates, including barriers. Physician age, absence of standardized guidelines, lack of written material, time constraints, and the use of medical record reminders were important variables related to melanoma risk communication practices. Although not all estimates reached statistical significance, the 95% CIs are consistent with an association. Specifically, for most of the outcomes of interest, older physician age was associated with greater likelihood of melanoma risk communication to patients. The use of medical record reminders was positively associated with melanoma risk communication practices. Absence of standardized guidelines, lack of written material, and time constraints decreased the likelihood of physicians' communicating melanoma risk to patients. The number of melanoma cases diagnosed per year by physicians was not associated with an increased likelihood of providing risk communication to patients.

The presence of "any risk communication barrier" (time constraints, absence of guidelines, or lack of written material) was associated with reduced melanoma risk communication practices by dermatologists. These results are summarized in Table 4.

COMMENT

Implicit in screening recommendations for high-risk individuals is the need for effective communication between physicians and their patients. Effective risk communication may optimize screening rates among patients diagnosed as having skin cancer and those at high risk, as well as among at-risk relatives.[22] However, to date no national studies have been published reporting the rates of counseling among dermatologists to patients about skin cancer risk for family members or reporting their screening rates of first-degree relatives.

In this study, the objective was to evaluate whether dermatologists routinely discuss skin cancer risk for family members of their patients with melanoma. Findings showed that most respondents reported that they routinely advise patients that their first-degree relatives and children may be at greater risk of skin cancer. However, less than half of dermatologists offered to screen first-degree relatives who live nearby. Disturbingly, these low rates are consistent with study[23] findings reported in 1992 among New England dermatologists. In the earlier study, most dermatologists encouraged screening of first-degree relatives among their patients with melanoma, but physicians perceived that family members infrequently accepted these recommendations. In the present study, more than 20% of respondents reported that time constraints and absence of standardized guidelines were moderate or major barriers to following up with first-degree relatives.

In this study, few respondents (19.7%) used medical record reminders to note communication of melanoma risk to family members. Paper and computer-based medi-

Table 4. Univariate Logistic Regression Analysis Estimates for Melanoma Risk Communication Practices

Characteristic of Responding Dermatologist or Barrier to Melanoma Risk Communication	Odds Ratio (95% CI)[a]					
	Teach the Patient How to Perform a Full-Body Skin Self-examination	Advise the Patient That His or Her First-Degree Relatives May Be at Greater Risk of Skin Cancer	Offer to Screen the Patient's First-Degree Relatives Who Live Nearby	Advise the Patient That He or She Should Make Special Effort to Use Sun Protection for His or Her Children Who Are <18 y	Advise the Patient That His or Her Children Who Are ≥18 y May Be at Greater Risk of Skin Cancer	Advise the Patient That His or Her Children Who Are ≥18 y Should Be Making Special Efforts to Use Sun Protection
Melanomas diagnosed per year, No.						
1-9	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
10-14	0.45 (0.18-1.10)	1.43 (0.48-4.31)	0.99 (0.52-1.90)	2.52 (0.98-6.53)	1.24 (0.43-3.59)	4.80 (1.31-17.64)
15-24	1.55 (0.52-4.66)	3.20 (0.82-12.46)	1.39 (0.72-2.69)	3.86 (1.34-11.12)	2.41 (0.70-8.28)	3.01 (1.01-8.92)
≥25	1.82 (0.57-5.79)	1.82 (0.57-5.79)	1.17 (0.61-2.26)	3.05 (1.13-8.25)	1.80 (0.57-5.74)	1.51 (0.60-3.79)
Age, y						
31-40	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
41-50	5.79 (1.56-21.43)	1.22 (0.39-3.76)	1.07 (0.57-2.03)	3.71 (1.36-10.08)	3.99 (1.21-13.17)	1.68 (0.70-4.02)
51-60	1.00 (0.44-2.31)	1.41 (0.44-4.52)	0.97 (0.52-1.83)	2.11 (0.89-5.00)	2.57 (0.90-7.36)	3.17 (1.14-8.81)
≥61	1.06 (0.41-2.72)	1.04 (0.30-3.54)	0.74 (0.37-1.47)	2.21 (0.80-6.06)	1.86 (0.61-5.73)	2.92 (0.90-9.48)
Teaching responsibilities	0.70 (0.36-1.37)	0.89 (0.39-2.02)	1.29 (0.82-2.03)	1.26 (0.63-2.53)	0.96 (0.43-2.17)	3.02 (1.33-6.88)
Male sex	0.99 (0.50-1.95)	0.43 (0.17-1.11)	0.89 (0.56-1.40)	1.09 (0.55-2.17)	0.41 (0.16-1.05)	1.32 (0.64-2.69)
Use of medical record reminders to communicate risk	1.73 (0.65-4.60)	5.97 (0.79-45.06)	1.23 (0.68-2.20)	2.87 (0.85-9.63)	3.07 (0.71-13.3)	1.07 (0.42-2.70)
Time constraints, no time to talk about risk						
No	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Yes	0.62 (0.31-1.22)	0.52 (0.23-1.21)	0.62 (0.39-0.97)	0.66 (0.33-1.32)	0.49 (0.21-1.12)	0.80 (0.39-1.64)
Time constraints, no time to follow up with first-degree relatives						
No	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Yes	0.90 (0.46-1.77)	0.52 (0.22-1.24)	0.57 (0.36-0.91)	0.53 (0.26-1.11)	0.40 (0.16-0.97)	1.09 (0.53-2.24)
Absence of standardized guidelines						
No	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Yes	0.35 (0.16-0.76)	0.33 (0.12-0.91)	0.42 (0.26-0.67)	0.38 (0.17-0.84)	0.22 (0.07-0.65)	0.26 (0.10-0.65)
Lack of written material						
No	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Yes	0.41 (0.20-0.84)	0.53 (0.23-1.25)	0.64 (0.41-1.01)	0.38 (0.18-0.79)	0.50 (0.21-1.15)	0.70 (0.34-1.44)
Presence of any risk communication barrier						
No	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Yes	0.81 (0.36-1.84)	0.13 (0.02-1.01)	0.44 (0.24-0.80)	0.17 (0.04-0.74)	0.12 (0.02-0.91)	0.30 (0.09-1.01)

[a] Odds of responding dermatologists' reporting "often or always" to communication of these practices to patients.

cal record reminders have been shown to increase the delivery of preventive care services.[24-26] Recording family screening in the medical record, developing a reminder system to facilitate screening, distributing literature on melanoma risk because of a family history, and, most important, offering to screen first-degree relatives who live nearby should increase compliance among these high-risk individuals. Furthermore, in-depth qualitative studies could explore ways to help dermatologists improve and maximize communication with patients.

Physicians were queried about screening first-degree relatives who live close by in an effort to identify relatives who would have an opportunity to be screened. Less than 50% of dermatologists routinely offered to screen first-degree relatives who live nearby. Communication to patients about their first-degree relatives can optimize screening of the at-risk relatives and works to increase awareness of risk and improve sun protection behaviors.[23,27-30] Hay et al[31] described the importance of family communication after a melanoma diagnosis.

On average, dermatologists in this study diagnosed about 15 melanomas per year. At the time of melanoma diagnosis or soon afterward, this potentially teachable moment can be used to alert patients to the risk of melanoma in their first-degree relatives and the compelling need to be screened. Communicating family risk deserves special attention because first-degree relatives are about 2 to 8 times more likely than the general population to be diagnosed as having melanoma during their lifetime.[32] Educational efforts using risk communication strategies can lead to positive outcomes.[9] In a study[9] of families with melanoma, 14 families with melanoma and dysplastic nevus syndrome underwent skin cancer screening and surveillance; 96% of family members reported that they had examined their skin thoroughly in the previous 2 months, and about 80% reported that they had been examined by a physician for skin cancer. In addition, the melanomas that were detected during the study were much thinner than lesions that had been found before the onset of the educational surveillance.

Given that time constraints were the most frequently cited barrier to risk communication, minimizing the burden through the assistance of nonphysician health care providers could improve office-based communication practices. Less than 20% of dermatologists reported that nonphysician health care providers were responsible for communicating skin cancer risk to family members of patients in their practice. Among these data, we examined risk communication and screening practices of physicians alone vs physicians plus physician extenders, such as physician assistants or nurses. There was little difference in risk communication practices between physicians alone vs physicians plus physician extenders.

Health risk communication is an emerging concept of contemporary medicine.[33] Rather than the traditional physician-patient relationship that was predicated on patients' obediently adhering to their physician's orders, many patients now demand more information. Information empowers patients, allows them to make informed decisions, and may reassure and prevent unnecessary anxiety.[34,35] In fact, patients who receive more information from their physicians are more satisfied and more likely to follow medical regimens.[36]

This study has several limitations. First, the findings may not reflect actual practices of dermatologists; communication practices reported herein may be inflated because physicians tend to overestimate their prevention efforts.[37] The sample may not represent the general community of dermatologists in the United States because 45.6% of physicians who responded teach residents, which suggests that academic dermatologists responded to the survey. Future research could be improved by conducting validation studies of self-reported physician behavior, such as surveying both physicians and patients after an encounter or videotaping actual encounters, which has been done to understand recommendations for colorectal cancer screening.[38] Second, bias is a concern because the response rate was only 41.7%, and it cannot be inferred that practices are similar among nonrespondents. Third, responding dermatologists were slightly younger than nonresponding dermatologists. Therefore, communication practices reported herein may not accurately reflect practices of the general dermatologist community, particularly those of older dermatologists.

In summary, these findings highlight the need for improved risk communication by dermatologists to patients with melanoma about their first-degree family members. Targeting patients with cancer and their at-risk relatives in health education intervention strategies has proven to be successful.[39-42] Enhancing communication of melanoma risk for family members by dermatologists could reduce the public health burden of the disease, optimize screening of at-risk relatives, and serve as a model for other cancers with high family risk, such as prostate, breast, and colorectal cancer.

Accepted for Publication: October 21, 2011.
Published Online: January 16, 2012. doi:10.1001/archdermatol.2011.2515
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Financial Disclosure: None reported.
Funding/Support: This research was supported by a grant from the Harry J. Lloyd Charitable Trust Foundation.
Role of the Sponsor: The Harry J. Lloyd Charitable Trust Foundation had no role in the design or conduct of the study; in the collection, analysis, or interpretation of data; or in the preparation, review, or approval of the manuscript.
Additional Contributions: Stephen W. Dusza, PhD, assisted with statistical programming. We thank the dermatologists who completed our survey.

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