Patterns and sources of information about family melanoma risk among melanoma survivors

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Summary points

Aim

- Melanoma survivors play a role in raising risk awareness throughout the family.
- The current study examines patterns and predictors of awareness of family risk in melanoma survivors drawn from the general population.

Patients & methods

- Melanoma survivors (n = 170) were recruited from a population-based New Jersey State Registry.
- Interested participants completed a 15-min telephone interview.
- The interview included questions about survivor's awareness of melanoma risk in their first-degree relatives (FDRs), sources of awareness and potential covariates of awareness (demographic, melanoma disease characteristics, phenotypic and psycho/behavioral factors).
- A series of univariable and multivariable logistic regressions examining covariates were conducted using awareness (yes vs no) of heightened risk to FDRs as the dependent variable.

Results

- Almost half (41%) were unaware that their FDRs faced heightened melanoma risk.
- Of those 59% who were aware, 71% were told and 13% found out by asking about it.
- The predominant sources for this information were physicians, including dermatologists (61%) and oncologists (9%).
- In multivariable analyses adjusting for demographics, melanoma disease characteristics, phenotypic and psycho/behavioral factors, perceived risk and body site remained significant such that those with higher risk perceptions and melanoma not on the head and neck, had higher awareness.

Conclusion

- A sizable proportion of melanoma survivors remain unaware that their FDRs are at risk for melanoma.
- The results underscore the important role that dermatologists play in fostering increased risk awareness.
- Sensitivity to providing family risk information to melanoma survivors who have lower risk perceptions, regardless of anatomic site, is warranted.

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Aim: Melanoma survivors can play a pivotal role in raising family melanoma risk awareness, but are not always aware of family risk. This study examines patterns and sources of survivors' awareness that first-degree relatives (FDRs) face heightened melanoma risk. **Patients & methods:** Population-based melanoma survivors ($n = 170$) completed a 15-min telephone interview. Logistic regressions examining covariates were conducted using awareness (yes vs no) of heightened risk to FDRs as the dependent variable. **Results:** Almost half (41%) were unaware that their FDRs faced heightened melanoma risk. Of those 59% who were aware, most learned this from dermatologists. In multivariable analyses perceived risk and body site remained significant. **Conclusion:** Many melanoma survivors remain unaware that their FDRs are at melanoma risk. The results underscore the role that dermatologists and other doctors play in fostering risk awareness. Sensitivity to providing family risk information to survivors who have lower risk perceptions, regardless of anatomic site, is warranted.

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KEYWORDS

- information sources
- melanoma risk in first-degree relatives
- melanoma survivors
- risk awareness

Aim

Awareness of personal melanoma risk prompts melanoma risk reduction and screening [1]. First-degree relatives (FDRs) of melanoma patients are at a two-fold increased risk of developing melanoma compared with the general population [2]. Melanoma survivors play an important role in raising family risk awareness [3]. Physicians are well positioned to educate melanoma survivors and FDRs concerning heightened family risk. Dermatologists, in particular, report that they frequently discuss family risk in melanoma patient encounters [4]. Such discussions can address informational inaccuracies and lead survivors to discuss melanoma risk and prevention with their families [3]. The purpose of the current population-based study was to examine melanoma survivors' awareness that their FDRs faced heightened melanoma risk, and to examine patterns of awareness across relevant demographic, medical and psychosocial factors. The findings will direct the development of interventions to increase family risk awareness in melanoma survivors across the general population, and to specifically address deficits in family risk awareness among any subgroups identified.

Patients & methods

In 1998–2000, melanoma survivors ($n = 329$) were recruited from the population-based New Jersey State Registry for the Genes, Environment and Melanoma study, a case–control study looking at genetics and environmental risk factors for melanoma at nine sites worldwide [5]. In this study, multiple primary melanoma participants were designated as 'cases' and single primary

melanoma participants were designated as 'controls'. Participants were recontacted by letter in 2006–2007 to request their participation and informed consent for a 15-min telephone interview. All study procedures were approved by the Institutional Review Board at Memorial Sloan–Kettering. Interviews were conducted with 170 participants (52% response rate). Reasons for nonparticipation included being unreachable (26%), deceased (8%), having medical issues (1%) and refusal (13%).

Survivor's awareness of melanoma risk in FDRs, and sources of that awareness, were evaluated. These items were derived from prior research [6], and included: "Have you ever been told that your FDRs (children, siblings and parents) are at an increased risk for developing melanoma?" Response categories were yes/no. If the answer to this first question was 'yes', participants were asked, "Did you find out about this increased risk by asking that person, or did that person tell you?" Finally, if the answer to the first question was 'yes', participants were asked, "Where did you learn of this?" Response categories included the following nonmutually exclusive options: primary care provider, dermatologist, oncologist, family member, friend, media and other.

Our statistical approach involved the following. Potential covariates of risk awareness (yes vs no) were examined, including demographic, melanoma disease characteristics, phenotypic and psycho/behavioral factors (perceived recurrence risk, recurrence concern, sun protection and screening). A series of univariable and multivariable logistic regressions examining covariates were conducted in SPSS using awareness

Table 1. Demographic, disease and phenotypic characteristics of the sample (n = 170).

Variable	n	%
Demographic factors		
Age at recruitment (average: 55.8 years, standard deviation: 14.1, range: 16–84):		
– ≤60 years	98	58
– >60 years	72	42
Gender:		
– Male	87	51
– Female	83	49
Education:		
– Less than high school	5	2.9
– High school graduate	37	21.8
– Partial college	40	23.5
– College graduate	52	30.6
– Graduate training	35	20.6
Phenotypic variables		
Skin color:		
– Fair	112	65.9
– Very fair	46	27.1
– Light olive	12	7.0
Eye color:		
– Blue	74	43.5
– Green	15	8.8
– Gray	1	0.6
– Hazel	47	28
– Brown	32	18.8
– Missing	1	0.6
Hair color:		
– Blonde/fair	40	23.5
– Light brown	60	35.3
– Dark brown	48	28.2
– Black	2	1.2
– Red	19	11.2
– Missing	1	0.6
Presence of freckles:		
– None	68	40.0
– Few	81	47.6
– Many	20	11.8
– Missing	1	0.6
Mole number (on back):		
– 0–4	47	27.6
– 5–10	41	24.1
– 11–15	47	27.6
– >25	28	16.5
– Missing	7	4.1
Sunburn:		
– None/light burn	87	51
– Burn easily/peel	71	42
– Missing	12	7
Tanning ability:		
– Freckle/occasionally	73	43

Table 1. Demographic, disease and phenotypic characteristics of the sample (n = 170) (cont.).

Variable	n	%
Tanning ability (cont.):		
– Deeply/moderately	90	53
– Missing	7	4
Breslow depth at diagnosis (average: 0.72 mm, standard deviation: 1.02, range: 0.0–5.0):		
– <i>In situ</i>	16	9.4
– Less than 0.75 mm	44	25.9
– Greater than 0.76 mm	8	4.7
– Greater than 1.5 mm	9	5.3
– Missing	93	54.7
Status:		
– Single melanoma	85	50
– Multiple melanoma	85	50
Tumor site:		
– Trunk/pelvis	66	38.8
– Arms	38	22.4
– Legs	35	20.6
– Head/neck	31	18.2
History of nonmelanoma skin cancer:		
– Yes	18	10.6
– No	152	89.4
Family history of melanoma:		
– Yes	37	21.8
– No	132	77.6
– Missing	1	0.6

(yes vs no) of heightened risk to FDRs as the dependent variable. The covariates found to be significant at the univariate level of analysis were considered in the multivariate logistic regression.

Results

The population-based sample included 50% with single primary melanoma and 50% with second/subsequent primary melanoma, and were equally split on gender (51% men); they were on average age 56 years, and 75% reported educational attainment beyond high school. Most participants had phenotypic melanoma risks such as fair skin (93%) and moles on the back (44% had five or more); 22% had a family melanoma history (Table 1).

Almost half (41%) were unaware that their FDRs faced heightened melanoma risk. Of those 59% who were aware, 71% were told, 13% found out by asking and 4% both asked and were told; 4% could not recall and 8% reported longstanding awareness of the risk to their FDRs. The predominant sources for this information were physicians, including dermatologists (61%), oncologists (9%)

and primary care providers (2%). Other sources included family members (8%) and media (6%). One-third of those aware (31%) reported having secondary sources of melanoma risk information including magazines, newspapers, prior participation in the Genes, Environment and Melanoma Study and family melanoma diagnoses. Of all participants, half (48%) recalled a conversation with their doctor regarding family risk and 46% indicated that they recalled a physician discussion regarding family screening.

In univariable analyses, females, frequent sunscreen users, those with greater perceived risk or greater concern about recurrence had significantly greater odds of being aware of family risk than males, infrequent sunscreen users and those with lower perceived risk or concern. Those older than 60 years and those with a head and neck diagnosis had significantly lower odds of being aware of family risk than those 60 years or younger or with a melanoma on trunk or limbs, perhaps indicating that some diagnoses are seen as typical of lifelong sun exposure or older age rather than family risk. Perceived risk and body site remained significant in the multivariable

Table 2. Univariable and multivariable logistic regressions examining covariates of melanoma survivors' awareness of family melanoma risk.

Variable	n	%	OR (95% CI)	Adjusted [†] OR (95% CI)
Demographic factors				
Age at recruitment (years):				
– <60	98	58	1.00	
– ≥60	72	42	0.46 (0.25–0.86) [‡]	1.15 (0.52–2.57)
Gender:				
– Male	87	51	1.00	
– Female	83	49	2.14 (1.15–4.01) [‡]	1.67 (0.82–3.38)
Education:				
– High school or less	42	25	1.00	
– At least some college	127	75	1.70 (0.84–3.44)	
Phenotypic variables				
Skin color:				
– Very fair/fair	158	93	1.00	
– Olive/dark	12	7	0.46 (0.14–1.52)	
Eye color:				
– Brown	32	19	1.00	
– Light (all other)	137	81	1.16 (0.53–2.52)	
Hair color:				
– Dark brown/black	50	29.4	1.00	
– Blonde/brown/red	119	70	1.40 (0.72–2.73)	
– Missing	1	0.6		
Presence of freckles:				
– None	68	40	1.00	
– Few/many	101	59.4	1.61 (0.86–3.00)	
– Missing	1	0.6		
Mole number (on back):				
– ≤10	88	52	1.00	
– ≥11	75	44	0.84 (0.45–1.57)	
– Missing	7	4		
Sunburn susceptibility:				
– None/light burn	87	51	1.00	
– Burn easily/peel	71	42	0.80 (0.42–1.53)	
– Missing	12	7		
Tanning ability:				
– Deeply/moderately	90	53	1.00	
– Freckle/occasionally	73	43	0.78 (0.42–1.48)	
– Missing	7	4		
Medical factors				
Breslow depth at diagnosis:				
– ≤1 mm	63	37	1.00	
– >1 mm	14	8	1.44 (0.43–4.79)	
– Missing	93	55		
Status:				
– Primary melanoma	85	50	1.00	
– Multiple melanoma	85	50	0.71 (0.38–1.31)	

[†]Adjusted for all variables significant in the univariable regressions.
[‡]Significance at p < 0.05.
[§]Significance at p < 0.001.
[¶]Significance at p < 0.10.
^{||}In the 10 years prior to melanoma diagnosis.

Table 2. Univariable and multivariable logistic regressions examining covariates of melanoma survivors’ awareness of family melanoma risk (cont.).

Variable	n	%	OR (95% CI)	Adjusted* OR (95% CI)
Tumor site:				
– Trunk/pelvis/arm/legs	139	82	1.00	
– Head/neck	31	18	0.36 (0.16–0.79) [‡]	0.32 (0.13–0.79) [‡]
History of nonmelanoma skin cancer:				
– Yes	18	11	1.00	
– No	152	89	0.71 (0.25–1.98)	
Family history of melanoma:				
– No	132	78	1.00	
– Yes	37	22	1.85 (0.85–4.06)	
Perceived risk:				
– ≤Same age/sex others	50	29.4	1.00	
– >Same age/sex others	119	70	5.10 (2.50–10.41) [‡]	4.72 (2.00–11.10) [§]
– Missing	1	0.6		
Recurrence concern:				
– Rarely/never	94	55	1.00	
– Sometimes/all the time	76	45	1.99 (1.06–3.74) [‡]	1.39 (0.67–2.89)
Behavioral factors				
Sunscreen use:				
– Sometimes or less	36	21	1.00	
– Always/nearly always	134	79	2.91 (1.36–6.21) [‡]	2.28 (0.96–5.41) [‡]
Skin self-examination:				
– Sometimes or less	123	72	1.00	
– Always/nearly always	47	28	1.47 (0.73–2.96)	
Average weekday sun exposure: [#]				
– <2.4 h	93	54.7	1.00	
– >2.4 h	71	41.7	1.43 (0.76–2.68)	
– Missing	6	3.5		
Average weekend sun exposure: [#]				
– <3.6 h	88	51.7	1.00	
– >3.6 h	76	44.7	1.17 (0.62–2.18)	
– Missing	6	3.5		

*Adjusted for all variables significant in the univariable regressions.

[‡]Significance at p < 0.05.

[§]Significance at p < 0.001.

[#]Significance at p < 0.10.

[#]In the 10 years prior to melanoma diagnosis.

analysis; sunscreen use approached significance ($p = 0.06$) (Table 2). In a multivariable analysis considering only those participants without a family melanoma history, results were the same. Intercorrelations among predictors are available in Supplementary Table 1.

Study limitations involve the modest sample size and moderate intercorrelations among some predictors of this pilot study. Findings will need to be confirmed in a larger sample.

Conclusion & future perspective

A sizable proportion of melanoma survivors remain unaware that their FDRs are at risk for

melanoma. The results underscore the important role that physicians, especially dermatologists, play in fostering increased risk awareness. Comprehensive melanoma survivorship care warrants inclusion of information regarding risk to family members, and recommendations for screening and sun protection that could reduce melanoma risk throughout the family system. Dermatologists are credible, well-received sources of such information, yet other providers, such as primary care physicians, have opportunity to increase awareness of risk for melanoma in FDRs of melanoma survivors as well. Sensitivity to informing melanoma

survivors who have lower risk perceptions, regardless of anatomic site, is warranted.

Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: www.futuremedicine.com/doi/full/10.2217/mmt-2015-0003

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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