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## Effects of web-based intervention on risk reduction behaviors in melanoma survivors

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### Abstract

**Purpose**—Melanoma is the most severe form of skin cancer, and survivors of melanoma carry increased risk of additional melanoma diagnosis. Multiple methods exist for primary and secondary prevention of melanoma in survivors. This study tested a web-based family communication intervention to improve these preventive behaviors in melanoma families.

**Methods**—Families (a survivor, at least one first-degree relative and a parent) were randomized either to receive the intervention package or to serve as comparison families. We assessed melanoma prevention behaviors in each cohort member before and after the intervention. The intervention was a web-based multicomponent intervention focused on increasing family communication and exchange of risk information.

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**Conflict of interest** Authors Bowen, Burke, Hay, Meischke, and Harris declare that they have no conflicts of interest.

**Informed consent** “All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.”

**Results**—Results indicated that, compared to comparison survivors, intervention survivors improved their skin self-examination and their sun protection behaviors significantly from before to after intervention.

**Conclusion**—These data support the use of web-based interventions for behavioral changes in survivors and allow for consideration of dissemination of this successful intervention. These data have implications for interventions that can help cancer families deal with issues of risk and illness.

**Implications for cancer survivors**—These data indicate that survivors can benefit from exposure to a website that helps direct their future health behaviors.

### Keywords

Melanoma; Prevention; Web-based; Family communication

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### Introduction

Melanoma is the most severe form of skin cancer, with rates increasing dramatically since the 1970s. In 2014, The American Cancer Society anticipates that 76,100 individuals in the USA will be diagnosed with melanoma and 9710 will die from melanoma [1]. Fortunately, many people survive with melanoma, as in 2010, there were 453,000 men and 469,000 women living with a history of melanoma in the USA [2]. New immune therapies are anticipated to further increase the number of individuals living with melanoma in the coming years [3]. Survivors of melanoma carry increased risk of additional melanoma diagnosis [4], and first-degree relatives (FDRs) carry increased familial risk for a primary diagnosis of melanoma [5]. As these numbers grow and as our understanding of melanoma deepens, we must identify methods of risk reduction and prevention of second primaries in these melanoma families. Risk factors for melanoma include both genetic (hereditary) and behavioral factors, and interventions which target both types of variables might be ultimately more effective in reducing overall risk.

Multiple methods exist for the primary and secondary prevention of new lesions in individuals who have had one diagnosis of melanoma. Currently, early detection through monthly skin self-examination (SSE) is recommended for melanoma survivors by several policy-making bodies [6–8]. Health care provider full-body screening (PS), at different intervals based on time since diagnosis, is also a recommended strategy to identify new primary disease in melanoma survivors [9]. We currently lack decisive data to support the role of sun protection and avoidance in minimizing risk of second primary disease, yet since sun exposure is a strong risk factor for primary melanoma, sun avoidance and sun protection are relatively common-sense recommendations in the melanoma survivorship context and are endorsed by physician groups, including the American Academy of Dermatology [7]. The following strategies to reduce sun exposure are recommended: staying out of the sun, using sun protective products and clothing, using shade when possible, and avoiding indoor tanning facilities [7].

Recent surveys from across the USA and Canada indicate that survivors are not consistently following these recommendations [10–12]. For example, only half (51 %) of a general US population of melanoma survivors perform thorough skin self-examinations [13]. Some of these studies employed clinic-based samples, which could selectively recruit more adherent individuals, those more worried about recurrence or those with better insurance coverage and SES than the general population. In fact, survivors drawn from the general population may likely be *less* adherent than more highly selected clinic populations. Similarly, existing intervention strategies have engaged survivors drawn from highly selected clinic populations that may overestimate adherence with screening and behavioral prevention strategies [14, 15]. The question remains about how we can help survivors in the general population engage in melanoma risk-reduction behaviors. Interventions to encourage and shape follow-up behaviors are needed in survivors. These interventions must be easily delivered in multiple settings and geographic locations, easy to use, and adaptable as new findings on best methods of risk reduction are identified. Interventions must be relatively low cost, to enable delivery to survivors of different SES strata and means, and must engage survivors as well as family. Finally, interventions must be able to be delivered not only to survivors but also to multiple family members, as both the melanoma survivor and the first-degree relatives (FDRs) are at risk for future melanoma.

We proposed to target the survivor’s risk-related behaviors through targeting the entire family’s risk, for multiple reasons. The “family” is an important social and biological construct in health research. First, family history of cancer is one reason that family members discuss and support each other after a diagnosis. A family history of melanoma has been consistently shown to be a risk factor for developing melanoma; a diagnosis of melanoma in one family member has implications for the health and potential risk for other family members [16]. This increase in potential risk leads to discussion and awareness of risk within families, and this could help the survivor make risk-reduction choices. Second, the family often serves as both the source of both information about disease risk and potential prevention and a source of support if one person is diagnosed with an illness [17]. Third, the family is arguably the most important social and cultural context for the development and establishment of most health risk behaviors, such as smoking and dietary habits as well as sun exposure patterns [18]. In the absence of intervention, dissemination of information about melanoma risk—from the survivor to unaffected relatives such as children and siblings as well as parents—may be based on misconceptions about family melanoma risk [19] or poor communication among family members about familial risk [12]. Accordingly, these extant connections within families are potentially untapped avenues for disseminating information not only to the entire family, including the survivor, but also to multiple generations and parents of younger family members, in particular, given that the entire family represents an important intervention target, particularly for family members who may be at risk for developing disease.

There has been little health-related research examining conceptualization of a family, beyond the conventional “family” as either two spouses or as a parent and child. However, in many health intervention studies, there might be great utility in recruiting beyond spouses or parent/child dyads. For example, a common family member for a survivor to speak to is a

first-degree relative, including siblings, parents, or children [15, 17]. Approaches that conceptualize families as including multiple generations and multiple adult members within each generation will be useful as we move forward to intervene more effectively to promote health and reduce disease outcomes for survivors.

The purpose of this study was to test the efficacy of a web-based melanoma prevention intervention in melanoma cases (survivors) recruited through a population-based registry. Specifically, we examined whether there were changes in sun protection behaviors and in self and health care provider screening for melanoma after cases were exposed to the family-based intervention. We developed a web-based intervention that was both interactive with participants and interactive among family members about melanoma risk. We also examined the extent to which survivors' cancer risk perceptions and cancer worry were related to changes in outcomes, in order to identify potential moderators of intervention effect regarding melanoma recurrence, as there is evidence that these variables are associated with self-protective behaviors and to screening behavior in other settings [20–23].

## 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 family member, and adult 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 communication-oriented system, for approximately 1 year. Enrolled family members completed a follow-up survey 1 year later, and then the comparison families received access to the study website. This paper looks only at the survivor outcomes. This report includes all Consolidated Standards of Reporting Trials (CONSORT)-required elements.

We used two sources for recruitment of families: (1) the Northwest Cancer Genetics Network (NWCGN) a regional site of the Cancer Genetics Network [24] and (2) the SEER registry (Cancer Surveillance System or CSS) at the Fred Hutchinson Cancer Research Center. Recruitment is described in detail in a previous manuscript [25]. Melanoma cases diagnosed with a first primary melanoma between April 1st 1998 and October 1st 2001 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 included being diagnosed with melanoma, being aged 18 years or older, and having 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 three stages: physician, case, and relative as previously reported [25]. 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 3 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 or refuse 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 enumerated the family with each case, and permission for staff to directly contact was documented for each relative. Study staff directly contacted and recruited FDRs and parents. If a case refused to give permission for study staff to contact relatives or did not have any FDRs, no further contact was made with that case and they were not eligible. Finally, all participants were asked to complete a baseline survey over the telephone, either immediately following the screening survey or at a later time. All of the case's FDR and parent relatives provided by the case were then approached using the same methods used to approach cases for participation. We have previously reported baseline values for the survivors [16]. 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. We developed this website specifically for this study, based on the print materials used in our successful breast cancer counseling research [26–29]. We will employ an eight-step process we have used previously to translate our print intervention. We created storyboards and sample content that will be reviewed by a panel of 10 population members. Their feedback was used to develop a beta version with minimum necessary content and basic navigation elements. Additional eligible women were given 2 weeks to navigate through the site. Following this period, they provided feedback by phone using a semi-structured interview to evaluate the relevance, acceptability, credibility, and comprehensibility of the information and interface. We monitored utilization metrics (page views, feature utilization, time on site, repeat logins). We completed testing and made changes in an iterative fashion. Changes were made based on team input. In addition to our team's expertise, we had all intervention content reviewed by a panel of medical experts at our home institutions. We recruited 10 women for *usability testing* of the final beta version of the complete intervention through one-on-one, in-person meetings.

The website consisted of a home page, with constantly changing messages about prevention [25]. Viewers were directed to a page with their own personal risk graphic and text for melanoma, using the model developed by colleagues at Harvard University [30] called “your chronic disease risk” using 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 about risk, 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 1-year study period. Every 3 months, prompts would be sent by the study team via email to check the website and check a new previously unviewed page.

### Outcome measures

**Skin self-examination**—We assessed whether cases performed deliberate and comprehensive skin self-examinations (SSEs) of specific bodily areas at least once every 2 months. The areas of the body to be examined were as follows: the front of the individual from the waist up, the front of the thighs and legs, the bottoms of the feet, the calves, the back of the thighs and legs, the buttocks and lower portion of the back, and the upper back [31]. We also explored whether or not individuals performed thorough skin examinations, looking for particular marks, freckles, or moles, just casually checking their skin. Those marking “I do a thorough skin examination” were considered adherent to the protective behavior.

**Sun protection behaviors**—Sun protection behaviors of the previous 7 days were assessed (wearing a long-sleeved shirt or blouse, wearing long pants or skirts, wearing sunscreen with an SPF of 15 or higher, wearing something on the head such as a hat, cap, or scarf, and staying in available shade such as under a tree, awning, or umbrella) [32]. Responses were dichotomized where those who responded “often” or “always” to the questions were analyzed as being adherent (adherence=1, non-adherent=0). Given that sun protection likely varies across the seasons of the year, we adjusted all regressions for season. The month in which baseline data collection occurred for each participant was used to determine the season for each observation. The seasonal categories were organized such that winter included December through March, spring included April through June, summer included July through September, and fall included October through November.

**Provider screening**—Skin screening conducted during a routine visit to a health care provider was assessed according to Weinstock and colleagues’ prior research [31]. Participants were asked “What does your provider do during a skin examination?” Participants could have checked any or all of the following response options: (a) look at all areas of your skin that you are concerned about, (b) check places exposed to the sun, (c) look at all your moles or freckles, (d) check all of your skin, by asking you to take your clothes off, (e) take pictures of your skin to record changes, (f) and others. For the purposes of the current analysis, having all of one’s skin checked, without clothing, was used as an outcome measure of provider screening. All other response options were coded 0 and checking skin without clothing was coded 1. Participants were also asked the type of provider who performed their most recent skin examination. Options included (a) dermatologist, (b) primary care provider, (c) nurse practitioner, (d) others, or (e) never had a skin exam.

**Other relevant measures**—According to multiple health behavior theories, perceived risk for developing melanoma in the future is a precursor to protective behavior change, and prospective studies are the appropriate study designed in order to assess this motivational hypothesis [20–22]. We addressed perceived risk for developing melanoma again in the future compared to most people (much lower than average=1 to much higher than average=5). Cancer worry, defined as an emotional reaction to the threat of cancer, is another area that was addressed. High-risk populations, designated by a cancer history in one or more first-degree relatives, report that worry is positively related to screening. We assessed cancer worry using the commonly used well-validated Cancer Worry Scale, which provided a summary score a summary score of 4–16, with those reporting a score of 8 or higher considered high worry and those with 7 and lower considered low worry [32].

We collected background information from cases using standard questions on age, gender, and ethnic/racial background: (White/Caucasian, Black or African-American, Native American or Aleut or Eskimo, Asian, Pacific Islander, Hawaiian, Spanish, Hispanic or Latino, others), education level (8 years or less, some high school, high school graduate or GED, some college or technical school, graduated from college or beyond), marital status (never married, married or living as married, separated, divorced, widowed), and income (less than \$15, \$15–\$30 k, \$31–\$50 k, \$51–\$70 k, \$71–\$99 k, \$100 k or above). Information obtained from the SEER database for each case included diagnosis date and stage at diagnosis. We used zip code to identify whether family members lived in the same city as the case. We asked about closeness to case by simply asking participants how close they felt to the case, using a scale of 1–5.

We programmed a simple page counter into the website and tied it to each participant's ID number and family ID number so that we could keep track of website use. The counter counted the number of pages visited and how long each participant remained on each page.

## Analyses

We focused these analyses on the data from the cases only, using an intention to treat principle, where if data were missing, we calculated the follow-up value as the baseline value. We first examined descriptive analyses of all variables to identify any outliers or aberrant data points. We then examined differences between intervention and control participants, and between participants who provided and did not provide follow-up data. We next examined the unadjusted outcomes of the study (sun protection behaviors, SSE, and provider screening) using the measures described above as dichotomized outcome variables. We tested these with chi-square tests after adjusting for season of the year. Finally, we tested for moderation using six variables previously shown to alter risk behaviors: perceived risk, cancer worry, stage of cancer, age at diagnosis, closeness to family, and website use frequency in intervention cases.

## Results

We randomized 311 families, each with a case of melanoma, one FDR, and one parent of a child 0–17. Therefore, there were 311 cases of melanoma enrolled in the study. We were able to collect follow-up data on 89 % of the cases at the 1-year follow-up. Table 1 presents

the baseline demographic data of cases. As seen in this Table, the participants were almost all Caucasian, slightly more likely to be female than male, mostly of moderate income and education, and mostly of lower stage of melanoma. Overall, the randomization process worked well, in that there were no differences between intervention and control participants on any demographic variable or any outcome variable.

In general, 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. Only 4 % of participants did not visit the website at all and therefore they never received their risk information sheet nor family communication messages through the website. The average number of pages per use was 8.4. The most frequently visited page was the risk information sheet (96 %) followed by the protecting one's skin from the sun (78 %), followed by talking to family (64 %) and providers (61 %). For analytic purposes, we divided the intervention cases into groups based on use frequency: 0–1 time (45 %), 2–4 times (37 %), or 5 or more times (18 %).

Table 2 presents the unadjusted outcome data at baseline and 1-year follow-up for melanoma cases. For the SSE variables, the intervention improved SSE in the body areas of examination that require a more thorough, effortful exam: the bottom of feet and lower back/buttocks. These are not the body parts that one casually sees in the shower or the mirror. There were no effects on health care provider screening, possibly due to a ceiling effect with baseline data. Fortunately, most of our participants were already receiving provider screening at baseline. Many of the sun protection variables were positively impacted by the intervention, in that several sun protection behaviors improved from before to after the intervention. However, even after the intervention, there was still room for improvement in sun protection, with nearly half our sample not regularly using sunscreen.

We tested a set of six possible moderators of the intervenient effects for each outcome and identified a few significant intervention modifiers. Perceived risk and cancer worry each moderated the intervention effect on SSE (interaction  $p < 0.01$ ), such that higher levels of perceived risk and higher levels of cancer worry were related to increased intervention effect. Closeness to family also significantly interacted with the intervention effect on several of the sun protection behaviors, including avoiding sun, wearing a hat, and staying indoors (interaction  $p < 0.01$ ), such that survivors who reported being closer to family members increased their sun protection behaviors. Neither stage of cancer, age at diagnosis, nor website use frequency interacted with the intervention effects of any outcome variable.

## Discussion

The purpose of this paper was to present the results of a rigorous test of the effects of a family-based behavioral intervention to reduce risk for melanoma among melanoma survivors. This test has yielded positive results, in that survivors in the intervention arm improved their patterns of skin self-examination (SSE) and sun protective behaviors. There were no significant intervention effects on health provider examination (HPE), possibly as a result of the baseline high levels of HPE before randomization. Taken together, these results provide some support for the usefulness of this intervention in preventing melanoma. Perhaps, if woven into a provider-driven intervention or one that was more geared toward



multiple uses, this effect would expand to include changes in sunscreen or changes in health care provider screening.

Additional disappointing results were found for sunscreen use, which did not change in response to intervention. We conducted post hoc analyses to determine whether any sunscreen changes existed for participants who did not make changes to sun protection. We reasoned that perhaps, individuals made changes in sun protection behaviors and so did not feel that they needed sunscreen as a result of the additional protection. We found no evidence of tradeoff between increasing sun protection behaviors and changing sunscreen use. Still, there is evidence that people trade off risk for primary prevention behaviors in primary prevention of melanoma, such that performance of wearing a hat and sunscreen might allow people to reduce their performance of other behaviors, like wearing long-sleeve shirts. So, it is possible that better more detailed measures of behaviors plus measurement of individuals' cognitive attribution of those behaviors might yield links in future research.

It is difficult to compare these results to other intervention studies, mostly because there are few points of reference. To our knowledge, there are only a few interventions targeting melanoma survivors that report on multiple effects [15, 33, 34]; survey data indicate that health care provider screening may be a better alternative than SSE [35]. Other interventions have targeted first-degree relatives (FDRs) with intervention [36]. Still, other interventions have targeted members of the general public with messages about use of sunscreen and avoiding sun protection behaviors. Therefore, there are no interventions to provide true comparisons to these data. Other interventions have targeted cancer families to increase screening behaviors [14], with effect sizes of 10 % above control. Our effects were at this level or larger, depending on the outcome measure.

Changing risk behaviors of the case through targeting a higher risk family through the case might be an additional strategy that could be implemented in health care setting and cancer diagnostic settings to complement these general public interventions. The nature of this intervention, which is easy to use, inexpensive to scale up to multiple families and survivors, easily updated, and quickly improved and added to, might make for positive implementation findings. Given the findings of efficacy in at least some of the outcomes, this intervention would make a strong target for implementation in a health care setting or cancer treatment setting.

There were elements to this study that limit the generalizability of these findings. First, we know from the baseline data that survivors of lower SES were more likely to refuse participation in the study [37]. Therefore, we cannot say that the findings will generalize to survivors of lower SES or for that matter to survivors of nonwhite races or ethnicities. These limitations are becoming increasingly important, given the rising rates of melanoma among Hispanic individuals [38]. This was a randomized trial, and therefore, there was a focus in this study on internal validity, perhaps in the expense of matters of external validity, such as a true population focus in recruitment or intervention flexibility and choice in intervention delivery. Future studies should focus on reach and sustainability, two qualities that were not the focus of the present study.

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**Table 1**Demographic Characteristics of Cases (*n*=313)

Variable	Categories	Number	Percentage
Age	–	Ave=56.11 (12.33)	–
	[Range]	[20–89]	–
Gender	Female	175	56
	Male	138	44
Ethnicity	Hispanic	1	0.32
	Non-Hispanic	312	99.68
Race	White	309	99.72
	Non-white	2	0.64
Education	High school degree	39	12.46
	Some college or technical school	78	24.92
	College degree	195	62.30
	Do not know	1	0.32
Marital status	Never married	19	6.07
	Married or living as married	253	80.83
	Separated/divorced	33	10.54
	Widowed	8	2.56
Income	50 K	51	16.3
	51–70 K	85	27.16
	70 K	150	47.92
	Refused/did not know	27	8.63
Stage at diagnosis	In situ	38	12.14
	Localized	247	78.91
	Regional, direct extension only	2	0.64
	Regional, regional lymph nodes only	17	5.43
	Distant	1	0.32
	Unstaged	2	0.64
	Other	6	1.92

**Table 2**

Changes in risk reduction behaviors from before to after web-based intervention in melanoma survivors

Outcomes	Baseline		Follow-up	
	I	C	I	C
Screening behavior	Once/more than once (%)	Once/more than once (%)	Once/more than once (%)	Once/more than once (%)
The front of you from the waist up	111 (70.70)	116 (74.36)	100 (70.92)	107 (73.79)
The front of your thighs and legs	108 (68.79)	114 (73.08)	101 (71.63)	109 (75.17)
The bottom of your feet**	56 (35.67)	62 (39.74)	91 (64.68)	55 (37.93)
Your calves	92 (58.60)	107 (68.59)	93 (65.96)	99 (68.28)
The back of your thighs and legs	77 (49.04)	87 (55.77)	76 (53.90)	79 (54.48)
Your buttocks and lower part of your back**	72 (45.86)	81 (51.92)	92 (66.81)	77 (53.10)
Your upper back	90 (57.32)	100 (64.10)	85 (60.28)	92 (63.45)
Self screening examination	Yes (%)	Yes (%)	Yes (%)	Yes (%)
Do a thorough skin examination**	41 (26.11)	27 (17.31)	54 (37.02)	24 (16.55)
Provider screening	Yes (%)	Yes (%)	Yes (%)	Yes (%)
Check all of your skin, by asking you to take your clothes off	142 (96.60)	133 (93.01)	132 (96.35)	127 (96.21)
Sun protection behaviors	Adherent (%)	Adherent (%)	Adherent (%)	Adherent (%)
Wear a long-sleeved shirt or blouse*	117 (74.52)	109 (69.87)	141 (90.85)	(82.76)
Wear long pants or long skirt	138 (87.90)	131 (83.97)	126 (89.36)	127 (87.59)
Wear sunscreen SPF 15+	78 (49.68)	82 (52.56)	96 (66.23)	80 (55.17)
Wear something on your head* (hat, cap, scarf)	59 (37.58)	68 (43.59)	91 (62.55)	65 (44.83)
Wear a hat with a brim at least 2.5 in wide all the way around	26 (16.56)	33 (21.15)	26 (18.44)	28 (19.31)
Wear sunglasses**	80 (50.96)	83 (53.21)	102 (70.35)	73 (50.34)
Stay in available shade**	68 (43.31)	70 (44.87)	91 (62.55)	57 (39.31)
Avoid outdoors when the sun is strongest**	37 (23.57)	42 (26.92)	70 (48.37)	38 (26.21)

\*  $p < 0.05$ . Significant change from baseline to follow-up in intervention group\*\*  $p < 0.01$ . Significant change from baseline to follow-up in intervention group