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Barriers and Facilitators to Melanoma Prevention and Control Behaviors Among At-Risk Children

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Abstract

Melanoma prevention is essential for children who are at elevated risk for the disease due to family history. However, children who carry a familial risk for the disease do not optimally adhere to recommended melanoma preventive behaviors. The current study sought to identify perceived barriers to and facilitators of children's engagement in melanoma preventive behaviors among children at elevated risk for melanoma due to family history of the disease (i.e., having a parent with a history of melanoma) from both parents' and childrens' perspectives. Qualitative methods were employed and consisted of separate focus group discussions with children (ages 8–17 years, $n = 37$) and their parents ($n = 39$). Focus group transcripts were coded using content analysis. Parents and children reported a number of barriers and facilitators, including on the individual (e.g., knowledge and awareness, preferences), social (e.g., peer influences, family modeling and communication), and contextual (e.g., healthcare provider communication) levels. The identified categories of barriers and facilitators both confirm and extend the literature documenting the reasons children who are at elevated risk for melanoma do not engage in melanoma prevention and control behaviors. Programs aiming to decrease melanoma risk among children of melanoma survivors could help families address their barriers to preventive behavior implementation and build on facilitators. Melanoma survivors and their children could benefit from support on their

Compliance with Ethical Standards

Conflict of interest Sancy Leachman serves on a Medical and Scientific Advisory Board for Myriad Genetics, for which she has received an honorarium. She collaborated with Myriad to validate an assay that is unrelated to research reported here. The other authors declare that they have no conflict of interest.

Informed Consent Informed consent and parental permission was obtained from all parent participants included in the study and assent was obtained from all child participants.

Research Involving Human Participants All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

interactions with healthcare providers, schools, peers, and other caregivers about melanoma prevention.

Keywords

Melanoma; Barriers; Prevention; Children; Disease risk

Introduction

Melanoma is the deadliest form of skin cancer and its incidence rates are rising [1]. It is increasingly being diagnosed among younger populations, and is the second most common cancer among adolescents and young adults ages 15–29 [2–4]. Encouragingly, there is some evidence that melanoma incidence is decreasing among teenagers in recent years [5]. Prevention of skin cancer in the general population and among at-risk populations, including children who have a parent with a history of melanoma, is a major public health priority [6]. Children who have a parent with a history of melanoma have a twofold increased risk for developing the disease themselves [7]. To mitigate risk for melanoma, children should engage in recommended melanoma preventive behaviors: Implementation of sun protective measures, such as use of sunscreen and protective clothing, seeking shade, and minimizing exposure to ultraviolet radiation (UVR) during peak hours (10 am–4 pm) [8–10]. Preventive behaviors can decrease childhood sunburn occurrence and UVR exposure, primary risk factors for melanoma [11–16]. Parents can also assist children with screening (e.g., implementing skin self-exams; SSEs), so that children learn the importance of and how to conduct SSEs, which can facilitate early detection and improve survival [17]. Screening for children with a familial risk for melanoma, is recommended to begin at age 10 [18, 19].

Results of prior studies indicate that children at elevated risk for skin cancer due to family history do not consistently implement recommended melanoma preventive behaviors [20–24]. Furthermore, interventions to improve adherence to melanoma preventive behaviors among at-risk children are scarce [25]. Before developing such interventions, it is essential to identify the range of systemic factors that may influence children's engagement in preventive behaviors and their parent's ability to assist. On the individual level, surveys with parents who have a personal history of melanoma indicate that their children are more likely to engage in melanoma preventive behaviors if children are younger, female and more sensitive to the sun [22, 23]. Parent-specific factors predicting greater likelihood of child use of sun protection include parent's own sun protection behaviors, perception that sun protection behaviors are efficacious, social norms, and lower barriers (e.g., child opposition, cost) [22, 23]. In addition, Australian parents of children ages 2–5 years reported that a number of factors impacted their sun protection decisions for their children, including implementing sun protection in order to decrease parental guilt [26]. However, no studies have elicited the perceptions of children themselves, nor compared these with parental perceptions of barriers to and facilitators of melanoma prevention and control behaviors. Further, few studies have been able to examine both barriers and facilitators simultaneously. A better understanding of barriers and facilitators from both parent and child perspectives could inform skin cancer prevention programs targeting children who are at elevated risk for

skin cancer. The goal of the current study was to identify at-risk childrens' and their parents' perceived barriers to and facilitators of adhering to recommended strategies for melanoma prevention and control.

Patients and Methods

In total, 39 biological parents of 37 children participated. Children were eligible if they had at least one first degree relative with a history of melanoma confirmed via medical records and were ages 8–17. The first degree relative with a history of melanoma could be alive or deceased; and either parent was eligible to participate in the study. If parents had minor children outside this age range, they were eligible to participate without their children (n= 13). No children participated without having a parent participate.

Procedures

Letters describing the study were sent to: (1) individuals ages 18–55 who had received care for melanoma at the University of Utah Huntsman Cancer Institute (N = 1052), and (2) individuals enrolled in a separate study about family risk for melanoma (n = 71). Study advertisements were made available in clinics, at a free skin cancer screening, via social media, and through melanoma advocacy groups. Of the 419 adults screened for eligibility, 141 were eligible, and 39 participated in the current study (primary reason for non-participation was scheduling difficulties). The 39 parents had 45 children ages 8–17, and 37 participated (8 children unavailable during scheduled focus groups). Informed consent was obtained from all parent participants included in the study and assent was obtained from all child participants.

Children and parents were invited to attend an in-person focus group session (six parent, six child groups). Parent participants provided written informed consent and children provided written assent. Groups consisted of an average of 12 participants (SD = 4). The child focus groups included children of all ages (8–17 years old). Focus groups were audio recorded and moderated by a clinical child psychologist, a master's-prepared public health researcher, a public health graduate student, and a clinical psychology graduate student. Participants received gift cards, and also received travel reimbursement if they lived > 40 miles away. Informed consent and parental permission was obtained from all parent participants and assent was obtained from all child participants. All procedures were approved by the University of Utah Institutional Review Board.

Survey and Focus Groups

Parents were asked to complete a self-reported questionnaire, including items on demographic characteristics. During the focus groups, participants were asked semi-structured questions (protocol available on request). The questions covered knowledge of melanoma prevention and control and barriers to and facilitators of implementing preventive behaviors in children. Two hypothetical scenarios were presented to encourage open discussion about potential challenges.

Analyses

Descriptive statistics were used to summarize survey data. Focus groups were transcribed and qualitative content analysis was conducted using NVivo 11 to code and compare these data.

Transcripts were coded in two phases. In the first phase, a codebook containing structural codes was used to identify barriers to and facilitators of melanoma preventive behaviors [27]. The codebook was created by three team members based on study goals, a priori theories that organized data collected [28], multiple readings of transcripts and field notes, and with modification based on initial coding of 4 out of 12 transcripts. After review and discussion of the first phase coding, the research team created a second codebook focused on content categories (e.g., knowledge and awareness of sun protective behaviors) based on team consensus [27, 29]. The transcripts were then coded a second time to describe the types of barriers to and facilitators of sun protective behaviors that participants reported. All data were coded by two independent, trained coders (Kappa = 0.79, which is adequate) [30]. Coding disagreements were resolved within the analysis team.

Results

Table 1 contains participant demographic characteristics. Barriers to and facilitators of melanoma prevention and control occurred on three socioecological levels: individual, social, and contextual levels.

Individual Level Barriers and Facilitators

Parents and children reported cognitive factors that served as barriers to and facilitators of engagement in melanoma prevention and control, including *knowledge and awareness*. Parents noted that children were not aware of how behaviors now could lead to melanoma in the future and that there was misinformation about preventive behaviors in the media. Many parents reported being unaware that children, potentially with help of parents, could engage in SSEs to get into the habit of performing regular SSEs. Other parents expressed lack of confidence in their ability to detect changing moles on their children's skin. Some children reported misconceptions about sun protection, such as not applying sunscreen at the beach, "Because I thought I was going to be in the water a lot and that the sun couldn't damage me in the water."

In addition, parents reported that their underestimates of the amount of UVR exposure children obtained (e.g., cumulative, intermittent UVR exposure over the course of the day, increased exposure at higher elevations or due to last minute plan changes) led to inconsistent implementation of preventive behaviors. One parent noted: "…you don't realize how much cumulative sun exposure you get just in your everyday life, like driving, going to the grocery store, running kids to school and practices and things. When you're not even outside but just in between, it really adds up." In terms of facilitators, parents expressed the importance of educating children about melanoma prevention and control strategies. Further, some parents' history of melanoma motivated them to be more vigilant about their children's engagement in prevention and control (Table 2).

Parents and children also reported that their *personal preferences* could serve as barriers or facilitators. Parents reported that children refused to wear protective clothing because it was uncomfortable or unfashionable, and that children did not like the smell or feeling of sunscreen. Facilitators included children who preferred indoor activities, and scheduling activities around peak UVR hours. In addition, participants reported that it was easier for children to implement melanoma prevention and control if they could flexibly choose the behaviors that best fit their activity or preferences (Table 2).

Parents expressed that *children's individual characteristics*, such as their age or developmental stage, personality, and physical attributes (e.g., skin color, number of moles) could be barriers to, or facilitators of, prevention and control. Most parents reported that older children, particularly teenagers, were more resistant to implementing sun protective behaviors and were embarrassed to have a parent assist with SSE (Table 2).

Parents expressed that *difficulty finding and cost of sun protection products* were barriers to prevention. Parents described experiencing challenges finding adequate protective clothing (UPF-rated clothing, long-sleeved swim shirts) for children. Both parents and children reported that adequate protective clothing and sunscreen recommended by healthcare providers (e.g., zinc oxide) were costly (Table 2).

Social Level Barriers and Facilitators

Parents and children endorsed *peer influences* as an important factor impacting children's engagement in sun protective behaviors. Children sometimes resisted engaging in sun protection to avoid appearing different from their peers: "It's not cool or because your friend's not doing it, so you're just like oh, I don't want to do it because my friend's not doing it." A few parents also expressed that their emphasis on sun protective habits with their own children garnered criticism from other parents (Table 2). On the other hand, some child participants reported that peers facilitated their engagement in sun protective behaviors: "Some of my best friends help me, because they know I'm also at a higher risk. They always tell me to do it and stuff like that."

Both parents and children expressed barriers and facilitators related to *family modeling and communication*. Parents described that their and their spouse's engagement or lack thereof in melanoma prevention and control influenced children's engagement: "Yeah, I'm not on [the children] every time, just because I'm guilty of not wearing [protective clothing] all the time." In contrast, parents who modeled implementing preventive behaviors and established a family norm of engaging in the behaviors reported that their children were more likely to similarly engage in the behaviors (Table 2). Parents also described challenges communicating with children about melanoma risk and prevention, including that they did not want to make their children excessively anxious about melanoma, and that repeated conflicts about preventive behaviors was tiring and made it challenging to enforce preventive behaviors.

Parents and children raised several categories of implementation barriers and facilitators. First, parents and children described that *forgetting* was a major barrier. Both parents and children reported that reminders were one way to address forgetting and ensure that children

engage in prevention and control (Table 2). Second, parents and children described that *hassle and time required to implement preventive behaviors* were barriers, including when applying sunscreen. Some parents addressed this by finding sun-screen that is easier and faster to apply, which included spray sunscreens. Third, families described *challenges ensuring adequate implementation of preventive behaviors*. Children may not thoroughly apply sunscreen, use enough sunscreen, or do not allow chemical sunscreens to set before swimming (Table 2). Some children reported that having parents help them implement prevention and control behaviors, such as SSE, was helpful. Fourth, parents described a variety of *behavior management strategies* that facilitated children's engagement in prevention and control behaviors, such as providing rewards, giving children choices, and establishing contingency rules such that preventive behaviors had to be implemented before desired activities (Table 2). Fifth, families discussed the *role of routine or habit*. Some families found it easier to engage in preventive behaviors that were a habit, or part of their day-to-day routine, whereas others found it easier when they were out of their routine, such as for vacation or an outing.

Sixth, parents described that it was particularly *difficult for children to consistently engage in melanoma preventive behaviors when they were away from parental supervision*, such as at school, extracurricular activities, or under the supervision of other adults (Table 2). In particular, parents expressed concern that while they could ensure initial sun-screen application, they were not confident that children would re-apply. Some schools had policies not allowing students to wear hats or sunglasses, or to freely use sunscreen, which was considered a medication.

Contextual Level Barriers and Facilitators

Parents reported that *communication with healthcare providers* could relate to both barriers to and facilitators of preventive behaviors, especially for screening. Some parents endorsed having conversations with physicians who recommended their children obtain regular total body skin exams from a health care provider, while others had not received this recommendation. Parents reported that receiving information from a healthcare provider about skin cancer prevention and early detection was helpful, because children were more likely to follow a doctor's (or "expert's") recommendation.

Parents and children described the *weather and season* as factors impacting children's engagement in preventive behaviors. Participants described not wanting to wear protective clothing in warm weather or having difficulty implementing sun protective behaviors when the weather changed (Table 2). On the other hand, families reported that hot weather motivated them to seek shade or stay inside. Parents and children also reported being less vigilant about implementing sun protective behaviors in the winter compared with in the summer, due to beliefs that there is less UVR exposure in the winter and because they were "out of the habit" of sun protective behaviors.

Discussion

The current study identified barriers to and facilitators of melanoma prevention and control among children at elevated risk for melanoma and their parents that occur on multiple

socioecological or systemic levels. Some factors identified are consistent with prior literature [26], including implementation challenges, children's resistance to using sunscreen, cost, greater attention to sun protection during hot weather, establishment of rules and habits related to preventive behaviors, peer influences, and perceived benefits to implementing melanoma prevention and control. However, unlike a prior study that included parents of young children in Australia, parents in the current study reported mixed levels of support from others on sun protection implementation in their children, including from peers and schools [26].

Our study also identified several new factors which have not yet been described in the literature, such as underestimation of UVR exposure, forgetting, implementation of preventive behaviors tailored to different settings, activities, or children's preferences, and family and healthcare provider communication. Some of these newly-identified factors highlight misperceptions that children and parents may have that could negatively affect engagement in preventive behaviors. For instance, parents described less vigorously insisting that their children who "tan well" engage in sun protective behaviors. Children described their reliance on the weather to cue their choices to use sun protection. The results also emphasized the potential positive influence that healthcare providers can have on promoting skin cancer prevention and screening behaviors among children and their families. Because our study was able to include children from a broad age range, the findings also highlighted the important role that children's age, in addition to their personality, had on interactions around melanoma prevention and control. For example, parents noted that in general, children of older ages (e.g., teenagers) were more resistant to implementing melanoma prevention and screening behaviors. Future studies could conduct a more detailed analysis of how child age impacts the barriers and facilitators observed, such as family interactions and changing levels of parental supervision as children age.

Our sample focused on a predominantly urban, geographic area. While the area features particularly high rates of melanoma compared to other US regions [31], our results may not be generalizable to at-risk families in other areas. In addition, while our study featured a sample size comparable to or larger than that of other qualitative studies [26, 32, 33], we had a modest participation rate. Our sample also included, on average, families with a relatively high reported income level. Strengths of the study included a qualitative approach that allowed us to explore families' perspectives without a priori notions of barriers and facilitators. We also were able to include children's perspectives, which could inform the design of child- and family-centered interventions.

Future efforts to understand factors that influence at-risk children's engagement in melanoma prevention and control behaviors could seek to replicate the current findings in larger samples (e.g., via survey), and in individuals from different geographic areas, including rural populations. In surveying larger samples, it may be useful to identify the barriers and facilitators that families most frequently endorse and have the most influence on engagement in preventive behaviors.

Our findings hold implications for the design of programs and policies [34, 35] to support children who carry a familial risk for melanoma in adhering to melanoma prevention and

control behaviors. Because preventive behaviors often originate in the family setting, programs should ideally involve both children and parents. Programs could support families in their interactions with schools, peers, other caregivers, and healthcare providers. Interventions to promote engagement in preventive behaviors could help families address their barriers to preventive behavior implementation and build on facilitators while still allowing families to engage in activities (e.g., sports) facilitating a healthy lifestyle. Interventions could also target modifiable factors, such as knowledge, parental modeling, and self-efficacy [24]. Less easily modified factors (e.g., child age) could be targeted through behavior management strategies for younger versus adolescent children. Effective interventions to support adherence to melanoma prevention and control among at-risk pediatric populations are needed [25], and could assist families by addressing the range of barriers and facilitators to prevention they face.

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Table 1

Participant demographic characteristics

Parents (n = 39)	**n**	**%**
Relation to child		
Mother	32	82.1
Father	7	17.9
Age	Mean (SD)	Range
	39.5 (6.6)	30–52
Highest level of school completed	n	%
High school graduate or GED	2	5.1
Some college, vocational school, Bachelor's	29	74.4
Graduate school	8	20.5
Marital status	n	%
Married/living in marriage-like relationship	35	89.7
Divorced, widowed, separated	3	7.7
Never married	1	2.6
Household income	Mean	Range
	$90,000–$99,999	≤$9999– ≥$100,000
Personal cancer history	n	%
Melanoma	36	81.8
Other skin cancer	6	13.6
Other cancer	2	5.6
Number of children < 18 years	Mean (SD)	Range
	2.4 (0.8)	1–4
Children (n = 37) Age	Mean (SD)	Range
	11.3 (2.6)	8–17
Sex	n	%
Male	24	61.5
Race	n	%
White	39	100.0
Has health insurance	n	%

Parents (n = 39)	n	%
Yes	39	100.0

Table 2

Barriers to and facilitators of adherence to melanoma prevention and control

Category	Description	Barrier	Facilitator	Exemplar quotation
Individual level				
Knowledge and awareness	Educating children on preventive behaviors	X	X	"Yeah, we talked with them even when they were young kids about how we look at them every month to see if there are changes or anything. That was when they were really little, so that was a really simplified version of why we were looking, and why we wanted to look at our moles and every- thing carefully." (Parent)
Personal preference	Child preference	X	X	"One will like the spray and I can spray him, and he's fine with the spray, so I spray his whole body. And the other one, he's okay with the spray, but he doesn't want it on his face…So I'm like whatever it takes, I will accommodate whatever makes you happy." (Parent)
	Child preference—smell of sunscreen	X	X	"We don't like the smell of the sunscreen, because it's just so weird, but we found this brand that smells like orange cream popsicles, and it's really good, so I'll put on as much as you'd like of it. It just smells so good." (Child)
Child characteristics	Child age	X		"My youngest two don't fight me on the board shorts and swim shirts, but again, my teenager…She says no other girls do that and these people are going to think I'm a complete dork." (Parent)
	Child physical attribute	X		"But yeah, my oldest…he has super white hair. He's really blonde, but he tans so well that you don't look at him like a fair kid…so I just kind of ignore him. The other two that are roaming with me I'm like oh, you guys need sunscreen. But I fail with the oldest." (Parent)
Finding sun protection products and cost	Difficult finding and cost of protective clothing	X		Parent 1: "Shirts that would be protective and cool for the summer are not readily available. You have to search for them. You have to buy them from certain stores online...Yeah, they're very expensive. So we have some of those shirts that are protective and cool but they're really expensive, and it's not something you grab at Target so it's never going to be at my house." (Parent)
Social level				
Peer influences	Criticism from children's peer's parents	X		"I've had other parents, and even the people that know my history [of melanoma], will say in front of my kids when I'm nagging them, 'Don't you think you're making too big of a deal?'" (Parent)
Family modeling and communication	Family norm of implementing preventive behaviors		X	"Yeah, that I think helps in every aspect of it. The whole family wears the UV clothing, so it's not unusual. It's something we've always done, so it's not like we go outside and we're the weird ones. It's how our family rolls. It's not unusual for them." (Parent)

Category	Description	Barrier	Facilitator	Exemplar quotation
Implementation factors	Reminder		X	"My grandma has a pool, so whenever we go over there our parents always make every kid and every grownup get out to put on sunscreen every 2 h." (Child)
	Adequate implementation of preventive behaviors	X		"I know my kids will take the sunscreen with them—not always—but they're really not good at doing it themselves. So they do it and then they'll have a streak of a sunburn…they don't do the best job." (Parent)
	Behavior management—giving choices		X	"But I can get my daughter to wear it. I give her the choice of reapplying or wearing the shirt, and so she'll often put the shirt on for the second half of the swimming adventure so she doesn't have to go through the reapply of the sunscreen." (Parent)
	Under other adult's supervision	X		"I think, too, when you send your kids with other family members when they're going somewhere. I feel like that's partially out of your control, too, because you feel like it might be an inconvenience for somebody to have to put sunscreen on your child. You still ask anyway but then you're not guaranteed that they did." (Parent)
Contextual level				
Communication with healthcare providers	No discussion of SSE with healthcare provider	X		"I feel like, at least for me, doctors don't put enough emphasis on self-exams, because I've never even heard of them, and I think a lot of people probably haven't. So maybe when you go to your yearly check-up, or whatever, that they actually bring that up." (Child)
Weather and seasons	Changing weather	X		"Sometimes it's hard for me to remember, because I sometimes really never know what type of weather it's going to be…because sometimes each day changes in the weather, so I kind of wait to put my sunscreen on until I know what the weather's going to be like." (Child)