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Development of an Educational Program Integrating Concepts of Genetic Risk and Preventive Strategies for Children With a Family History of Melanoma

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Abstract

Efforts to prevent melanoma, especially for those at elevated risk for the disease, should ideally begin during childhood. However, there are few preventive interventions targeting children who are at higher risk for melanoma due to a family history of the disease. Further, there are no educational interventions that aim to help these at-risk children understand their risk for melanoma and the ways in which preventive behaviors, such as sun protection, can mitigate their risk. The current paper describes a multidisciplinary team's process for creating a developmentally appropriate educational intervention about melanoma risk and prevention for children ages 8-17 years who have a family history of melanoma. Drawing from the fields of dermatology, health behavior change and education, genetic risk communication, science education, and graphic arts, the multimedia intervention created covers key learning points relevant to understanding melanoma, the role of DNA damage in melanoma development, inherited risk factors for melanoma, environmental factors causing DNA damage, and methods for preventing DNA damage, such as sun protective behaviors. Lessons learned during the development of the

educational intervention, particularly relevant to multidisciplinary team interactions, are discussed. Implications for future testing and refinement of the novel educational content are also reviewed.

Introduction

Melanoma is the 6th most common cancer, and as the deadliest form of skin cancer, leads to significant morbidity and mortality [1, 2]. Because key risk factors for the disease include childhood sunburns and early life ultraviolet radiation (UVR) exposure [3, 4], prevention should begin in childhood. Particularly at risk may be children who have a family history of the disease. Increased familial risk for melanoma may be due to inherited factors contributing to a melanoma-prone phenotype (e.g., fair skin, freckling, red hair) and/or mutations in cancer predisposition genes (e.g., *CDKN2*, *CDK4*), as well as shared environmental risk factors such as UVR exposure. Children who have a parent with a history of melanoma have a 2-fold increased risk for developing melanoma later in life [5]. The population of children who have a parent with a history of melanoma will continue to grow because the incidence of melanoma among adolescents and young adults is increasing [1].

Melanoma preventive interventions for at-risk children are therefore greatly needed. Such interventions could foster children's engagement in sun protective behaviors, such as use of sunscreen and protective clothing, re-application of sunscreen, and avoiding UVR exposure during peak hours (10 AM – 4 PM). However, there is a dearth of preventive interventions for at-risk children [6, 7] despite their suboptimal adherence to melanoma preventive behaviors and the recommendation that children who have risk factors for skin cancer (e.g., fair skin) should receive counseling about preventive behaviors [8-11]. Existing interventions for at-risk children [6] do not yet include strategies for incorporating genetic risk conferred by family history and how preventive behaviors mitigate this risk. However, health behavior theories such as the Protection Motivation Theory [12] and others on maximizing the impact of the genetic basis of risk information on behavior [13] posit that people could become more engaged in health behaviors, such as melanoma preventive behaviors, when their perceived vulnerability to the health condition increases and when they understand the role of health behaviors in mitigating disease risk. Based on these theories, children at risk for melanoma could benefit from interventions that include specialized and developmentally appropriate information about their personal risk for melanoma and the ways in which preventive behaviors, such as use of sun protection, can mitigate risk. While there is mixed evidence on the effectiveness of genetic risk communication for effecting preventive behavior engagement among populations at risk for melanoma [14, 15], to our knowledge, there have been no published studies on such risk communication techniques with pediatric populations.

The current paper describes the development of an educational intervention on genetic risk (the Melanoma Education and Risk Information Team (MERIT) intervention) that emphasized the mechanisms through which sun exposure amplifies genetic risk and the corresponding preventive behaviors that may mitigate that risk. MERIT was designed to be delivered concurrently to children and their parents. Specifically, the educational materials were designed for children ages 8 through 17 years who are at risk for melanoma due to

family history of the disease (e.g., a parent with melanoma, multiple extended family members with melanoma) and their parents. The program was developed by a multidisciplinary team based on current clinical recommendations, relevant scientific literature on melanoma development and risk communication, health behavior theory, and results of preliminary studies focused on children at elevated risk for melanoma.

Theoretical Basis of Educational Intervention

The educational materials were grounded in theories relevant to health behaviors and understanding about the interaction between genetic and environmental factors leading to illness. The materials drew from Protection Motivation Theory (PMT) [12], which helps to explain how health information, such as information about one's risk for a disease, could impact engagement in health behaviors. The PMT posits that an individual's intention to engage in a health behavior and their actual engagement in the health behavior is influenced by a threat appraisal (comprised of the *perceived severity* of the health condition and one's *perceived vulnerability* to the health condition) and coping appraisal (comprised of *response efficacy* or one's beliefs about the efficacy of the health behaviors in preventing the health problem and *self-efficacy* or beliefs about one's ability to implement the health behaviors). Given our goal of providing developmentally-appropriate melanoma risk information and education on preventive behaviors that could mitigate risk for melanoma, we targeted individuals' perceived vulnerability and response efficacy. Based on PMT, increased perceived vulnerability and increased response efficacy are expected to contribute to higher levels of engagement in the desired health behaviors. The educational materials therefore aimed to increase children's and their parents' perceptions of children's vulnerability to melanoma due to family history of the disease. We targeted DNA damage from UVR exposure, which could lead to skin cancer development, as a primary learning outcome in order to increase perceived vulnerability. To promote perceptions of the response efficacy of preventive behaviors (i.e., that engaging in the recommended sun protective behaviors would help prevent melanoma), the materials highlighted the mechanisms through which preventive behaviors worked – for example, that sunscreen application protects one's DNA from the damaging effects of UVR. Our inclusion of information on the ways in which protective behaviors, such as use of sunscreen and protective clothing, decrease melanoma risk is also consistent with existing theories advocating discussion of the mechanisms of action of preventive approaches to encourage adherence [13]. Specifically, Marteau and Weinman [13] expanded on the common sense model of self-regulation of health and illness [16] to propose that genetic risk information may be more likely to lead to behavior change if individuals are provided with information that illustrates the interaction between genetic and environmental causes for a disease.

Overview of Team and Setting

We assembled a multidisciplinary team to create the educational materials. Our team was co- led by a pediatric psychologist with expertise in adherence to medical recommendations among pediatric populations and experience delivering health-focused interventions to children and families, and a social health psychologist with expertise in health cognitions and future-oriented thinking, including among individuals who carry genetic risk for cancer.

Two board-certified dermatologists who specialize in melanoma provided expertise on management of individuals and families at elevated risk for melanoma, and melanoma screening and prevention. Several additional team members provided input on specific characteristics of the educational materials. A certified genetic counselor and a health communication researcher provided input on methods for communicating genetic risk to clinical populations and the public. We also engaged two health educators who provided input on national recommendations for skin cancer prevention and on the health literacy level of the materials. To develop the educational materials, the aforementioned team members collaborated closely with a science writer and a graphic artist with experience developing genetics-focused curriculum and educational materials for K-12 students, educators, and the public. Throughout the development process, a graduate student in public health assisted in coordinating team members.

All team members were affiliated with an academic medical center or the institution's NCI-designated comprehensive cancer center. The cancer center has a focus on cancer genetics, including genetics of melanoma, and the identification of individuals who are at elevated risk for melanoma. The cancer center serves a catchment area in the Intermountain West, an area with one of the highest rates of melanoma in the United States [17] and a relatively large proportion of children (31% of the population are under age 18) [18].

Educational Intervention Development

The MERIT educational intervention was based on several sources. First, we solicited input from our two dermatologists and one of our health educators to identify and interpret current clinical guidelines for skin cancer prevention (e.g., use of sun protection, screening methods), including recommendations for individuals at elevated risk. Second, we attempted to identify relevant scientific literature. Related to melanoma and its development, we identified articles on carcinogenesis, mutagenesis, DNA repair mechanisms, and diagrams of moles used in medical education. We did not identify any scientific articles that described evidence-based practices for genetic risk communication with pediatric populations. Existing literature on genetic risk communication with pediatric populations focuses on the psychological, social, and behavioral impacts of reporting genetic test results to children, and there is limited information presented on the actual communication methods used, including whether the communication methods employed convey how genetic factors confer risk through inherited factors [19, 20].

In the absence of evidence-based methods for effective risk communication with children, we drew on several related literatures to inform our methods for communicating genetic risk and preventive recommendations, including literature on adults' and children's risk perceptions and children's understanding of genetic concepts. This literature suggests that individuals may underestimate their risk for a number of potential adverse events that could occur in the future, such as cancer and other health problems, or other events causing harm (e.g., being in a car accident) [21, 22]. Thus, we set out to design educational materials that conveyed that individuals who have family members who had melanoma are at greater risk for melanoma. Specifically, in the MERIT materials, we used the height of one's shadow to depict melanoma risk, with a taller shadow indicating greater risk. We also designed content

on genes and DNA to explain how risk is inherited, a concept that may be a difficult or unfamiliar to children [23].

Third, we developed the educational content based on our team's prior studies with families who carry genetic risk for melanoma. Across these studies, adults expressed their desire for resources that would help them communicate with their children about the family's risk for melanoma and ways to prevent it, which they believed could increase children's melanoma risk awareness and improve children's engagement in melanoma preventive behaviors [24]. However, in a separate analysis from the same study sample, more than half of the parents who had reported intending to discuss preventive behaviors with their children and/or grandchildren reported that they had not done so 6 months after genetic test reporting [7]. Parents in this sample suggested that educational materials on melanoma risk and prevention would be useful for their conversations with children about these topics. Our results from a separate study with families in which a parent has a history of melanoma have similarly indicated that children and parents could benefit from receiving information on preventive behaviors and strategies to communicate effectively about melanoma risk and prevention within the family. For example, children and families reported being unfamiliar with skin screening options for children (e.g., conducting skin self-exams with parental assistance), and experiencing challenges implementing preventive behaviors (e.g., difficulty monitoring cumulative UVR exposure over the course of a day). Parents also expressed difficulty talking with their children about increased familial risk for melanoma and how this risk related to regular engagement in melanoma preventive behaviors [25, 26].

Building on the above sources, our team drafted an initial outline of the essential teaching points, which was iteratively refined based on feedback from all team members. Our science writer collaborator drafted an annotated outline, which organized teaching points into a cohesive 'story' for families using age-appropriate language, along with ideas for communicating as many concepts as possible through images. During this process, the graphic artist developed a visual style for the materials and began drafting illustrations for the primary teaching points. The entire team assisted in editing and finalizing the annotated outline, and the science writer and graphic artist created the educational materials using this final annotated outline.

Description of the MERIT Educational Intervention

The educational materials focus on several key content areas, with the goal of improving children's and parent's knowledge: foundational concepts for understanding DNA damage, mutation, and melanoma development, regulating cell growth, and concepts related to genetic and environmental risk for melanoma and methods for prevention and control of melanoma (Table 1). In the materials, the size of a person's shadow was used as a pictorial way of depicting children's risk for melanoma, with a taller shadow indicating higher risk (Figure 1). In addition, we designed the materials to maximize their applicability to children from different racial or ethnic backgrounds and who had different skin types. For example, the illustrations about genetic risk and photographs depicting melanoma preventive behaviors included individuals of different racial backgrounds and with different skin types.

The materials contained information on both melanoma prevention and screening behaviors. Screening behaviors covered included implementation of skin self-exams and seeing a dermatologist for skin concerns detected during skin self-exams. For instance, the materials present the ABCDE guidelines for recognizing potentially problematic moles, recommends that children get familiar with their moles and freckles, and suggests that trusted family members or caregivers (such as a parent) can assist with skin exams and hard to see places such as the scalp or back. Also, one of the educational slides depicted a teenager receiving a total body skin exam by a health care provider. Screening for children with a familial risk for melanoma is recommended by some to begin at age 10 [27, 28].

Each slide included text and an illustration or photograph (Figures 1, 2). We collaborated with a photographer to create custom photographs with age-appropriate models to illustrate melanoma preventive behaviors that children can engage in, in their daily lives (e.g., teammates at soccer practice applying sunscreen together) and with healthcare providers (e.g., total body skin exam). The final educational materials were designed to be viewed in PowerPoint, as both videos and slides. Videos were included to provide families with a variety of engaging visual materials, especially for complex topics (e.g., DNA, inheritance).

We expect delivery of the complete presentation to take 30 minutes. Delivery time will be examined in the context of a planned evaluation (see below). Families also receive a summary handout containing both text and graphics from the PowerPoint presentation of the main educational concepts. The MERIT materials were designed to be implemented in clinical settings, such as pediatric healthcare settings (e.g., children identified as being at elevated risk for melanoma when obtaining family health history) or in the context of family-focused care within adult oncology settings (e.g., at-risk children identified through the diagnosis and treatment of a parent with melanoma). Pending planned testing of the materials, the materials could be shortened in future versions to increase feasibility of implementation.

Planned Evaluation

We plan to conduct an initial pilot test of the materials with children and their parents, where a parent has a history of melanoma. Families will be recruited from the cancer center affiliated with our institution (described earlier). Families will be asked to complete self-reported measures immediately before and after receiving the intervention, and then one month following the intervention. Because the educational intervention focuses on providing melanoma risk and prevention information to children and families, knowledge is the primary outcome. We created 32 items to assess children's and their parents' knowledge of the most essential concepts presented in the educational materials. The knowledge domains we assessed include the following (number of items for each domain and corresponding concept numbers in Table 1 are included in parentheses): foundational concepts for understanding DNA damage, mutation, and melanoma development (7 items; concepts 1-3, 5), melanoma development (3 items; concept 4), concepts related to genetic risk for melanoma (5 items; concept 6), environmental factors that cause DNA damage (8 items; concept 6), and strategies to prevent DNA damage and melanoma (9 items; concept 7).

Consistent with Protection Motivation Theory, we will assess children's and their parents' perceptions about the children's likelihood of developing melanoma in their lifetime. Specifically, we created two questions to assess for children's and their parent's perceptions about the children's likelihood of developing melanoma in their lifetime and likelihood of developing melanoma compared to other children and adults. We will also examine secondary outcomes, including intentions to engage in melanoma preventive behaviors and reported improvements in prevention and screening behaviors. To examine the extent to which the educational intervention was associated with intentions to change melanoma preventive behaviors, we will assess parents' stage of change related to protecting their and their children's skin, drawing from the Transtheoretical Model [29, 30]. We will also examine potential changes in reported implementation of prevention and screening behaviors (i.e., use of sun protective behaviors, minutes of UVR exposure, intentional tanning, skin self-exam occurrence and thoroughness).

Children and parents will be asked to evaluate the acceptability of the educational materials (e.g., comprehensibility, length) and their perceived relevance. We will also assess the extent to which child age moderated outcomes, and child and parent perceptions of specific concepts presented in the materials, including the 'shadow metaphor' used to convey degree of melanoma risk.

Discussion

There are few melanoma preventive interventions targeting children who are at risk for disease [7], despite the fact that engagement in melanoma preventive behaviors such as sun protection is particularly important during childhood and counseling about these behaviors is recommended for children at-risk for skin cancer [3, 4]. To our knowledge, the MERIT educational intervention is the first to convey key risk and prevention concepts to children at risk for melanoma that are theorized to maximize the impact of genetic risk information [12, 13]. The materials were designed to convey that children are at higher risk for melanoma if they have family members who had melanoma, and that preventive behaviors mitigate genetic risk by preventing DNA damage that can lead to melanoma. The materials incorporated current knowledge from several relevant fields (i.e., dermatology, science and health education, health behavior change, risk communication), scientifically and medically accurate information, and developmentally appropriate methods of conveying this information. In addition, the educational materials were unique in their employment of content and formats tailored for children, including illustrations and the use of 'shadow' metaphor to symbolize degree of risk.

Our team's experience creating the MERIT materials yielded several lessons learned related to the development process. Due to the multidisciplinary nature of our team, each team member had a wealth of expertise on particular topics (e.g., molecular processes associated with melanoma development, genetics-focused science education). Thus, a challenging task was striking a balance between covering topics thoroughly and ensuring that the content was succinct enough to maintain children's attention. The education expanded on the topics considered to be standard of care elements for providing genetic counseling and testing for hereditary cancer [31], to include more in-depth discussion of genetic mechanisms in order

to clearly illustrate for children the biological link between UVR exposure and melanoma risk. A second challenge our team faced was resolving differing opinions among team members on specific content to be presented. For instance, team members differed on whether the term ‘mutation’ should be used in the materials when covering DNA damage. Such differences in opinion were discussed and resolved based on relevant scientific literature and clinical expertise. In the case of the term *mutation*, concern was raised about misconceptions about and negative connotations associated with the term [32], and the potential for children to associate the term ‘mutation’ with popular culture characters (e.g., superheroes). However, team members who work clinically with populations at elevated risk for cancers expressed that it was important to use scientifically accurate terms as a foundation for conveying cancer risk information. Ultimately, we elected to use the term; however, we included an open-ended question in the acceptability assessment to understand participants’ reactions to it, including potentially negative reactions.

If the MERIT educational materials are found to be effective in increasing children's and parents’ knowledge about melanoma risk and prevention, perceived risk for melanoma, and intentions to change or actual changes in melanoma preventive behaviors, MERIT could be tested within the context of larger efficacy trials. These trials would also allow an examination of potential moderators of MERIT's effectiveness, including child age [6] and gender and time since parent's melanoma diagnosis. Future iterations of MERIT and other educational programs for children at risk for melanoma could also include content and intervention modalities adapted for children of different ages or developmental levels, and could adopt formats that can be more easily disseminated, such as a web-based or other self-guided resource. In addition, MERIT content applicable to all children (e.g., UVR's role in DNA damage, implementation of sun protective behaviors), regardless of familial risk, could be tested among children who are at population risk for the disease.

Interventions for children who carry a familial risk for melanoma are greatly needed. Programs such as MERIT could serve as an educational tool for delivering risk information and preventive behavior recommendations to families affected by melanoma. In addition, such educational programs could promote children's engagement in preventive behaviors by promoting family communication about melanoma. If children and parents require additional support beyond risk and prevention education, programs could address psychosocial needs (e.g., stress and anxiety management, problem-solving, coping strategies [21]) and support families in addressing their specific barriers to engaging in melanoma preventive behaviors [9, 10].

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GENETIC RISK

Some genetic risk factors for melanoma are easy to see, like skin tone and hair color.

ENVIRONMENTAL RISK

The biggest environmental risk factor for melanoma is exposure to sunlight.

Fig. 1.
Example slides on use of shadow size to depict degree of melanoma risk

WHAT YOU CAN DO

Protect your DNA

Re-apply often!

Follow the instructions on the sunscreen label. In general:

- Re-apply after sweating or swimming
- Re-apply every 2 hours

WHAT YOU CAN DO

Protect your DNA

Physical barriers:

- Wear a hat with a 4-inch-wide brim all the way around
- Wear sunglasses with UV protection

Fig. 2.
Example preventive behavior slides

Table 1

Summary of MERIT educational material concepts

Concept	Presentation Method	Example content
1) Traits & the environment	Video	Each person has traits. The combination of genes and experiences makes a person unique. Some inherited traits (e.g., disease risk) can be inherited, but can also be mitigated by behavior.
2) DNA & genes	Video	All living things are made up of DNA. Small differences within the bases of DNA are what make each person's genetic traits different.
3) Mutation	Slides	Mutation is an important part of how melanoma develops. Environmental factors can cause mutation. DNA damage accumulates over a lifetime in tissue that divides regularly, like skin.
4) Melanoma development	Slides	Cancer results from uncontrolled cellular division. Melanoma can develop from the melanocytes in normal skin or those in a mole.
5) Regulating cell growth	Slides	The cell's anti-cancer systems can repair DNA damage and control cell division.
6) Genetic and environmental risk	Video and Slides	For individuals who begin life with higher genetic risk due to family history, managing environmental risk through preventive behaviors is especially important. Shadows were used to visualize one's risk for melanoma (Figure 1).
7) Melanoma prevention and control ^a	Slides	Melanoma preventive behaviors that families can use to “protect their DNA from damage.” Conducting regular screening (e.g., skin exams) could help catch problematic skin changes early on.

Note.

^aPrevention and control behaviors reviewed included use of sun protective strategies (using broad-spectrum sunscreen at least 30 minutes prior to UVR exposure, re-application of sunscreen, avoiding peak UVR exposure 10 am – 4 pm, seeking shade, wearing protective clothing including long-sleeves and pants, wide-brimmed hats, and UV protective sunglasses), avoiding intentional tanning, learning how to conduct thorough skin self-exams [27, 28] using the ABCDE guidelines for detecting potentially problematic skin features, and seeing a dermatologist for skin concerns detected during skin self-exams.