

Perceptions of Risk of Developing Skin Cancer for Diverse Audiences: Enhancing Relevance of Sun Protection to Reduce the Risk

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Abstract Sixty-five percent of kidney transplant recipients (KTRs) develop squamous cell carcinoma (SCC). Perceptions of risk of developing skin cancer, amelioration of this risk with sun protection, and having choices among sun protection strategies may enhance sun protection use by KTRs, who are at greater risk than the general population. Thirty KTRs stratified among non-Hispanic Whites, non-Hispanic Blacks, and Hispanic/Latinos evaluated three versions of the interactive, web-based, electronic sun protection program and suggested refinements. The sequence of content presentation prepared the participant to accept the credibility, accuracy, and relevance of the message. Beginning with informing participants that using sun protection reduces the chance of developing skin cancer made the information credible to KTRs. Showing skin cancer on all skin types and patient testimonials enhanced participants' awareness of their susceptibility to develop skin cancer and primed patients to receive their personal risk of developing skin cancer. Coupling presentation of knowledge about the benefits of sun protection in reducing the risk of developing skin cancer with the personal risk of getting the

disease was essential to KTRs believing that they could influence their health outcome.

Keywords Skin cancer · Risk perceptions · Kidney transplant recipients · Patient education

Many patients desire more information than can be provided during the traditional physician-patient clinical visit. Patient decision aids empower patients, allow them to make informed decisions, and may lead to adoption of sun protection behaviors by an at-risk population of kidney transplant recipients (KTRs) that may prevent skin cancer [1, 2]. The approximately 180,000 living KTRs in the United States (US) are at increased risk of developing skin cancer, especially squamous cell carcinoma (SCC), because of the lifelong immunosuppression needed to prevent rejection of the transplant [3]. While non-Hispanic White (White) KTRs with fair skin have the greatest risk of developing SCC, SCC also occurs in many Hispanic/Latino and non-Hispanic Black (Black) KTRs [4]. In temperate climates with moderate solar exposure, 65 % of KTRs developed a SCC 20 years after transplant [5]. While precise incidence studies are lacking, SCC incidence in the general population was about 0.1 % [6, 7]. A randomized controlled trial in KTRs showed that development of SCC was significantly reduced by effective sun protection practiced over 2 years by KTRs (no SCC in the sunscreen group vs. eight in the control group) [8]. Sun protection education with a workbook improved sun protection by KTRs [2].

Risk perceptions—a patient's beliefs about their personal likelihood of a negative event occurring—play a central role in patients' health behavior. Perceived risk is a core component in health behavior theories, i.e., Health Belief Model and Precaution Adoption Process Model [9]. Individuals who believe both that they are at risk for a negative health outcome,

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such as skin cancer, and that this negative outcome can be ameliorated by their actions may be more likely to take action [10]. Socially and culturally structured concepts inform actions and understandings about risks [11]. Since minorities comprise 42 % of living KTRs in the US [1], it was important to understand Hispanic/Latino and Black KTRs’ perception of skin cancer and their risk of developing skin cancer in order to develop a patient decision aid. The patient decision aid, which provided information to increase knowledge and offered options for sun protection, was intended to supplement information provided by the physician by helping patients to clarify the personal value they attached to skin cancer prevention and select the best course of action for them [12]. Prototypes of an electronic interactive program, SunProtect™, were developed by the authors and evaluated using a tablet personal computer (tablet) to deliver the program. Qualitative research with Hispanic/Latino, Black, and White KTRs of both genders informed the development of the prototypes.

Methods

Sun Protection Program Content

The interactive, electronic educational program, SunProtect™, was designed to be delivered by a touch screen tablet with text and audio narration in English and Spanish in about 20 min. The SunProtect™ goals were to (1) increase KTRs’ understanding of their probability of developing skin cancer; (2) the relevance of sun protection to avoid skin cancer; (3) present options among four sun protection strategies including seeking shade when outdoors, shifting the time of

outdoor activities, using protective clothing such as hats, shirts, and sunglasses, and sunscreen; and (4) allow the user to establish knowledge-based sun protection preferences with the intention of using sun protection. Chapters presented the following topics: benefits of sun protection, skin cancers, risk of developing skin cancer, common outdoor activities, sun protection options, and a personal recommendation for the KTR about sun protection based on their preferences, skin type, and habits of outdoor activities (Table 1).

Participants Evaluating the Sun Protection Program

KTRs without a skin cancer history who received a kidney transplant within the last 2 years were recruited by telephone using a registry of 200 KTRs with known self-reported race/ethnicity. Participant recruitment was stratified by race/ethnicity. Eligibility criteria included the ability to read at an eighth-grade level, see the screen on the tablet, and being capable of verbal discussion.

Cognitive Interviews: Exploring Framing

The cognitive interview sessions were conducted by three trained research staff of the same ethnicity/race as the participant. Participants completed a self-administered questionnaire with demographic items. During a structured 1 h interview, the KTRs viewed the eight chapters by viewing and commenting about individual screens displayed on the tablet (Table 1). In addition to eliciting comments about the content of the individual chapters, the order in which the content was viewed was evaluated with three different iterations of the program (Table 1).

Table 1 Chapter order and content

Chapter order no. 1	Chapter order no. 2	Chapter order no. 3	Chapter no. 3 screens Picture (n)	Supplementary final files	
				Picture (n)	Video (n)
Risk of developing skin cancer	Skin cancer (sunburn + skin cancer pictures)	Sun protection benefits	1 1	4	0
Skin cancer (sunburn + skin cancer pictures)	Sun protection benefits	Skin cancer (sunburn + skin cancer pictures)	5 5	6	0
Sun protection benefits	Risk of developing skin cancer	Risk of developing skin cancer (select skin tone)	6 3	4	1
ABC rules of sun protection (avoid, block, cover up)	ABC rules of sun protection (avoid, block, cover up)	How people get sun exposure (select outdoor activities)	3 0	2	0
How people get sun exposure	How people get sun exposure	ABC rules of sun protection (avoid, block, cover up)	3 3	0	3
Frequently asked questions about sunscreen	Frequently asked questions about sunscreen	Frequently asked questions about sunscreen	9 4	3	8
Protective clothing	Protective clothing	Protective clothing	2	4	0
Personal score for getting skin cancer and tailored sun protection recommendation	Personal score for getting skin cancer and tailored sun protection recommendation	Personal score for getting skin cancer and tailored sun protection recommendation	5 4	0	0

After viewing the individual screen, participants were asked a series of structured questions requiring KTRs to give their impression of the screen viewed on the tablet and relate details of the material, which is the first step in the cognitive interview. In addition, participants were prompted for their immediate evaluation of the credibility, accuracy, and relevance of the content. Next, participants were asked if they desired further information about the content presented on the screen. If so, they were asked to describe what they wished to learn. After completing all of the screens in a chapter, participants were asked to describe their overall impression of the content of the chapter and how it made them feel. Then, the KTRs were invited to continue with the rest of the program by selecting another chapter. After the initial 10 participants, this question was changed to inviting the KTRs to continue with the next chapter. After completing the evaluation of the program, the research assistant invited the KTR to discuss their concerns with the doctor.

During the first set of 10 cognitive interviews, KTRs started by viewing the risk of developing skin cancer chapter. The probabilistic information was presented as text on the screen with audio narration as the following: “About 65 out of 100 (65 %) kidney transplant recipients get skin cancer. In the general public, fewer than 1 out of 100 (1 %) people get skin cancer. Kidney transplant recipients have a greater chance of getting skin cancer than other people.” After exploring their feelings about this chapter, KTRs were asked to give their opinion about including a visual display of the risk of developing skin cancer. If KTRs desired a visual display, then they were shown an icon array of stick figures, a bar or pie graph and asked for their preference.

In the second version of the prototype, the order was changed to place examples of skin cancer and the benefits of sun protection before the risk of developing skin cancer (Table 1). In addition, the individual screen presenting the risk of developing skin cancer was positively framed by stating that KTRs’ sun protection could make a difference in developing skin cancer [8], e.g., “The chance of getting skin cancer can be greatly reduced by using sun protection.” Numerical text and visual magnitude as pie graphs were presented on the same screen, which compared the percentage of KTRs expected to develop skin cancer with the general population [13, 14]. Affective responses to this chapter on their risk of developing skin cancer were probed by asking if this chapter made them worry or anxious.

In the third and final iteration, the benefits of sun protection were placed at the beginning of the program and followed by the skin cancer chapter with images of sunburn and skin cancer occurring on people with differing skin colors.

The interviews were audio-recorded, summarized, and analyzed for key patterns and themes using principles from Interpretative Phenomenological Analysis [15]. The research staff’s field notes recorded non-verbal communications. Three

reviewers independently reviewed the audiotapes, field notes, and coded the data. The team met to discuss the interpretations, come to consensus, and identify data-driven approaches to revise the content. Revisions to content presented on the screens of the tablet were made in an iterative process after conducting 10 interviews with at least three individuals from each racial/ethnic group. Interviews were continued until at least two KTRs of the same race/ethnicity and gender had no further suggestions for changes. The Northwestern University’s Institutional Review Board approved the research protocol. All participants provided written informed consent and received \$60 to compensate them for their time and a parking voucher.

Results

Population

Saturation was achieved after 30 cognitive interviews. Thirty KTRs representing the following ethnic/racial groups: White (10), Black (10), and Hispanic/Latino (10) evaluated the program. Participants included 14 women and 16 men with a median age of 50 y.

Graphic Preference

The initial 10 participants favored the use of pie graphs with the text. The figure of 1 stick figure in 100 was “too much to have to look at”. Participants had difficulty understanding the *x*- and *y*-axis of the bar graph and found “all of the little lines are hard to see”. The remaining 20 participants viewed the pie graphs and agreed that the pie graphs helped them to understand their chance of getting skin cancer.

Chapter Selection

The program was designed to allow the participant to select the order of the chapters they wished to view from the table of contents and the menu bar. None of the initial 10 KTRs navigated among the chapters. All used the program by tapping the next page button, thus, the viewing order was established by the table of contents. This way of accessing content meant that the order of the chapters was important to framing or conditioning the participants’ response to numerical presentation of their risk of developing skin cancer.

Cognitive Interviews: Exploring Framing of Risk Perception

The KTRs in the first set of cognitive interviews [$n=10$, 4 White (2 women, 2 men), 3 Hispanic/Latino (1 woman, 2

men), and 3 Black (1 woman, 2 men)] doubted the credibility of the statement that 65 KTRs in 100 will develop skin cancer. A White woman said, “This seems not true. This is very different from what my other doctors told me. You must check your facts.” Two White women KTRs became angry with the research staff and one refused to continue. The KTR, who refused to continue evaluating the program, accepted the offer to discuss her concerns with the doctor. All KTRs expressed surprise at being told they could get skin cancer. A White man said, “It seems no matter what you do, you will get skin cancer.” A Hispanic/Latino woman expressed her sense of hopelessness by saying, “After all I have been through, now this. My gift of life, my kidney, will give me cancer.” All the Black KTRs doubted the relevance. A Black man said, “That cannot be right. Skin cancer is for White people.” Changing the chapter order by starting with pictures of skin cancer on all skin types was recommended by KTRs, who reported that they would believe skin cancer could happen to them if they saw a skin cancer on someone with skin that looks like their skin.

In the second iteration, the order of the content of SunProtect™ was changed to start with descriptions and pictures of skin cancer. The risk of developing skin cancer was expanded to include, “The chance of getting skin cancer can be greatly reduced by using sun protection.” None of the KTRs, who participated in the second set of interviews [$n=20$, 6 White (2 women, 4 men), 7 Hispanic/Latino (4 women, 3 men), and 7 Black (3 women, 4 men)] doubted the credibility, accuracy, or relevance of the message. In the second set of interviews, KTRs recommended “easing into the scary pictures of skin cancer and the scary number of 65 KTRs in 100 will get skin cancer.” The suggestion was to begin with a chapter on the benefit of sun protection. Their suggestion for the chapter about the risk of developing skin cancer was to start with telling why KTRs have a greater chance of getting skin cancer and “slip in 65 % of KTRs will get skin cancer along with using sun protection will make this better.” Seven of the 10 participants suggested that the program begin with the chapter describing the reason to avoid getting too much sun is to keep from getting skin cancer. All participants wanted more detailed description of how to use sunscreen and more testimonials.

The order of the chapters in the final version of the program was considered appropriate by KTRs. The video content in the chapter of frequently asked questions about sunscreen was received without suggestions for change. Participants stated that they would use sun protection because it would keep them from getting skin cancer. Many KTRs described their immediate plans to begin using sun protection, e.g., a Black woman said she would get a great hat.

Discussion

The primary finding that emerged from the series of cognitive interviews about the three iterations of SunProtect™ was the need to start the program with the benefit of sun protection followed by showing skin cancer on all skin types and providing testimonials, which enhanced the relevance for the KTRs. The secondary finding was that framing the numerical risk of developing skin cancer with the positive message that sun protection reduced the risk set the stage for KTRs to accept the information as credible.

Visual images and testimonials can be highly persuasive and increase comprehension and relevance of medical information [16, 17]. In our prior research using a printed workbook, pictures of skin cancer occurring on people with skin color helped KTRs progress from having knowledge of skin cancer to believing that they could develop skin cancer because they observed skin cancers on people with their skin color [18]. The tablet format supported video presentation; therefore, narratives in the form of storytelling and testimonials by KTRs from each ethnicity were created to demonstrate the risk of skin cancer and the relevance of sun protection, which was very important among Blacks and Latinos. Transportation theory holds that testimonial narratives can have uniquely persuasive effects in overcoming preconceived beliefs and cognitive biases because people transported into a narrative world will alter their beliefs based on information, claims, or events depicted [19, 20]. These narratives seem real, and people identify with characters in a story, thus, increasing the likelihood of social influence, and shift normative beliefs about risks.

Starting SunProtect™ by presenting KTRs with probabilistic information about the percentage of KTRs expected to develop skin cancer caused KTRs to use their affective framework to make sense of the information. Since KTRs had limited or no experience with skin cancer, and their cultural beliefs often contradicted the information presented in SunProtect™, they could only respond affectively. The KTRs' negative affective reactions to being presented with the risk of developing skin cancer were in part caused by their being surprised by the news. The intensity of the participants' anxiety or anger may have been amplified by KTRs believing that the “new kidney” gave them the gift of life, and it was snatched away by the inevitability of getting cancer [21].

Hispanic/Latino and Black KTRs had difficulty accepting the accuracy of the risk statement as they did not know anyone with skin cancer. In addition, in our prior research, we identified a misconception among Hispanics and Blacks that skin pigment completely protects against skin cancer [22]. Others have reported that Blacks' and Hispanics' self-reported low sunscreen use was due in part to the misconception that it is unnecessary to use sun protection to prevent skin cancers because their skin pigment was protective [23]. In fact, Hispanic

and Black people exhibit considerable diversity in sun sensitivity of their skin with some individuals in each group having sun-sensitive skin that becomes irritated after sun exposure [24]. Others found that Blacks and Hispanics were more likely to believe that little can be done to decrease the risk of developing skin cancer than non-Hispanic Whites [25]. Hispanic and Black KTRs in this study needed to be given information to personalize the relevance of the content before stating the risk of developing skin cancer. Personalizing the relevance of the risk of developing skin cancer was enhanced by placing pictures of skin cancers occurring on skin with a range of tones at the beginning of the application.

The study is not without some limitations. The findings may not generalize to other KTR populations or to the general public as this study was conducted in one urban medical center. Because two changes were made concurrently, it was not possible to determine if either positively framing the message or personalizing the risk to develop skin cancer by starting with images of skin cancers would have been sufficient.

Patient's cognitive and affective feelings of vulnerability, and perceptions of being at risk to develop skin cancer, may vary depending upon their gender, race/ethnicity, and/or having a chronic disease, such as being a kidney transplant recipient. Coupling the presentation of the knowledge about the benefits of sun protection in reducing the risk of developing skin cancer with the personal risk of getting the disease was essential to KTRs believing that they could influence their health outcome. Pictures and testimonials enhanced the personal relevance of skin cancer and its prevention. A randomized controlled trial will define the initiation of sun protection by KTRs using SunProtect™.

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