Squamous Cell Carcinoma in Solid Organ Transplant Recipients: Influences on Perception of Risk and Optimal Time to Provide Education

Squamous cell carcinoma (SCC) has a mortality rate of up to 8% in solid organ transplant recipients (OTRs), and the risk of OTRs developing SCC is up to 250-fold greater than that of the general population. Despite these risks, patients commonly do not seek health care for skin checks, nor do they routinely perform skin self-examinations (SSEs). Moreover, although patients in 1 study recalled being told to use sunscreen, few were aware that their immunosuppressive medication increased skin cancer risk. The present study assesses (1) the optimal time after transplantation to deliver SSE educational intervention; (2) the relationship between lifetime sun exposure and OTRs’ perception of SSE importance; and (3) the impact of SCC discussion with a healthcare worker on the likelihood of SSE performance.

Methods. Participants were solicited from Northwestern Memorial Hospital’s OTR registry into 2 phases of the research.

Focus Groups. Twenty-two OTRs with and without SCC history were interviewed with regard to their perceptions of relevance and acceptance of performing SSEs and the best time to receive SCC early detection information.

Cognitive Interviews. Twenty-five OTRs completed self-report questionnaires 3 to 6 months, 1 to 2 years, or 3 to 7 years after transplantation to assess lifetime sun exposure, SCC awareness and risk perception, perceived importance of and confidence in performing SSEs. Participants’ comprehension of an SCC brochure and the optimal time to receive early detection of SCC educational information was assessed via standardized interview.

Results. Focus Groups. Recurrent themes showed that the first few months after transplantation were too early for SCC education. Participants expressed concern about the viability of their new organ, a sense of being overwhelmed by physician visits and new medications, and hesitation to learn about a potential new disease, especially cancer.

Cognitive Interviews. An optimal time for SCC education is 1 year after transplantation (Table). Perception of the importance of checking the skin did not relate to subjects’ lifetime sun exposure (P = .30). Prior discussion with a member of the transplant team about skin cancer did not relate to SSE performance (P = .41).

Comment. The AT-RISC Alliance has recommended skin cancer prevention, including sun protection and SSE, as part of posttransplantation care. While studies have shown that perceived risk and distress can be used as teachable moments for skin cancer education and intervention, the time period when OTRs feel that they are ready to receive SCC education has not been addressed. As OTRs are faced with many stressors that can affect their adherence to the medical regimen and physician instruction, it is important to present the educational intervention when the OTR is ready to receive and possibly act on it. Because the process of assimilating information and acting on it may extend over a period of time, patient education is a repetitive process. Patients’ responses may be improved by delivering the message when the patient is ready. Most of our OTRs believed that 1 year after transplantation was the optimal time for SCC education.

Moreover, we determined that OTR’s lifetime sun exposure did not relate to the perceived importance of SSEs. Perceived skin cancer risk has been associated with higher frequency of SSEs. Heightening patients’ awareness of the cumulative risks of chronic immunosuppression and past sun exposure may improve SSE performance.

Squamous cell carcinoma discussion with a health care worker during posttransplantation care did not make OTRs more likely to perform SSEs. During cognitive interviewing, participants stated that they did not clearly understand instructions to “stay out of the sun and use sunscreen.” Even when OTRs were aware of their increased risk, they did not recall being specifically told or taught to do SSEs during routine posttransplantation follow-up. Patients may not be performing SSEs because they do not fully understand their risks for SCC and have not received education regarding skin cancer warning signs. We believe that giving patients specific information regarding the importance and systematic methods of performing SSEs may increase patient-provider communication and enhance SSE efficacy. Although our study did not address the time to present sun protection information, it would be prudent to consider doing so within the first 6 months after transplantation, thus providing the opportunity for a scaled approach to cushioning the psychological impact of the patient’s discovery of increased skin cancer risk.

Our small sample and the use of a single institution’s population limit the conclusions to be drawn from this qualitative study. Observations made during focus group interviewing, participants stated that they did not clearly understand instructions to “stay out of the sun and use sunscreen.” Even when OTRs were aware of their increased risk, they did not recall being specifically told or taught to do SSEs during routine posttransplantation follow-up. Patients may not be performing SSEs because they do not fully understand their risks for SCC and have not received education regarding skin cancer warning signs. We believe that giving patients specific information regarding the importance and systematic methods of performing SSEs may increase patient-provider communication and enhance SSE efficacy. Although our study did not address the time to present sun protection information, it would be prudent to consider doing so within the first 6 months after transplantation, thus providing the opportunity for a scaled approach to cushioning the psychological impact of the patient’s discovery of increased skin cancer risk.

Our small sample and the use of a single institution’s population limit the conclusions to be drawn from this qualitative study. Observations made during focus group sessions might not be generalized to other OTRs.

Our future research will examine the efficacy of a written educational intervention. We conclude that information from health care providers presented at the optimal, most receptive time will likely increase SSE performance by OTRs.

Nikki N. Kim, BS
Susan L. Boone, MD
Sara Ortiz, BA
Kim Mallett, PhD
Jerod Stapleton, BS
Rob Turrisi, PhD
Simon Yoo, MD
Dennis P. West, PhD
Alfred W. Rademaker, PhD
June K. Robinson, MD

Correspondence: Dr Robinson, 132 E Delaware Pl, No. 5806, Chicago, IL 60611 (june-robinson@northwestern.edu).

Author Contributions: Study concept and design: Kim, Boone, Ortiz, Stapleton, Yoo, and Robinson. Acquisition of data: Kim, Boone, Ortiz, Mallett, and Robinson. Analysis and interpretation of data: Kim, Boone, Ortiz, Turrisi, West, and Rademaker. Drafting of the manuscript: Kim, Boone, and Robinson. Critical revision of the manuscript for important intellectual content: Boone, Ortiz, Mallett, Stapleton, Turrisi, Yoo, West, and Rademaker. Statistical analysis: Turrisi and Rademaker. Obtained funding: Robinson. Administrative, technical, and material support: Boone, Ortiz, Yoo, West, and Robinson. Study supervision: Boone, Ortiz, and Robinson.

Financial Disclosure: None reported.

Disclaimer: Dr Robinson is the editor of the Archives and was not involved in the editorial evaluation or decision to accept this work for publication.

Additional Contributions: The members of the Solid Organ Transplantation Team of Northwestern Memorial Hospital provided valuable support, especially the physician members, Michael Abecassis, MD, MBA, Daniel R. Friedewald, MD, Josh Levitsky, MD, Xunrong Luo, MD, PhD, and Daniel R. Ganger, MD.