ORIGINAL ARTICLE

Validity of skin cancer malignancy reporting to the Organ Procurement Transplant Network: A cohort study

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Background: The Organ Procurement Transplant Network (OPTN) registry collects data on posttransplant malignancies in solid organ transplant recipients. Complete and accurate registry data on skin cancer is critical for research on epidemiology and interventions.

Objective: The study goal was to determine the validity of Organ Procurement Transplant Network skin cancer data.

Methods: This cohort study compared reporting of posttransplant squamous cell carcinoma (SCC) and malignant melanoma (MM) in OPTN to medical-record review-derived data from the Transplant Skin Cancer Network (TSCN) database. In total, 4934 organ transplant recipients from the TSCN database were linked to patient-level OPTN malignancy data. We calculated sensitivity, specificity, correct classification (CC), positive predictive value (PPV), and negative predictive value (NPV) for SCC and MM reporting in the OPTN database.

Results: OPTN reporting for SCC (population prevalence 11%) had sensitivity 41%, specificity 99%, PPV 88%, NPV 93%, and CC 93%. OPTN reporting for MM (population prevalence 1%) had sensitivity 22%, specificity 100%, PPV 73%, NPV 99%, and CC 99%.

Limitations: Only a subset of patients in the TSCN cohort had matched United Network for Organ Sharing cancer registry data for comparison.

Conclusion: OPTN reporting had poor sensitivity but excellent specificity for SCC and MM. Dermatologists and transplant physicians are encouraged to improve the validity of OPTN skin cancer data through improved communication and reporting. (J Am Acad Dermatol http://dx.doi.org/10.1016/j.jaad.2017.09.003.)

Key words: cancer registry; melanoma; organ transplant; squamous cell carcinoma.

The Organ Procurement Transplant Network (OPTN) database collects data on organ transplant recipients (OTRs), such as transplant history, patient characteristics, graft and patient status, and posttransplant outcomes, including malignancy. Malignancy reporting to the OPTN database informs epidemiologic research and cancer surveillance for OTRs.[1] The registry is intended to

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capture all posttransplant de novo malignancies, including skin cancers not normally captured in cancer registries such as squamous cell carcinoma (SCC). Complete and accurate cancer reporting depends on efforts by transplant centers to submit posttransplant malignancy (PTM) forms to the OPTN.

Unfortunately, cancer reporting to OPTN is incomplete for many malignancies. Yanik and colleagues compared the Scientific Registry of Transplant Recipients database, which derives its data primarily from the OPTN, with malignancy reporting from 15 state cancer registries in the Transplant Skin Cancer Match study.[1] The specific malignancies studied were non–Hodgkin lymphoma; lung, prostate, kidney, colorectal, liver, and breast cancers; and melanoma, all of which are captured in standard cancer registries. Agreement between the Scientific Registry of Transplant Recipients database and cancer registries was poor, and varied depending on the malignancy of interest (kappa 0.41 for melanoma and 0.28-0.66 for other cancers).

CAPSULE SUMMARY

- Cancer reporting to the Organ Procurement Transplant Network (OPTN) database is incomplete for many malignancies.
- This cohort study demonstrated that OPTN reporting had poor sensitivity but excellent specificity for squamous cell carcinoma and malignant melanoma.
- Physicians are encouraged to improve OPTN skin cancer data validity through improved communication and reporting.

The Transplant Skin Cancer Network (TSCN) recently reported the incidence of posttransplant skin cancer in the United States on the basis of detailed medical record review.[2] The incidence rate of SCC was 1355 per 100,000 person-years or 35-fold higher than that in the general population. The incidence rate of malignant melanoma (MM) was 125 per 100,000 person-years or 9-fold higher than that in the general population.[2] Skin cancer is not only the most common malignancy in OTRs,[3-5] it also runs an aggressive clinical course in this population, with high rates of metastasis and poor outcomes.[6-10] Given the major implications of skin cancer for posttransplant health outcomes, complete and accurate registry data on skin cancer is critical for understanding epidemiology and for informing interventions to reduce morbidity. Although cutaneous SCC is the most common skin cancer in OTRs[4] and leads to significant morbidity and mortality,[6-10] it is not included in the National Cancer Institute's Surveillance, Epidemiology, and End Results Program registries or other state cancer registries. For this reason, SCC was not included in the study by Yanik et al[1] on the accuracy of malignancy reporting to the OPTN.

We hypothesized that the OPTN registry undercaptures skin cancer diagnoses, leading to an underestimation of the significance of this posttransplant adverse outcome. The aim of this study was to assess the validity of SCC and MM reporting to the OPTN. We defined medical chart review from the TSCN study as the gold standard of cutaneous malignancy documentation and sought to determine the accuracy of the OPTN against this standard.

METHODS

The overall design was a cohort study validating correct patient classification of SCC and MM in OPTN against the TSCN database, the gold standard of medical record review. This study was approved by the University of California, San Francisco Institutional Review Board.

Study population

The TSCN incidence study included all adult (≥18 years) recipients of primary solid organ transplants performed at 26 transplant centers in the United States, in the years 2003 and 2008 (N = 10,649).[2] The TSCN database captured incident posttransplant SCC, MM, and Merkel cell carcinoma through medical chart review, with data matched and merged with demographic and transplant data from OPTN at each of the individual centers. Seventeen of the TSCN centers were granted institutional review board approval to share patient-level OPTN registry data with the central study team and were included in the current study. The other centers were not approved to share protected health identifiers and could not be linked to the OPTN registry for posttransplant malignancy reporting, resulting in 4934 OTRs for inclusion in this study. Subjects were linked to OPTN registry data by name, date of birth, transplant date, and transplant identification.

All included subjects were followed forward from the time of transplantation to the last available follow-up in the medical chart or the last follow-up date in OPTN, whichever was earlier. For any given