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International Travel for Organ Transplantation: Provider and Patient Perspectives

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Background. Organ allocation in the United States to non-US citizen, non-US residents who travel for transplant (NC/NRTx) is controversial. Current policies may not be informed by stakeholder opinions, as limited data exist assessing the knowledge or opinions of providers or patients on this issue. **Methods.** A cross-sectional, hospital-based pilot survey was distributed to providers and patients from December 2019 to June 2020 at a single large urban transplant institute. Providers were members of the departments of surgery and medicine and included both transplant and nontransplant providers. Surveys included 10 questions on eligibility, prioritization, and limitations for deceased donor transplantation and 12 demographic questions. **Results.** A total of 209 providers responded (61% women, median age 40) and 119 patients responded (62% women, median age 54). Awareness of eligibility for transplantation of US citizens, non-US citizens residing in the United States (NC/R), and NC/NRTx was high in both groups, though providers and patients lacked awareness of the eligibility of nonlegal NC/R (those who live in the United States who are not citizens and are not legal residents) to donate and receive organs. Overall, 79.3% of patients stated that NC/NRTx should be eligible for transplant in the United States compared with only 60.7% of providers ($P = 0.001$). Providers were more likely than patients to prioritize transplant to legal NC/NR over NC/NRTx (58.2% versus 35.1%, $P < 0.001$) and reported that families should be able to limit donations to NC/NRTx (34.9% versus 23.2%, $P = 0.03$). **Conclusions.** Surveyed patients and providers generally support transplant in non-US citizens; however, the strength of support varied considerably based on the legal status of the patient and the occupation of those surveyed. Larger studies are necessary to develop data-informed policy.

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The allocation of scarce medical resources, such as donated organs, remains a central ethical dilemma in the practice of medicine. In the United States, the United Network for Organ Sharing manages the Organ Procurement and Transplantation Network (OPTN), which is charged with the fair and equitable allocation of donated organs. As the number of patients waiting for organs exceeds the number donated¹ and many patients die awaiting transplantation,² parity in allocation is critical. Current criteria for allocation rely on medical necessity and proximity of available organs

and are explicitly designed to avoid political questions, such as citizenship and residency.³ It is thus deferred to individual transplant centers to determine their own listing eligibility with regard to these political designations.

A 2008 summit brought transplant experts together to establish clear definitions, principles of practice, and recommendations on transplant across national borders.⁴ The resulting *Declaration of Istanbul on Organ Trafficking and Transplant Tourism* stressed “self-sufficiency in organ donation and transplantation,” meaning a country’s ability to

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meet its own needs by use of “donation and transplant services provided within the country and organs donated by its residents.”⁵ The 2018 update explicitly stated that travel for transplant becomes unethical if the resources diverted to nonresidents undermines the country’s ability to provide for their own residents.⁵ Although no ban or explicit rules regarding the transplant of noncitizens were ever established, OPTN policies historically recommended limiting transplanting noncitizens, by way of “the 5% rule,” allowing for auditing programs if this threshold was passed. However, no program exceeding 5% was ever brought up for formal review.⁶

In 2012, the “5% rule” was replaced with an alternative policy that publicly made data surrounding residency and citizenship status available. Data collection categories were revised on the basis of citizenship and residency status: US citizen, non-US citizen residing in the United States (NC/R), and non-US citizen not residing in the United States (NC/NR).³ Importantly, OPTN does not distinguish between non-US citizens who reside in the United States based on the legality of residence within the United States. Additionally, a field was added indicating whether NC/NR candidates had traveled to the United States for the sole purpose of transplantation (NC/NRTx). These changes were made to guide future policy decisions and to achieve greater transparency for the US public regarding transplant practices.⁶

As organ supply depends on public engagement with the system by way of donation; providers, patients, and the general public represent key stakeholders in this system.⁷ However, current policies may not be informed by the opinions of these stakeholders, as review of the literature review shows limited assessment of opinions of providers, patients, or the general public on the issue of transplantation of noncitizens, particularly NC/NRTx, in the United States. To begin to address this gap, we designed a pilot survey project at a single transplant center to gain insight into the opinions of 2 participant groups, patients and medical providers, on this controversial issue.

MATERIALS AND METHODS

Study Design and Participants

This study is a cross-sectional, hospital-based survey conducted from December 2019 to June 2020 at a single urban transplant institute performing over 200 heart, liver, kidney, pancreas, and lung transplants annually with no formal policy on NC/NRTx. A web-based survey was sent via e-mail to providers within the departments of medicine and surgery across multiple disciplines, including but not limited to those who work in transplantation. Providers were a diverse group that included physicians, advanced practice providers, dietitians, social workers, case managers, and pharmacists. Three reminders were sent to nonrespondents who had not opted out of receiving further contact. Primary care clinic patients, as representatives of patient participants in our center’s healthcare system, were randomly surveyed while waiting in the clinic. A study coordinator asked patients if they were willing to participate in a study regarding transplantation but did not guide participants while completing the survey. Participants provided verbal consent and were allowed to terminate the survey at any time. Anonymity and confidentiality were ensured. Approval

from the Institutional Review Board of the University of Chicago Medicine (IRB19-1805) was obtained before study initiation.

Survey Questions

Directors from the University of Chicago Survey Lab worked with the principal investigator to develop survey questions aligned with the intent of the investigator and utilized best practices with regard to survey methodology. After initial drafts were completed, questionnaires were refined in an iterative manner. The provider surveys were programmed for online self-administration using Qualtrics software (Seattle, WA, and Provo, UT). Survey Lab staff tested the online questionnaire using Survey Lab Research Assistants. The patient surveys were formatted into paper format for self-administration.

The surveys included 22 identical questions, aside from different background questions for providers and patients. The first 10 questions assessed knowledge and opinions on transplantation, including eligibility, prioritization, and limitations for deceased donor transplantation of different groups. The final 12 questions collected demographic data, including age, gender, ethnicity, level of education, and whether the participant had lived in or was born in another country outside of the United States. Additionally, participants were asked if they or their family had ever donated or received an organ and if they had ever agreed to be an organ donor. The survey in its entirety is available in **Figure S1** (SDC, <http://links.lww.com/TXD/A681>).

Statistical Analysis

Categorical variables were expressed as relative counts and percentages and compared using the chi-square test of association or the Fisher’s exact test. Tests were 2-tailed and considered statistically significant with a *P* value of <0.05. Subanalyses were performed to determine within-group differences (age, sex, race, level of education, and history of experience with organ donation or receipt), with the median used to group by age. All statistical analyses were conducted using STATA MP version 15 (College Station, TX) and SPSS version 24 (Armonk, NY).

Terminology

OPTN terminology regarding citizenship and residency of transplant candidates includes US citizen, non-US citizen residing in the United States (NC/R), and non-US citizen not residing in the United States (NC/NR), with the further designation of NC/NR into those who traveled specifically for transplant (NC/NRTx) and those who traveled for other purpose.³ OPTN does not differentiate NC/R based on the legality of residency in the United States. To obtain more granularity on opinions, our survey additionally differentiated those noncitizens who reside in the United States as legal and nonlegal.

RESULTS

Baseline Characteristics

The characteristics of the provider and patient groups are summarized in Table 1. Of the 628 providers asked to participate, 209 (33.3%) completed the survey partially or fully, with an average response rate for all questions of 89%. The provider group was mostly female (61%) and white (69%) with a median age of 40 y (IQR, 34–52). Most were advanced practice providers, including physicians and

TABLE 1.
Respondent baseline characteristics

	Providers (N = 209)	Patients (N = 119)
Age, y	40 (IQR, 34–52)	54 (IQR, 35–65)
Sex	N = 189	N = 107
Male	73 (39%)	41 (38%)
Female	116 (61%)	66 (62%)
Race	N = 190	N = 118
Black	14 (7%)	59 (50%)
White	127 (67%)	41 (36%)
Other ^a	49 (26%)	16 (14%)
College degree and beyond	N = 170	N = 115
Yes	169 (99%)	3 (3%)
No	1 (1%)	112 (97%)
Received an organ transplant	N = 194	N = 115
Yes	1 (1%)	2 (2%)
No	193 (99%)	113 (98%)
Checked a box to donate an organ	N = 194	N = 114
Yes	169 (87%)	78 (68%)
No	25 (13%)	36 (32%)
Have friends/family who have donated an organ	N = 194	N = 110
Yes	59 (30%)	31 (28%)
No	135 (70%)	79 (72%)
Have friends/family who received an organ donation	N = 192	N = 111
Yes	66 (34%)	34 (31%)
No	128 (66%)	77 (69%)
Lived in a country outside of United States	N = 192	N = 114
Yes	61 (32%)	28 (25%)
No	131 (68%)	86 (75%)
Born outside of United States	N = 106	N = 47
Yourself	35 (33%)	11 (23%)
Parents	67 (63%)	23 (49%)
Grandparents	89 (84%)	31 (66%)
Spouse	32 (30%)	9 (19%)
Have health insurance	N = 191	N = 115
Yes	189 (99%)	111 (97%)
No	2 (1%)	4 (3%)

^aOther includes Hispanic/Latino, Asian, Native American or American Indian, Middle Eastern or North African, multiple races, and unknown.
IQR, interquartile range.

advanced nurse practitioners (77%); others included nurses (12%), dietitians (2%), pharmacists (4%), social workers/case managers (2%), and others (3%). In this group, 30% had friends or family members who had donated organs and 34% had friends or family members who had received organ transplantation.

Of the 220 patients asked to participate, 119 (54.1%) completed the survey partially or fully, with an average response rate for all questions of 90%. The patient group was predominantly female (62%) and Black (54%) with a median age of 54 y (IQR, 35–65). Among this group, 28% had friends or family members who had donated organs and 31% had friends or family members who had received organ transplantation.

Awareness of Current Eligibility for Transplantation

Nearly all providers (99.5%) and patients (97.4%) correctly responded that US citizens are eligible to receive transplanted organs (Figure 1A). More providers than patients

correctly responded that noncitizens who legally reside in the United States are eligible to receive transplanted organs (97.5% versus 88.8%, $P < 0.05$). Only 61.5% of providers and 51.8% of patients correctly identified that noncitizens who reside in the United States without legal status are eligible to receive organ transplants. By contrast, a greater number of patients and providers were aware that noncitizen, nonresidents are eligible for organ transplantation in the United States. More providers (78.2%) than patients (64.5%) correctly identified that noncitizen, nonresidents who are in the United States when the need for an organ arises are eligible to undergo transplantation ($P < 0.05$). Similarly, 74.8% of providers and 69.6% of patients correctly responded that noncitizen, nonresidents are eligible for transplantation when they travel to the United States solely for that purpose.

All providers and 98.3% of patients correctly responded that US citizens are eligible to donate organs for transplantation (Figure 1B). More providers than patients correctly responded that noncitizens legally residing in the United States are eligible to donate organs (98.0% versus 85.8%, $P < 0.05$). Only 58.4% of providers and 49.1% of patients correctly identified that noncitizens who reside in the United States without legal status are eligible to donate organs. Even fewer providers (52.5%) and patients (42.1%) correctly responded that noncitizen, nonresidents are eligible to donate their organs.

Respondents' Opinions on Eligibility for Transplantation

Providers and patients unanimously agreed that US citizens should be eligible for transplantation in the United States (Figure 2A). Almost all agreed that legal NC/R should be eligible for transplantation in the United States, but a much smaller proportion (78.3% of providers and 75.4% of patients) felt that nonlegal NC/R should be eligible to receive organs donated in the United States. Most providers (93.5%) and patients (88%) believed it appropriate for organs donated in the United States to be transplanted into non-US citizens who happened to be traveling in the United States when the need for transplantation arose. However, providers were significantly less likely than patients to believe that NC/NRTx should be eligible to receive organs donated in the United States (60.7% versus 79.3%, $P = 0.001$). Specifically, more patients than providers responded that NC/NRTx definitely should be able to travel to the United States in order to receive organ transplantation (40.7% versus 24.4%, $P = 0.002$; Figure 2B). More providers (11.7%) than patients (4.2%) responded “definitely not” to that question ($P = 0.002$), and more providers (28.9%) than patients (13.6%) responded “probably not” ($P = 0.002$). In summary, nearly 40% of providers indicated that NC/NRTx probably should not or definitely should not be allowed, as opposed to <18% of patients.

Respondents were then asked to prioritize allocation of an organ donated in the United States between 2 patients with varying citizenship and residency statuses but with equal medical need. When asked if a US citizen or legal NC/R should be given priority, more patients than providers responded that the US citizen should have priority (37.3% versus 19.2%, $P < 0.001$; Figure 3A). Conversely, more providers than patients responded that 2 such patients should be given equal priority (80.8% versus 60.2%, $P = 0.001$; Figure 3A). When

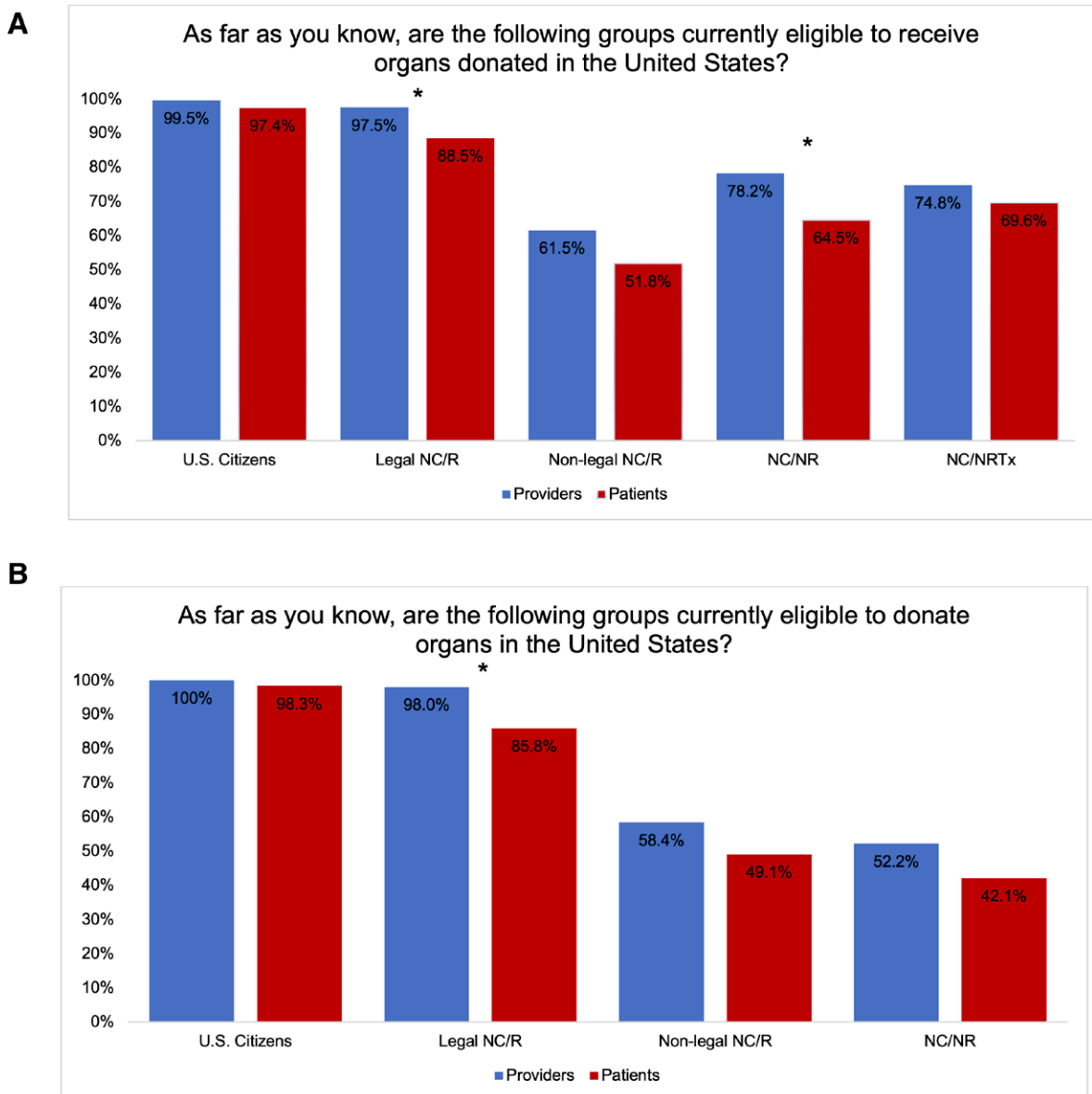


FIGURE 1. Provider and patient awareness of eligibility for transplantation. A and B, Awareness of eligibility for transplantation (* $P < 0.05$). NC/NR, noncitizen, nonresident of United States; NC/NRTx, NC/NR who traveled to the United States specifically for transplantation; NC/R, noncitizen, resident of United States.

asked if a legal NC/R or an NC/NRTx should be given priority, more providers than patients responded that the legal NC/R should have priority (58.2% versus 35.1%, $P < 0.001$), and more patients than providers believed that the 2 candidates should have equal priority (59.6% versus 41.2%, $P = 0.002$; Figure 3B).

Finally, respondents were asked whether donors or donor families should be able to prevent certain groups from receiving their or their family members' donated organs. A minority of patients and providers responded that donors or donor families should be able to limit donations to US citizens (16.8% versus 9.8%, $P = 0.07$) or legal NC/R (16.1% versus 9.3%, $P = 0.08$). There was no difference between patients and providers with regard to nonlegal NC/R, with <25% in both groups believing that families should be able to limit donations to this group. Providers were more likely than patients to believe that families should be able to limit donation to NC/NRTx (34.9% versus 23.2%, $P = 0.03$).

Differences Among Provider and Patient Subgroups

More male than female providers stated that NC/NRTx should be eligible to receive donated organs (69.9% versus 54.5%, $P = 0.04$; Figure S2, SDC, <http://links.lww.com/TXD/A681>). There were no differences in patient opinions on this item when stratified by sex.

Providers younger than 40 y were more likely than older providers to state that NC/NRTx should be eligible to receive organ donation in the United States (73.6% versus 48.4%, $P < 0.001$; Figure S3A, SDC, <http://links.lww.com/TXD/A681>). Providers older than 40 y were more likely than younger providers to state that families of US organ donors should be able to prevent nonlegal NC/R (25.6% versus 14.1%, $P = 0.046$) and NC/NRTx (46.4% versus 23.1%, $P = 0.001$) from receiving their donated organs (Figure S3B and S3C, SDC, <http://links.lww.com/TXD/A681>).

Patients with a college degree were more likely than those without a degree to give equal priority for transplant to a

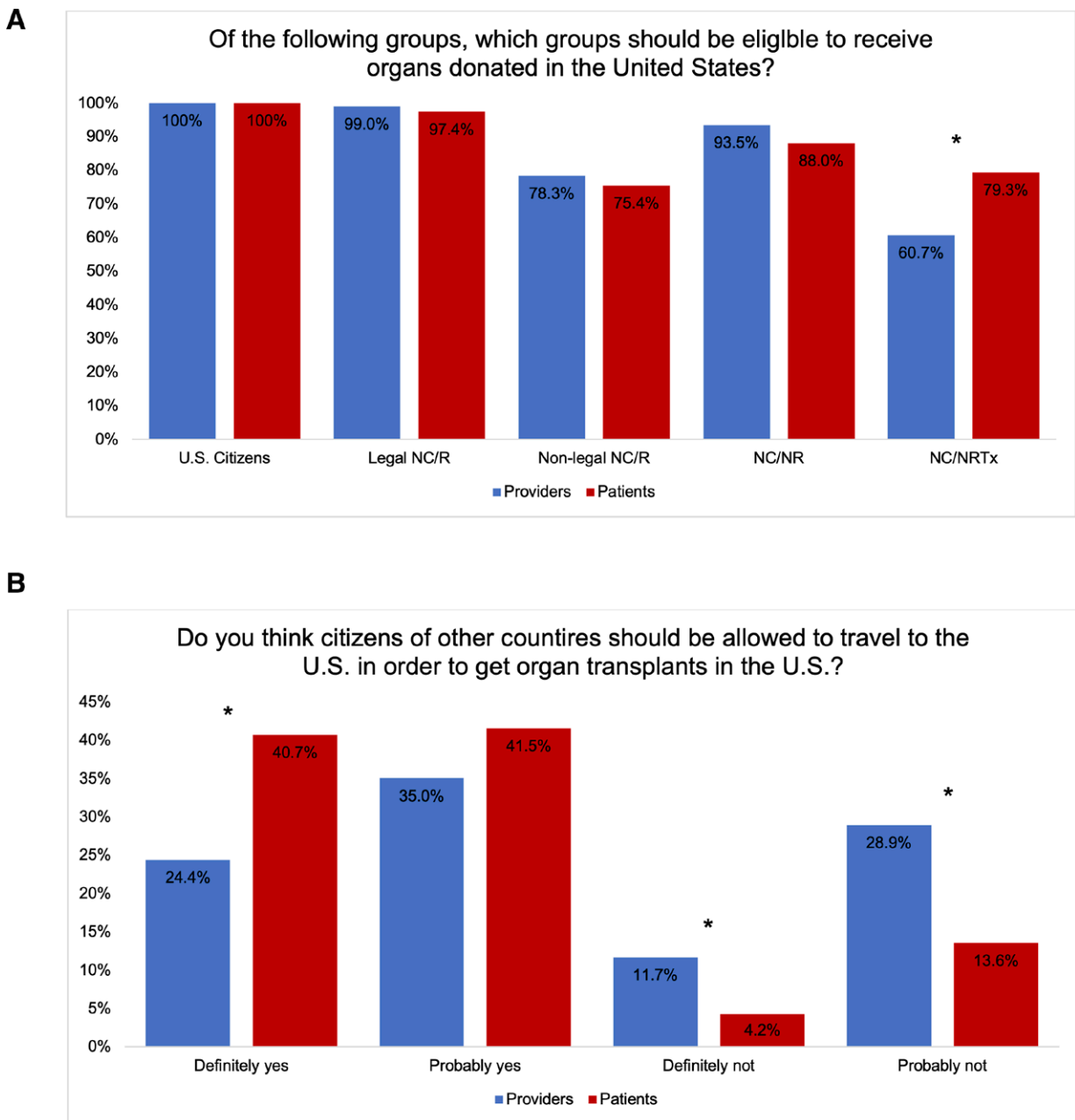


FIGURE 2. Provider and patient opinions on travel for transplantation. A and B, Opinions on travel for transplantation (* $P < 0.05$). NC/NR, noncitizen, nonresident of United States; NC/NRTx, NC/NR who traveled to the United States specifically for transplantation; NC/R, noncitizen, resident of United States.

US citizen and legal NC/R (67.2% versus 46.3%, $P = 0.03$; **Figure S4A, SDC**, <http://links.lww.com/TXD/A681>). Patients without a college degree were more likely to believe that families of organ donors should be able to prevent NC/NRTx (33.3% versus 15.4%, $P = 0.03$) from receiving their donated organs (**Figure S4B, SDC**, <http://links.lww.com/TXD/A681>).

There were no significant differences in opinion among providers or patients when stratified by race, history of organ donation, or history of receipt of a transplanted organ for themselves, friends, or family members.

DISCUSSION

Since the 2012 policy change calling for greater transparency of residency and citizenship status of patients listed for

transplantation, only 1 report has analyzed the rates of overall organ transplant for noncitizens.⁸ From 2013 to 2016, 1.2% of the total number of transplants in the United States were performed on NC/NR, of which 45% were performed in patients who were NC/NRTx. These transplants were concentrated at a few high-volume centers, defined as >5% of transplants or >5% of candidates listed as NC/NR. However, there were notable regional differences. For example, in regions 5 and 9 (including New York and California), 2.5% of listed deceased donor transplants and candidates were NC/NR, well above the national average of 1.2%. Region 3 (Southeast United States) had the highest number of registrations and deceased donor transplants of NC/NRTx during this time period.⁸ Most NC/NRTx were from the Gulf countries of the Middle East; 49% of total NC/NRTx liver and kidney listings

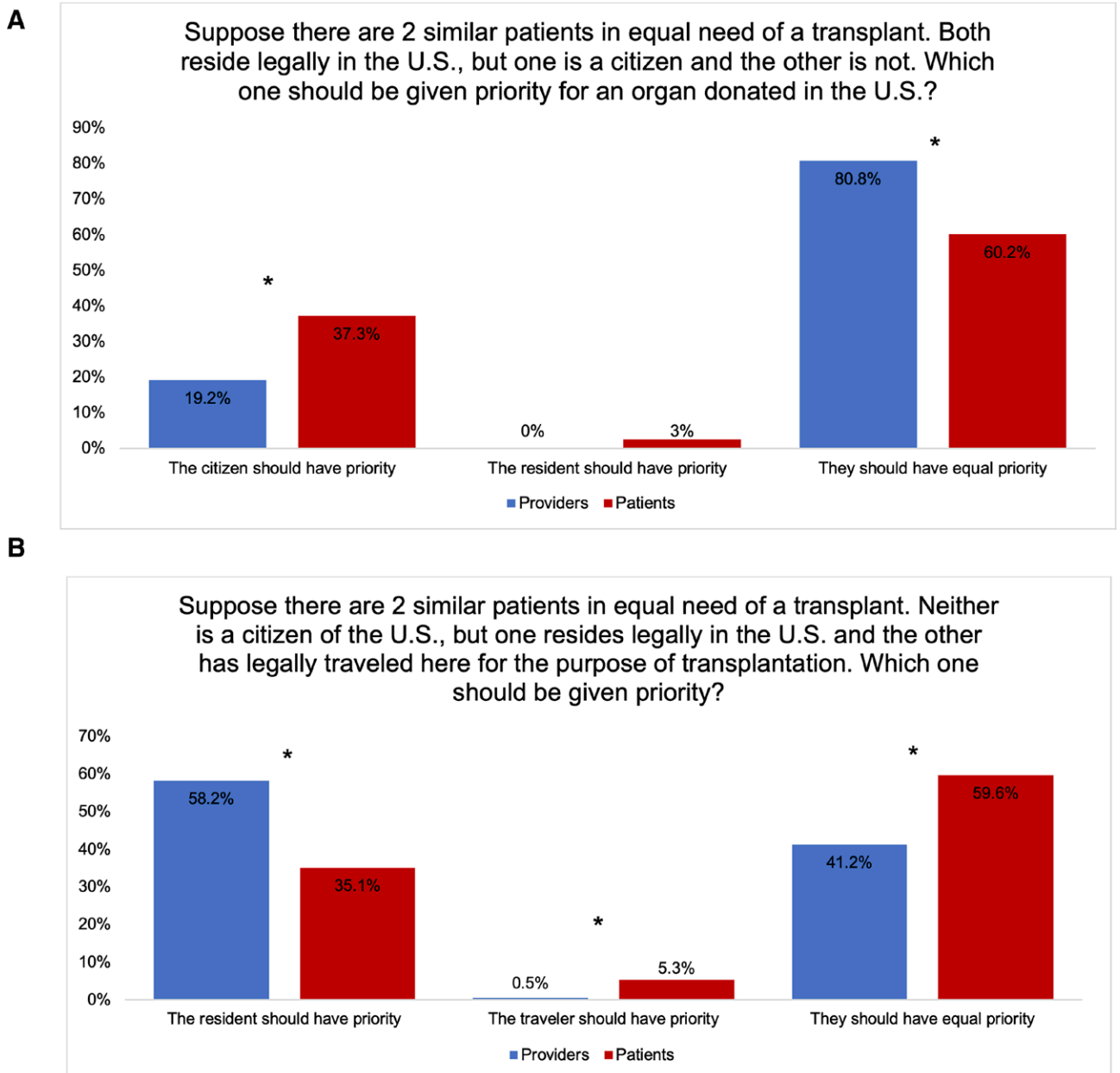


FIGURE 3. Provider and patient opinions on prioritization for transplantation. A and B, Opinions on prioritization for transplantation (* $P < 0.05$).

and transplants from 2013 to 2016 were from Saudi Arabia and Kuwait alone. Importantly, during this period, there was a steady increase in the number of waitlist additions and transplants of NC/NRTx.⁸

Many forces lead to the transplantation of NC/NRTx in the United States. These include patients who need transplantation for survival but who live in a country where transplantation is either not performed or is performed with poor outcomes, providers in the United States who wish to provide medical care to those in need regardless of citizenship status, and the financial incentive medical centers may experience as many NC/NRTx are self-pay.⁹ However, as those waitlisted in the United States outnumber those transplanted, the allocation of organs to NC/NRTx appears to conflict with the principle of self-sufficiency of the system.⁸ Furthermore, data collected in the years since 2012 have revealed a small,

generally socioeconomically advantaged group of persons who travel to the United States solely to obtain organ transplantation, which may lead to an exacerbation of existing disparities, as those with financial means experience shorter wait times and higher transplantation rates because of an ability to “region shop” and travel.¹⁰ That said, data collected by the 2017 Ad Hoc International Relations Committee for their report to UNOS/OPTN reviewed centers with the most transplants to NC/NR and concluded that there was no noticeable difference in time to transplant, suggesting that transplant to NC/NR may not impact access to transplant of US citizens and residents.¹¹

There is an overall paucity of data regarding the knowledge and attitudes of medical professionals, patients, and the public surrounding NC/NRTx. Our data reveal that knowledge of eligibility to donate and receive organ transplants had

limitations, even among providers. Although the majority correctly identified US citizens and legal NC/R as eligible for both donation and receipt of organs, far fewer recognized that non-legal NC/R were eligible for the same. In fact, 42% of physicians and 51% of patients were unaware that this group was eligible to donate organs, and 32% of physicians and 48% of patients were unaware that they were eligible to receive organs. This knowledge gap was even greater than awareness of NC/NRTx, with only 27% of all respondents unaware that NC/NRTx were eligible for transplant.

We recall that OPTN does not collect data on the legality of a patient's residency status to ensure that political agendas do not interfere with the provision of life-saving healthcare. Our survey, which distinguished between legal and non-legal residents, reveals that both patients and physicians lack awareness of this policy, and an opportunity for educational intervention is identified.

Only 2 studies in the past decade have assessed opinions regarding this controversial issue. In 2010, Volk et al¹² conducted a national survey of adults older than 18 y to determine the attitudes of the American public toward NC/NRTx. Of 1049 surveys completed, 30% of participants felt that NC/NRTx should not be allowed. Furthermore, 38% of participants responded that they might be discouraged from donating organs if they knew that NC/NRTx could be listed for transplantation in their area. Volk et al concluded that negative media attention can be mitigated through improved educational efforts.¹²

A more recent study surveyed transplant professionals in Canada.¹³ Respondent numbers were low ($n = 87$), of which 56.7% were transplant physicians. In that study, 50% agreed or strongly agreed that transplantation should not be offered to NC/NRTx, compared with 40.6% of our provider respondents, who believed that NC/NRTx should definitely not or probably not be offered transplant. Given that the Canadian respondents were all transplant providers, it is possible that this difference can be attributed to a greater understanding of transplant infrastructure, including waitlist times and the number of patients who die awaiting organs. Further studies are needed to compare nonprovider attitudes across different countries.

Among our respondents, there was a general consensus that US citizens and legal NC/R should be eligible for transplant. However, attitudes toward NC/NRTx were more diverse. Compared with patients, providers were more likely to reject traveling to the United States to obtain organ transplants, favor legal NC/R obtaining a transplant over NC/NRTx, and limit the number of transplants for non-US citizens. These results suggest an increased desire for limitations in NC/NRTx among providers compared with patients.

The disparities between provider and patient attitudes toward NC/NRTx are striking. Although we did not question respondents' reasoning for their responses, which might be an interesting addition to a future survey, there are several possible explanations for our findings. Providers may have been less accepting of NC/NRTx for reasons stemming from a more nuanced understanding of the dynamics of the transplant ecosystem. For example, providers may feel it is not fair to provide organs to NC/NRTx, given the lack of reciprocity and the overall shortage of organs. Providers may have more concerns about the self-sufficiency of the transplant infrastructure in our domestic healthcare system

than individual outcomes, which may have been the focus of patient respondents. This focus on reciprocity and self-sufficiency may also have been exacerbated by personal experiences of providers caring for patients awaiting organs that may not have ultimately received the life-saving treatment they required. Physicians may also be more aware of the financial implications of policies surrounding NC/NRTx, and their opinions may be rooted in beliefs surrounding potentially unfair monetary incentives. Furthermore, providers may have had concerns about NC/NRTx access to posttransplant care, as suboptimal care can lead to graft loss and the need for retransplantation. Finally, our patient population was not only more accepting of NC/NRTx than provider respondents but also more accepting than other populations studied, as only 18% of patients compared with 30% in the Volk study felt that NC/NRTx should not be allowed.¹²

The results of our study suggest several areas for exploration regarding citizenship status and NC/NRTx organ transplantation in the United States. Our survey was unique in that we surveyed both providers and patients, compared the 2 groups, and distinguished the legality of NC/R. We found that opinions regarding this controversial topic may be more nuanced than expected and, importantly, are not fully known. Our sample is limited by a lack of generalizability as we surveyed 1 patient and provider community within the United States; however, it shows that heterogeneity of attitudes exists. This would help to inform future policies, both governmental and organizational, because it demonstrates that attitudes on NC/NRTx exist on a spectrum and that there are subtleties to the matter that would make a "one size fits all" solution problematic. Broad and sweeping changes to US policy regarding NC/NRTx may not align with the attitudes of all Americans who may donate organs and pay taxes that indirectly support the US transplant infrastructure.

Given that individual centers regulate their own transplant volumes and the number of NC/NRTx transplanted each year, in concert with the potential financial incentives to perform these transplants, it seems likely that these numbers will continue to grow. This autonomy has led to significant regional variation, and although overall numbers are low, this variation may create pockets of higher NC/NRTx activity, which may have a significant impact at a local or regional level.¹⁴ In this way, different populations within the United States are impacted to differing degrees, making local opinions as important as national ones.

It is incumbent on individual centers to determine their own ability to meet the needs of their communities in alignment with the attitudes of that community. This could be done with self-auditing to determine whether transplant waitlist times and short- and long-term outcomes are similar between NC/NRTx and residents (legal or not) of that community. To ensure that policies are just and fair and in keeping with the attitudes of the community the center provides care for, opinion data should be gathered and combined with established ethical principles. Furthermore, we would advocate for a process that would ensure that community stakeholder opinions and needs are being fairly represented and documented as part of the policy justification of each institution.

Limitations

Survey responses were conducted at a single, large, urban academic institution and, therefore, represent a narrower

perspective for both providers and patients and are not necessarily reflective of the opinions of the general public. However, the results of this study represent attitudes regarding NC/NRTx that are possible in 1 community. The hypothesis beyond this is that differences can exist in communities throughout the country and are important to discover. Not all data were complete for each survey, which may introduce some bias when analyzing data among the respondents for any individual question. The percentage of patient respondents self-identifying as black was 54%, significantly greater than the general population, impacting generalizability to the American public. Additionally, while 14% of Americans were born abroad,¹⁵ 33% of our provider respondents and 23.4% of patient respondents reported having been born abroad which may have impacted their views. As NC/NRTx transplants are performed at our institution, the potential exposure of providers may also have impacted their attitudes toward the practice. We did not query the provider scope of practice, which may have provided additional interesting findings. No distinction was made between adult and pediatric transplants or type of transplants, particularly those that are life-saving, such as heart, liver, or lung, as opposed to kidney transplants, where patients can be maintained on dialysis. If only life-saving transplants had been included, respondents may have answered differently. Finally, inherent in any survey study is a selection bias toward those who agree to take the survey. This selection bias may be reflected in the high proportion of respondents who had friends or family who had donated or received a donated organ, which may have impacted responses.

CONCLUSIONS

Patients were significantly more likely than providers to accept the practice of noncitizens traveling to the United States for the purpose of organ transplantation. Future policy development surrounding the transplantation of NC/NRTx should consider a diversity of provider voices and the opinions of patients and the general public, which may differ substantially from those of medical providers.

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