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System-level Barriers Reducing Access to Transplantation: Results of a Global Survey

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Background. Global organ shortage is well documented; yet systemic barriers constraining access to transplantation remain poorly defined. Our study aimed to identify and map these barriers. **Methods.** A web-based survey was conducted from May 2022 to March 2023 among physicians and surgeons involved in organ donation and transplantation (ODT) from transplantation societies worldwide: (1) Hospital structure, legislation and policies, and financial barriers, addressed to program directors; (2) Questions on education on ODT directed to all participants, and questions about donor acceptance for transplant specialists; (3) Questions on donor identification for critical care specialists and questions about organ acceptance directed to transplant specialists; (4) Demographic questions for everyone. Respondents were grouped according to the mean deceased donation (DD) rate per million population from years 2016 to 2019 and 2021: Group (G) 1 (G1) No DD reported, or no data provided to global observatory on donation and transplantation; (G2) <10 DD per million population; (G3) 10–19.9; (G4) 20–29.9; (G5) ≥30. **Results.** We present answers from program directors. There were 150 program directors from 438 respondents. Financial barriers ranked highest, negatively affecting access to transplantation worldwide. G1 indicated the highest percentage of challenges. Those from G4 and G5 provided the least amount of challenges; however, training programs remain areas for improvement. Responses from G2 and G3 were similar, positioned between those from G1, and G4 and G5. **Conclusions.** The organ shortage emergency is exacerbated by parallel system-level deficiencies. This global survey identifies specific, actionable deficits that must be addressed to build equitable transplant systems worldwide.

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Solid organ transplantation (SOT) is a life-changing/life-saving procedure for patients suffering from organ failure.[1-8] The successful implementation and delivery of transplant programs require the melding of several elements, spanning multidisciplinary clinical teams, suitable infrastructure, and permissive legislation.

Donor organ shortage is a universal challenge, as <10% of global demands are met.[9,10] Although novel approaches such

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as bioengineering[11,12] and xenotransplantation[13,14] may one day provide alternative sources of organs, we currently rely on those from living and deceased donors (DDs). Unfortunately, in several countries, deceased donation (DD) rates are low, and transplantation mainly relies on living donors.[9] Even in countries with high DD rates, there is no universal agreement on the use of specific types of DDs, such as those with infections[15] or a history of cancers.[16,17]

To obtain a general needs assessment of the barriers to SOT globally, we prepared a survey to collect information about hospital structure, legislation and policies, and financial situation, as well as knowledge and comfort gaps in various medical conditions. A working group composed of members of The Transplantation Society (TTS) was established to identify needs and challenges in mapping the architecture of global transplant access. Following multiple rounds of discussions, several priorities were identified. We designed a detailed survey to move beyond mere organ counts and quantify the real-world operational, financial, and legislative challenges faced by transplant programs. In this report, we present information about the survey and data obtained exclusively from program directors across all transplant specialties. Two companion manuscripts report responses from the entire cohort regarding identification and acceptance of DDs and organ-specific questions, as well as education on organ donation and transplantation (ODT).

MATERIALS AND METHODS

Survey: Questionnaire

We conducted a web-based survey (SurveyMonkey) from May 2022 to March 2023 among physicians and surgeons involved in donation and SOT from various national, regional, and international transplant societies.

The survey was created and tested by members of a working group of the TTS. It was approved by both the TTS Executive and the TTS Ethics Committee.

The questionnaire was composed of 4 sections: (1) Hospital structure, legislation and policies, and financial barriers, addressed to program directors; (2) Questions on education on ODT directed to all participants, and questions about donor acceptance for transplant specialists; (3) Questions on donor identification for critical care specialists and questions about organ acceptance directed to transplant specialists; (4) Demographic questions for all participants. Questions from sections 1–3 are shown in Table S1 (SDC, https://links.lww.com/TXD/A903).

A link to the questionnaire (web-based platform) was sent by email to members of 19 international, national, and regional transplant societies, and 6 TTS Sections (Table 1).

The survey was available from May 2022 to March 2023. It was written in English. Everyone who completed and submitted the questionnaire was deemed to have consented to the use of their answers.

Analysis

The participants were divided into 5 groups based on the mean DD rate per million population (PMP) in their country of practice (Figure 1). To calculate the countries' PMP rates, we used data from the Global Observatory on Donation and Transplantation (GODT) website for 2016–2021 (excluding 2020 due to the COVID-19 pandemic). The groups (G) were as follows: (G1) No DD reported, or no data provided to GODT; (G2) <10 DDs PMP; (G3) 10–19.9; (G4) 20–29.9; and (G5) ≥30.

The answers to the closed-ended questions could be yes, no, or unsure. They were classified as nominal categorical data, as they represent distinct, mutually exclusive, nonnumerical categories. These categorical variables were reported descriptively (number of answers per group and percentages). The graphs were made using GraphPad Prism 7.0e (GraphPad Software Inc., San Diego, CA).

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TABLE 1.

List of societies and TTS sections

International	National	Regional	TTS sections
TTS	ABTO	AST	CTRMS
ILTS	ACTO	ASOT[a]	IPITA
ISHLT	COTRS	ASOT[b]	IIRTA
	CST	MESOT	ISODP
	ISOT	STALYC	IXA
	JST	TSANZ	TID
	SAT		
	ONT		

[a]African Society of Organ Transplantation, [b]Asian Society of Transplantation.
ABTO, Associação Brasileira De Transplante De Órgãos; ACTO, Asociación Colombiana de Trasplante de Órganos; AST, American Society of Transplantation; CST, Canadian Society of Transplantation; COTRS, China Organ Transplant Response System; CTRMS, Cell Transplant and Regenerative Medicine Society; IIRTA, International Intestinal Rehabilitation and Transplantation Association; ILTS, International Liver Transplantation Society; IPITA, International Pancreas and Islet Transplantation Association; ISHLT, International Society for Heart and Lung Transplantation; ISODP, International Society for Organ Donation and Procurement; ISOT, Indian Society of Organ Transplantation; ISODP, International Society for Organ Donation Professionals; IXA, International Xenotransplantation Association; JST, The Japan Society for Transplantation; MESOT, The Middle East Society for Organ Transplantation; ONT, Organización Nacional de Trasplantes, Spain; SAT, Sociedad Argentina de Trasplante; STALYC, Sociedad de Trasplante de América Latina y el Caribe; TID, Transplant Infectious Disease; TSANZ, Transplantation Society of Australia & New Zealand; TTS, The Transplantation Society.

RESULTS

Participant Demographics

We received 535 responses from 68 countries. We removed 97 respondents (80 with incomplete information, 15 duplicate answers, and 2 pediatric physicians). Here, we present only the answers from program directors about hospital structure, legislation and policies, and financial barriers. There were 150 (32%) program directors from 46 countries, separated into 5 groups according to their mean DD rate PMP (Figure 1 and Table 2). Age and biological sex are described in Table 3.

Answers From Program Directors

Hospital Structure

University Affiliation

More than 50% of respondents were affiliated with a university medical school (Figure 2A1) with a curriculum dedicated to ODT (Figure 2A2).

Local Recovery Teams and Healthcare Professionals

Program directors from groups 2–5 acknowledged the presence of local recovery teams (Figure 2B1) and healthcare professionals working as transplant coordinators at their hospitals (Figure 2B2) or in their provinces/states/regions (Figure 2B3), with positive answers ranging from 77% to 100%. However, those from G1 provided a high proportion of negative answers (60%–80%).

Management of Donors With Neurological Determination of Death or Donors With Circulatory Determination of Death

We gathered information on strategies to increase the identification of potential deceased donors at their hospitals (Figure 2C1); also, on the presence of training programs for the management of brain-dead donors at their hospitals (Figure 2C2), and for critical care specialists at their universities (Figure 2C3) and provinces/states/regions (Figure 2C4). Moreover, it was important to know about training addressed to critical care specialists on the management of donors after circulatory declaration of death (DCD) at their hospital (Figure 2C5) and provinces/states/regions (Figure 2C6).

Negative answers to all the former questions ranged from 0% to 80%. Program directors from G1 provided the highest number of negative responses (80%), and those from G4 had the highest proportion of positive responses (61%–100%).

Continuing Medical/Healthcare Education

Continuing medical and healthcare education (CME/CHE) is one of the main pillars for upskilling the transplant workforce. We inquired about CME/CHE activities related to ODT at hospitals (Figure 2D1), universities (Figure 2D2), and regional levels (Figure 2D3). Positive responses ranged from 40% in G1 countries to 94% in the G5 group.

Critical Care Facilities, Trained Personnel, and Quality Assurance Systems

Critical care facilities (Figure 2E1), trained personnel for organ recovery (Figure 2E2), and quality assurance systems (Figure 2E3) are essential for managing DDs. Positive answers ranged from 20% from the G1 group to 100% from the G4 countries. There were similar positive and negative responses across all groups regarding critical care settings specifically designated for organ recovery at their hospitals (Figure 2E2).

Pathology and Histocompatibility (HLA) Laboratories

Pathologists specialized in pre- and postimplantation biopsies are key members of the transplant team, assisting surgeons and clinicians with the acceptance of organs and with management decisions (Figure 2F1), with 100% of affirmative responses in G4 and 91% in G5 (Figure 2F2). A range of 60%–79% of positive responses was given by those from G1 to G3. Once the presence of pathologists was confirmed, there was a similar number of positive and negative responses when asked about their 24/7 availability (Figure 2F3).

One fundamental element in selecting the best donor is HLA matching. There was a clear need for HLs in G1 (Figure 2F4). Most of the laboratories were accredited by national or international organizations (Figure 2F5).

Legislations, Policies, and Allocation Systems

Countries around the world have different organ donation and transplant legislation and policies. There is a need for a well-defined legal framework that clarifies the definition of death, providing support for the ethical principles of

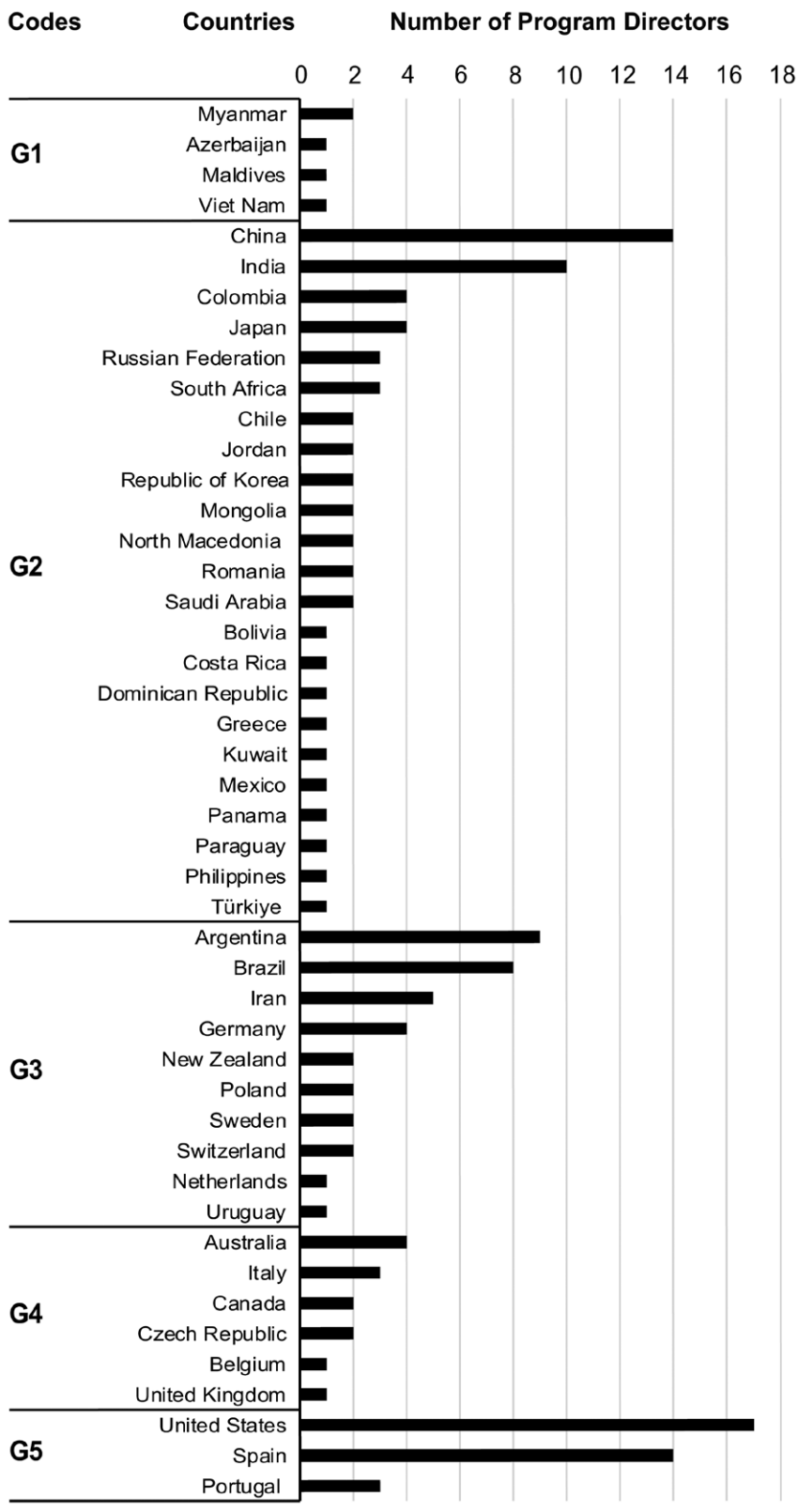

FIGURE 1. Number of respondents—Program Directors—per country, and country code according to deceased organ donation rate PMP. PMP, per million population.

ODT. Policies, allocation systems, and registries are needed to establish higher standards for the practice of ODT, with the utmost respect for the rights of donors, their families, and recipients.

Legislation

We inquired about legislation that regulates ODT activities in their countries, including the confirmation of brain death. As seen in Figure 3A1, almost all respondents confirmed that

TABLE 2.

Number of program directors according to their countries' deceased donation rate per million of population

Country deceased donation rate[a] PMP	Group	Number of respondents
No data or no reported data	1	5
<10	2	62
10–19.9	3	36
20–29.9	4	13
≥30	5	34
Total		150

[a]Mean value from 2016, 2017, 2018, 2019, and 2021.
PMP, per million population.

TABLE 3.

Age (A) and biological sex (B)

A		B	
Age range	**n**	**Groups**	**M/F**
25–34	1	1	4/0
35–44	9	2	45/13
45–54	29	3	26/8
55–64	53	4	11/2
65–69	34	5	21/12
70–74	17	**Total**	**107/35**
75+	4		
Total	**147**		

A. 3 missing.
B. 8 missing.
M, male; F, female.

legislation was in place. However, 20% of respondents in G1 denied this. Regarding the regulation of brain death confirmation, negative responses ranged from 60% in G1 to 3% in G3 (Figure 3A2).

Transplant Programs and Accreditation

Transplant programs are vital units of interprofessional teams, providing medical and surgical care, and social, spiritual, and psychological support for both recipients and donors. Program accreditation confirms adherence to established standards of practice. As depicted in Figure 3B1, there was an increasing need to create transplant programs, with 18% of respondents in G5 and up to 100% in G1 reporting this need. In cases where transplant programs were already in place, most of them were nationally or internationally accredited (Figure 3B2).

Allocation Practices

Allocation practices are needed to ensure the ethical and equitable sharing of organs. We inquired about government agencies and allocation systems involved in ODT activities in their provinces/states/regions/countries. As shown in Figure 3C1, almost all respondents from G2 to G5 confirmed the presence of a government agency regulating and supervising ODT in their provinces/states/regions/countries. The highest need was seen in G1 (40%). Mandatory registries (Figure 3C2), posttransplant registries (evaluation of outcomes) (Figure 3C3), and allocation criteria for organ transplantation controlled by an organ procurement organization were available in a high percentage in most geographies other than G1 (Figure 3C4).

Waitlists and Access to Deceased Donors

Waitlists need to be regularly assessed to ensure there is no discrimination against certain groups of patients because of their race, ethnicity, religion, sex, gender, sexual orientation, citizenship, or medical conditions. As depicted in Figure 3D1–5, almost all respondents from G2 to G5 agreed about the availability of waiting lists in their provinces/states/regions (Figure 3D1), in which, apart from natives (Figure 3D2), expatriates (Figure 3D3), and resident minorities (Figure 3D4) were allowed to register. The main differences were observed in G1, which had a high number of negative answers. Most visitors (not involved with transplant tourism) were denied access to DD organs; only in G5 countries did 53% of visitors have access to DD (Figure 3D5).

Circulatory Determination of Death and Neurological Determination of Death

The legal definition of death has evolved, is complex and may face resistance to its implementation. There are two universally accepted definitions: neurological determination of death (NDD), also known as brain-dead donors, and DCD. Therefore, it is essential to be aware of the criteria used globally. As depicted in Figure 3E1, countries from G4 to G5 showed the highest availability of regulatory mechanisms for DCD, with more than 85% of positive responses; G2, 55%; and G3, 53%, while G1 was the one with the highest percentage of negative answers (60%). In contrast, most countries (except G1) showed high acceptance of donors with NDD (Figure 3E2). Answers related to the adoption of policies at their hospitals regarding criteria for NDD (Figure 3E3) and DCD (Figure 3E4) showed that G4 and G5 respondents had the highest percentages of positive responses. Affirmative replies from G2 were 85% and 55%; from G3, 86% and 44%; and from G1, 60% and 80%, respectively.

Different Approaches to Increase the Donor Pool

There is a need to facilitate transplantation activities and increase the donor pool. It is vital to have knowledgeable teams able to approach families to discuss organ donation, spiritual leaders to provide support, and policies to manage end-of-life care and potential DD. The evaluation of donor medical suitability, including the presence of viral infections, is of high importance. As depicted in Figure 3, a high percentage of respondents from G2 to G5 confirmed the availability of policies (Figure 3F1) and the presence of accredited (or formally trained) clinical counselors on how to approach families to discuss DD at their hospitals (Figure 3F2). On the contrary, 40% and 20% of those from G1 responded positively. Religion plays an essential role in organ donation; therefore, we inquired about the need to cooperate with religious leaders. G1 showed the highest need (80%, Figure 3F3). Regarding the presence of regulatory mechanisms for the acceptance of donors with HBV, HCV, or HIV (Figure 3F4), or protocols for donors with SARS-CoV-2 in their provinces/states/regions/countries (Figure 3F5), the highest percentage of positive answers was seen in G4–G5, followed by those from G3 and G2. The lowest affirmative answers were from G1. A high level of positive responses was observed in all groups when inquiring about policies

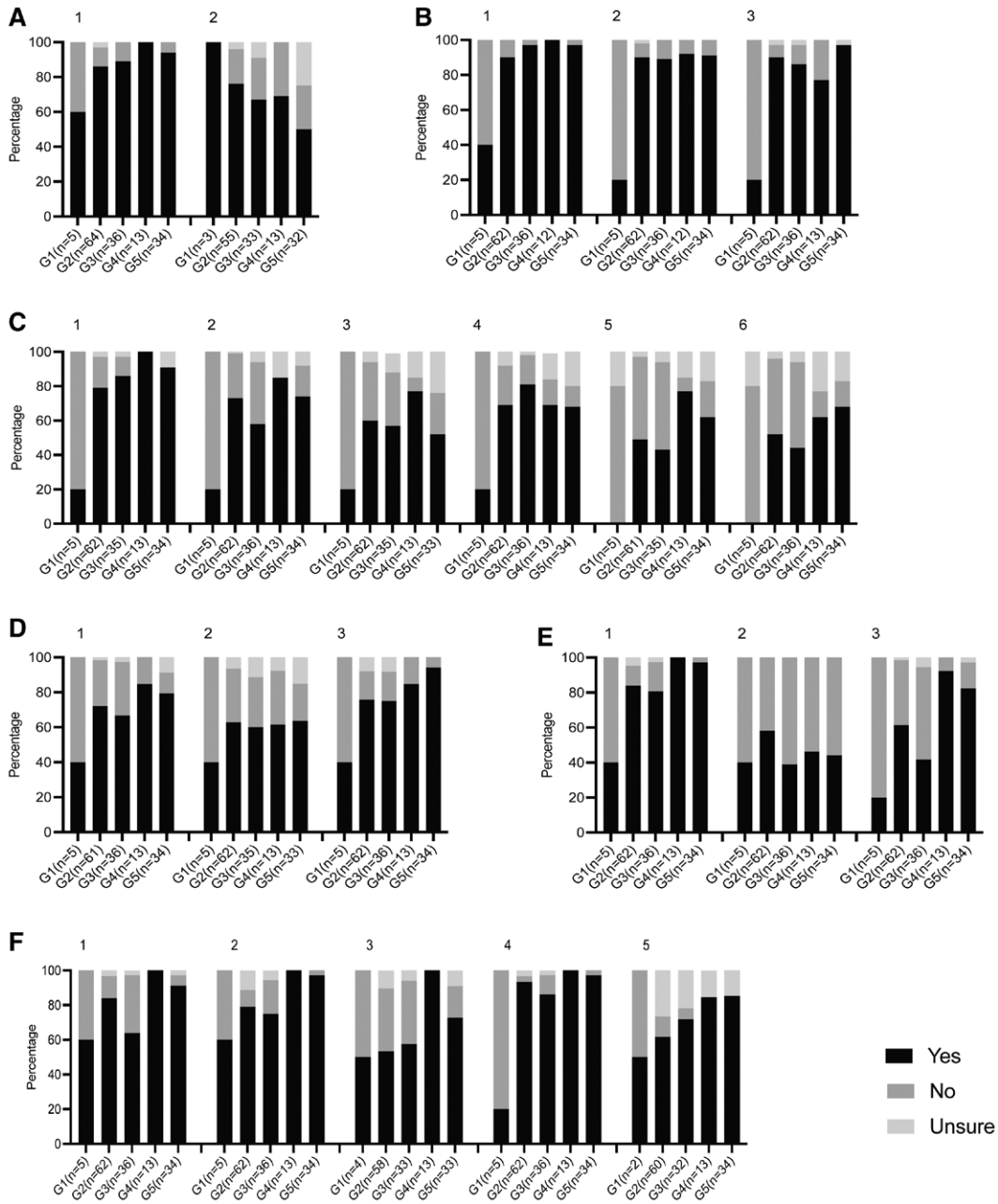

FIGURE 2. Survey about hospital infrastructure, trained personnel, and continuing healthcare education/continuing professional development. The x-axis represents the respondents' groups (G) 1 to 5 according to their mean DD rate PMP: G1) no DD reported or no data provided to GODT; G2) <10 DD PMP; G3) 10–19.9; G4) 20–29.9; and G5) ≥30. The y-axis denotes the % of responses as either yes, no, or unsure. The description of questions coded in the figure is as follows: A1, Is your hospital linked to a university medical school? A2, If yes to the previous question: Is organ donation and transplantation included in the university medical school curriculum? B1, Are there local organ recovery team(s) in your province/state/region/country? B2, Are there local transplant coordinators (MD or RN) working in organ donation at your hospital? B3, Are there local transplant coordinators (MD or RN) working in organ donation at other hospitals in your province/state/region? C1, Are there strategies to increase the identification of potential deceased donors at your hospital? C2, Are there training programs for the management of brain-dead donors at your hospital? C3, Are there training programs addressed to critical care specialists for the management of brain-dead donors at your university? C4, Are there training programs for the management of brain-dead donors in your province/state/region? C5, Are there training programs addressed to critical care specialists for the management of donors after circulatory declaration of death at your hospital? C6, Are there training programs addressed to critical care specialists for the management of donors after circulatory declaration of death in your province/state/region? D1, Are there continuing educational activities for the healthcare professionals involved in organ donation and transplantation at your hospital? D2, Are there continuing educational activities for the healthcare professionals involved in organ donation and transplantation at your university? D3, Are there continuing educational activities for the healthcare professionals involved in organ donation and transplantation in your province/state/region? E1, Are there critical care (intensive care) capacities (beds, equipment, and qualified personnel) available to manage deceased donors at your hospital? E2, Are there critical care (intensive care) settings specifically designated for organ recovery at your hospital? E3, Are there quality assurance systems and metrics to measure the performance in deceased organ donation at your hospital? F1, Are there pathologist(s) to read preimplantation biopsies in your hospital? F2, Are there pathologist(s) to read pre- and postimplantation biopsies in your province/state/region? F3, If the answer is yes to the previous question: Are the pathologists available 24/7? F4, Are there transplant tissue typing laboratories in your province/state/region? F5, If you answered yes to the question above: Are the tissue typing laboratories accredited by national or international organizations (eg, ASHI and CAP)? ASHI, American Society for Histocompatibility and Immunogenetics; GODT, Global Observatory on Donation and Transplantation; PMP, per million population.

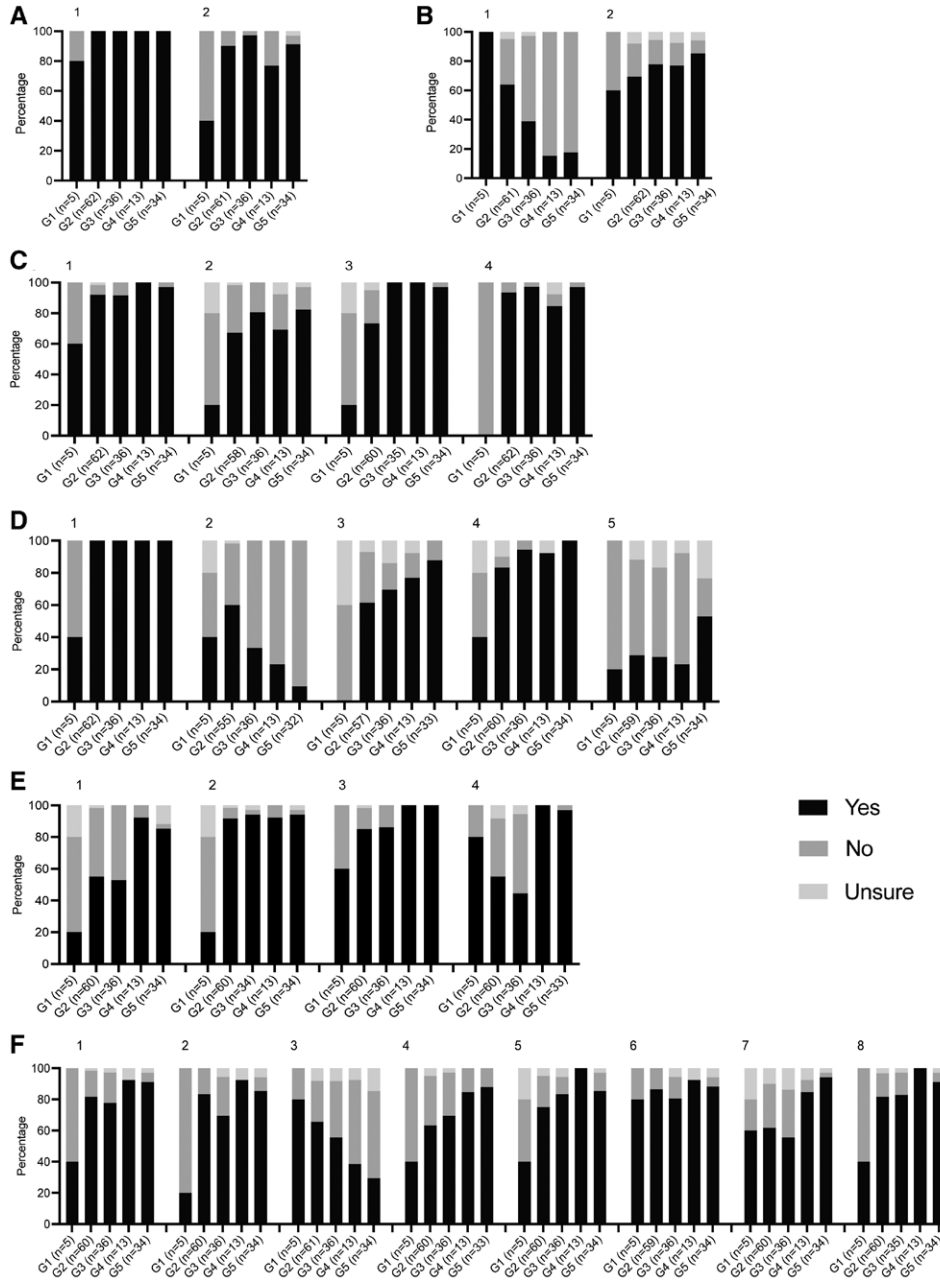

FIGURE 3. Legislation, policies, and allocation systems. The x-axis represents the respondents' groups (G) 1 to 5 according to their mean DD rate PMP: G1) no DD reported or no data provided to GODT; G2) <10 DD PMP; G3) 10–19.9; G4) 20–29.9; and G5) ≥30. The y-axis denotes the % of responses as either yes, no, or unsure. The description of questions coded in the figure is as follows: A1, Is there a legislation that regulates donation and transplantation activities in your country? and A2, Does the legislation regulate brain death confirmation? B1, Is there a need to create transplantation programs in your country/province/state/region? and B2, Does your transplant program have national or international accreditation? C1, Is there a government agency to regulate and supervise organ donation activities and control the quality, safety, and equity of organ donation and transplantation in your country/province/state/region? C2, Is there a mandatory registry of organ donation and transplantation in your country/province/state/region? C3, Are there posttransplantation registries to evaluate outcomes in your country? and C4, Are there allocation criteria for organ transplantation controlled by the organ procurement organization, under the Ministry of Health or government authority? D1, Is there a waiting list in your province/state/region/country? D2, Does the waiting list include only natives? D3, Does the waiting list include residents (expatriates)? D4, Do resident minorities have access to deceased donor organs in your province/state/region/country? and D5, Do visitors have access to deceased donor organs in your province/state/region/country? E1, Is there a regulatory mechanism for donation from circulatory determination of death (controlled and uncontrolled) and consideration of organ donation in your country? E2, Is there a regulatory mechanism for determination of death by neurological criteria and consideration of organ donation in your province/state/region? E3, Is there a policy regarding criteria for neurological determination of death at your hospital? E4, Is there a policy regarding the determination of death by circulatory criteria at your hospital? F1, Is there a policy regarding how to approach families to discuss organ donation at your hospital? F2, Does your hospital have accredited or formally trained clinical counselors (transplant coordinators) to conduct discussions about organ donation with families of potential deceased donors? F3, Is there a need to cooperate with religious leaders to support/facilitate transplantation activities? F4, Are there regulatory mechanisms for the acceptance of donors with HBV, HCV, or HIV in your province/state/region/country? F5, Is there a protocol for donors with SARS-CoV-2 virus in your province/state/region/country? F6, Is there a policy regarding the evaluation of donor medical suitability at your hospital? F7, Is there a policy regarding end-of-life care at your hospital? F8, Is there a policy regarding the management of potential deceased organ donors at your hospital? GODT, Global Observatory on Donation and Transplantation; PMP, per million population.

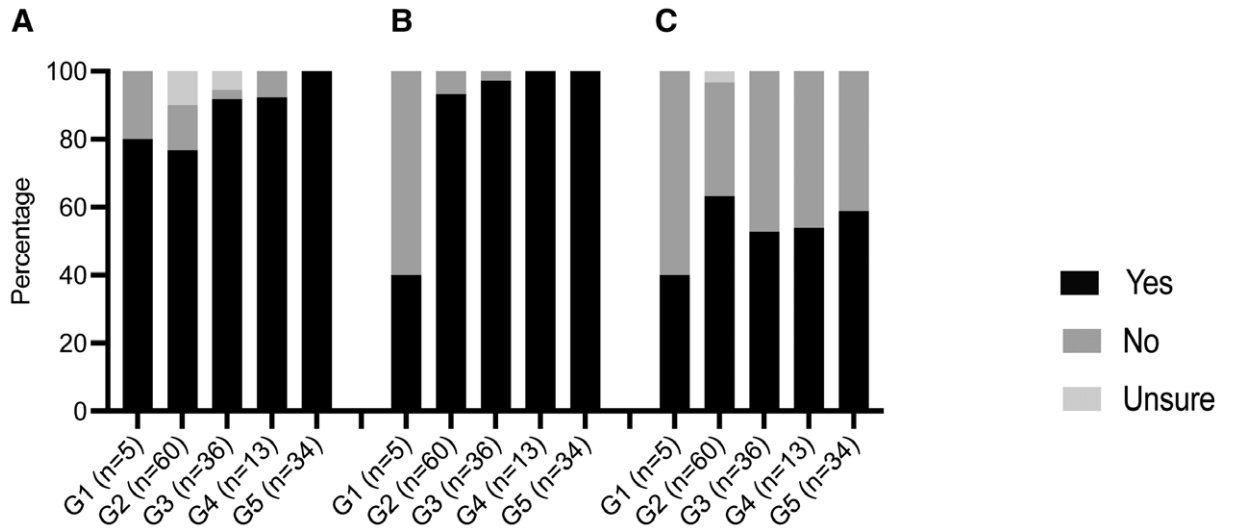

FIGURE 4. Survey on access to experts and participation in medical societies. The x-axis represents the respondents' groups (G) 1 to 5 according to their mean DD rate PMP: G1) no DD reported or no data provided to GODT; G2) <10 DD PMP; G3) 10–19.9; G4) 20–29.9; and G5) ≥30. The y-axis denotes the % of responses as either yes, no, or unsure. The description of questions coded in the figure is as follows: (A) Do you have access to a pool of expert reference transplant centers to discuss challenging cases in your province/state/region/country? B, Is there a national transplantation society in your country? C, Is there a regional transplantation society in your province/state/region? GODT, Global Observatory on Donation and Transplantation; PMP, per million population.

regarding the evaluation of donor medical suitability at hospitals (Figure 3F6). A high percentage of affirmative answers was observed from respondents in G5 (94%) and G4 (85%) when inquiring about policies regarding end-of-life care at their hospitals, followed by those from G2 (62%), G1 (60%), and G3 (56%) (Figure 3F7). All or almost all countries from G2 to G5 had policies for managing potential DDs at their hospitals (range: 82% to 100%), versus those in G1 (40%), as shown in Figure 3F8.

Access to Experts and Participation in Medical Societies

Being part of a national or international medical society offers several advantages, including staying up to date on new diagnostic methods and therapies, gaining access to experts in the field, and fostering valuable networking opportunities. The majority of the respondents have access to a pool of expert reference transplant centers to discuss challenging cases in their provinces/states/regions/countries (Figure 4A), as well as having a national transplantation society in their countries, except for G1 (40%; Figure 4B). The presence of a regional transplantation society was less common (40% to 63%) across all groups (Figure 4C).

Financial Barriers

Caring for patients with end-stage organ failure is costly. ODT procedures and posttransplant care are expensive. The healthcare system incurs costs related to expenses for donor and recipient evaluations, organ recovery, transplant surgery, and posttransplant management. Depending on the country, insurance companies or recipients may cover the costs of services or medications.

Financial Barriers Within the Healthcare System

We asked about the presence of financial barriers within the healthcare system that limit access to treatment for end-stage organ failure, excluding transplant, such as the availability of dialysis, lack of reimbursement for dialysis, ICU care, or other services in their provinces/states/regions/countries. G2 showed the highest percentage of positive answers (45%), followed by G5 (36%), G3 (34%), G1 (20%), and G4 (15%; Figure 5A1).

Almost all directors from G3 to G4 denied out-of-pocket payments, compared with G5 (71%), G2 (50%), and G1 (40%; Figure 5A2); 77% of respondents from G4 denied that payments were related to health insurance or other subsidized methods (Figure 5A3), followed by G3 (62%), G1 (60%), G5 (44%), and G2 (39%). Results from both questions showed that between 3% and 60% of recipients pay directly or indirectly for the services provided.

Financial Barriers Limiting Access to Transplantation at Hospitals

When inquiring about the presence of financial barriers limiting access to transplantation at their hospitals, 80% of respondents from G1 answered positively, followed by 45% from G2, 38% from G5, 11% from G3, and 15% from G4 (Figure 5B1). A similar pattern of answers was observed when asking about the existence of financial barriers in their provinces/states/regions (Figure 5B2), and in their countries (Figure 5B3)—the highest percentages in G1 (80%, 80%) and G2 (52%, 55%), followed by G5 (41%, 38%), G4 (15%, 15%), and the lowest percentages from G3 (8%, 8%) respectively.

Financial Barriers Related to Access to the Treatment of Posttransplant Complications

Regarding financial barriers impacting access to the treatment of posttransplant complications in their hospitasl (Figure 5C1), in their provinces/states/regions (Figure 5C2), or in their countries (Figure 5C3), a similar pattern of answers was observed as previously reported, with a range of positive responses from 3% up to 60%. Program directors in G1–G2 gave the highest positive answers, followed by those in G5–G4. Those in G3 provided the lowest percentage.

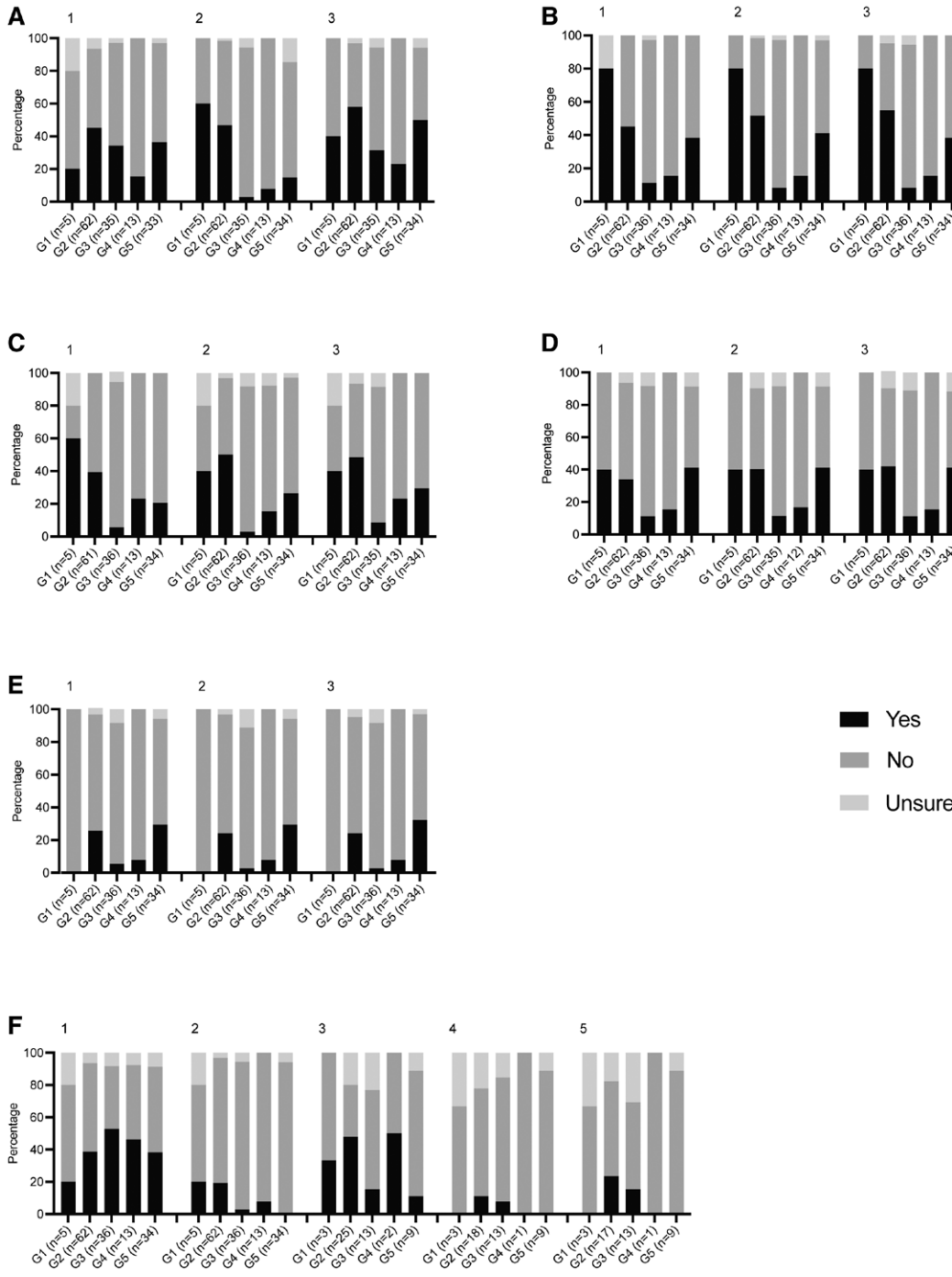

FIGURE 5. Financial barriers. The x-axis represents the respondents' groups (G) 1 to 5 according to their mean DD rate PMP: G1) no DD reported or no data provided to GODT; G2) <10 DD PMP; G3) 10–19.9; G4) 20–29.9; and G5) ≥30. The y-axis denotes the % of responses as either yes, no, or unsure. The description of questions coded in the figure is as follows: A1, Are there financial barriers from the healthcare system limiting access to treatment for end-stage organ failure (excluding transplantation; eg, availability of dialysis, lack of reimbursement for dialysis, ICU care, or other) in your province/state/region/country? How do recipients pay for services in your province/state/region/country?: A2, out of pocket; A3,subsidy, health insurance. B1, Are there financial barriers limiting access to transplantation in your hospital? B2, Are there financial barriers limiting access to transplantation in your province/state/region? B3, Are there financial barriers limiting access to transplantation in your country? C1, Are there financial barriers limiting access to the treatment of posttransplant complications in your hospital? C2, Are there financial barriers limiting access to the treatment of posttransplant complications in your province/state/region? C3, Are there financial barriers limiting access to the treatment of posttransplant complications in your country? D1, Do financial barriers contribute to nonadherence to immunosuppression in your hospital? D2, Do financial barriers contribute to nonadherence to immunosuppression in your province/state/region? D3, Do financial barriers contribute to nonadherence to immunosuppression in your country? E1, Do financial barriers contribute to gender disparity in access to transplantation in your hospital? E2, Do financial barriers contribute to gender disparity in access to transplantation in your province/state/region? E3, Do financial barriers contribute to gender disparity in access to transplantation in your country? F1, Is there reimbursement for expenses related to organ donation? F2, Is there a reward for the deceased donor's family in your province/state/region/country? (with an incentive?), If so, F3, financial; F4, tax deduction; and F5, educational benefits. GODT, Global Observatory on Donation and Transplantation.

Financial Barriers in Relation to Patients' Nonadherence

Financial barriers may contribute to nonadherence to medications by transplant recipients. We inquired about this situation in their hospitals(Figure 5D1), in their provinces/states/regions (Figure 5D2), and in their countries (Figure 5D3). Again, a similar pattern of positive responses was observed, ranging from 11% to 42%. The highest positive answers were given by those in G1, G2, and G5, followed by G4, and the lowest percentage was from G3.

Financial Barriers and Gender Disparity

Financial barriers may have a role in gender disparity in access to transplantation in their hospitals (Figure 5E1), provinces/states/regions (Figure 5E2), and countries (Figure 5E3) in G2–G5. Positive answers were observed as follows: G5 (29%, 29%, 32%), G2 (26%, 24%, 24%), G4 (8%, 8%, 8%), and G3 (6%, 3%, 3%). Responders from G1 (n = 5) responded negatively to all these questions.

Incentives

Reimbursement to donor families for expenses or in the form of incentives is an approach that may foster positive attitudes toward organ donation and is consistent with the WHO's principles of financial neutrality. As shown in Figure 5F1, between 39% and 60% of responders answered that expenses related to organ donation were not reimbursed. Additionally, a high percentage of responders did not use incentives (60%–94%; Figure 5F2). In the event of incentives, these were in the form of financial aid (a range of 11%–50% depending on the group; Figure 5F3), tax deductions (11% in G2 and 8% in G3; Figure 5F4), and education aid (24% in G2 and 15% in G3; Figure 5F5).

DISCUSSION

In this global survey on access to transplantation, the trichotomous closed-ended questions were designed to collect clear, fast, and actionable data. As such, we observed that the main barriers negatively affecting access to transplantation globally were of financial origin.

Program directors from G1 countries indicated the highest percentage of challenges. Those with the highest DD rates (G4-G5) provided the highest percentage of positive answers. Responses from G2-G3 were very similar, positioned between those from G1 and G4-G5. Program directors from G4 countries reported fewer financial issues than those from G5. This may be due to the differences in universal health care coverage. We found a higher acceptance of DCD in G4-G5 versus G2-G3, which could be related to structural barriers that need to be addressed. The different types of barriers highlighted in this survey have been discussed in the literature, not always as barriers in themselves but also as concepts and requirements in need of clarification and/or agreement. For example, the management of NDD and DCD relies on the basic concept of death. Participants at the Santander Global Summit sought a unified concept of death, based on the permanent cessation of brain function. With the objective of reducing disparities and attaining self-sufficiency, they recommended increasing DD and the use of DCD.[18] Financial barriers related to challenges faced by donors and their families were also discussed during the summit. Participants suggested maintaining financial neutrality for both living and DD.[19] Moreover, they made recommendations to health authorities regarding the creation of policies to guide fair access to transplantation and organ allocation, as well as the establishment of registries for data collection, analysis, and reporting of outcomes.[20]

Our findings regarding the challenges faced by different countries in educating healthcare professionals (HCPs) complement what has been observed in the literature. For example, to reduce the gaps in knowledge and attitudes toward ODT for HCPs and non-HCPs in Europe, The EUDONORGAN project was created and implemented.[21] This program consisted of web-based and face-to-face training, resulting in positive outcomes regarding the beneficial role of ODT. Other initiatives to assist HCPs in their continuing educational efforts are evidenced by the interest of universities and medical societies in fulfilling gaps in knowledge, attitude, and practice, such as the Summer School Transplantation Medicine given by the University of Groningen[22] or the Hesperis course.[23] In our report, we showed that countries with low or no DD had the lowest number of histocompatibility laboratories (HLs). The Accreditation Review Board of The American Society for Histocompatibility and Immunogenetics established a task force to gather information about the global distribution and characteristics of HLs.[24] They described the presence of 593 HLs in 58 countries across six continents, which were accredited by ASHI and the European Federation for Immunogenetics. They reported that the economy of the countries had an impact on the distribution of HLs. For example, the country with the largest number is the US (163), and the continent with the highest number is Europe (244), with Africa having the lowest number (2). These findings underscore the need for international cooperation to address disparities.

As we mentioned, HCPs in countries with low or no DD had the highest need to engage with religious leaders. It is clear from the literature that different religions support ODT.[25,26] However, it was also noted that the public's perception of ODT, based on their interpretation of their faith, was a key element that needed to be addressed through education.[27,28]

A limitation of this study is the low response rate. Based on the TTS membership (excluding pediatric HCPs), the response rate was 7.3% (438/6060). Regarding the non-TTS members, we were unable to determine if the responders were members of >1 society. Unfortunately, we cannot ascertain how many program directors received the survey. Several researchers have analyzed survey-response rates. Wu et al[29] examined 1071 online survey-response rates from education-related research reports published between 2007 and 2014. The average online survey-response rate was 44.1%. They observed that increasing response rates by contacting more participants did not achieve their objective. A study analyzing higher-education surveys by Fosnacht et al,[30] did not find that a high response rate (75%) versus a low one (5%) would yield better results. A low response rate may or may not lead to nonresponse bias; therefore, they encouraged evaluating the collected data rather than focusing on the low response rate. Lastly, we did not perform country-level comparisons within DD rate groups, as the study was not designed or powered to assess inter-country variability within strata.

To the best of our knowledge, this is the first worldwide survey to collect information from program directors and transplant specialists. The goal of our study is not merely to diagnose the problem but to inform the development of implementable strategies for adoption by the global community. Therefore, we could build a future in which access to life-saving transplantation is determined by medical need, not by geographic privilege or economic circumstances. These findings provide a foundation for dialogue with governments, international agencies, and the public to address challenges and expand access to transplantation worldwide.

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