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Patient and Caregiver Perceptions on the Allocation Process and Waitlist, and Accepting a Less-Than-Ideal Kidney: A Canadian Survey

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Abstract

Background: Transplanting less-than-ideal (LTI) kidneys could help optimize organ utilization, but little is known about how patients and caregivers perceive the allocation process, waitlist, or LTI kidneys.

Objective: To explore the perspectives of patients and caregivers on the Canadian kidney transplant allocation process, waitlist, and LTI kidneys.

Design: Electronic survey.

Setting: Canada.

Patients: Transplant recipients, candidates, and caregivers.

Methods: A bilingual electronic national survey was administered from January to March 2024. The questionnaire contained sections on demographics, perceptions of organ allocation and acceptance, LTI kidneys, and educational preferences. Descriptive analysis was performed.

Results: Two hundred fifty-one responses were analyzed, including patients (63%, n = 159), and caregivers (37%, n = 92), from 11 provinces and territories. Three-quarters (74%, n = 186) understood how patients are placed on the waiting list, and 65% (n = 162) understood how donor kidneys are allocated, but 72% (n = 181) and 68% (n = 171) wanted more information about the waitlist and donor kidney allocation criteria, respectively. Approximately 20% felt that the waitlist and allocation processes were not transparent. Awareness about the option to refuse a deceased donor kidney offer was high (69%, n = 174), yet nearly half of respondents (46%, n = 115) expressed concern about being disadvantaged if an offer for a deceased donor kidney was refused. One-third of participants (33%, n = 83) were open to accepting an LTI kidney.

Limitations: Compared to the general population, more study participants were white, and the majority were educated and financially at ease. This limits the generalizability of the results.

Conclusion: Enhanced communication is required to improve transparency and information about the allocation system and waitlist in Canada.

Abrégé

Contexte: L'utilisation de reins moins idéaux (RMI) pour la transplantation pourrait contribuer à optimiser l'utilisation des organes disponibles. Il existe peu de données sur la perception des patients et du personnel soignant quant aux processus d'attribution et d'inscription à la liste d'attente, et sur l'utilisation des RMI.

Objectif: Explorer les perspectives des patients et du personnel soignant à l'égard des processus canadiens d'attribution des greffes rénales et d'inscription à la liste d'attente, ainsi qu'à l'acceptation de RMI.

Conception: Sondage en ligne.

Cadre: Canada.

Sujets: Receveurs d'une greffe, candidats à la greffe et soignants.

Méthodologie: Un sondage national bilingue réalisé par voie électronique entre janvier et mars 2024. Différentes sections du questionnaire portaient sur la démographie, les préférences en matière d'éducation et les perceptions à l'égard du processus d'attribution et d'acceptation des organes, ainsi que des reins moins idéaux. Une analyse descriptive a été effectuée.

Résultats: Les réponses de 251 questionnaires ont été analysées. Les répondants (63 % de patients [n=159] et 37 % de soignants [n=92]) provenaient de 11 provinces et territoires. Les trois quarts des répondants (74 %, n=186) comprenaient le processus d'inscription des patients sur la liste d'attente et 65 % (n=162) comprenaient le processus d'attribution des reins des donneurs, mais la majorité des répondants souhaitait obtenir plus d'information sur les critères d'inscription sur la liste d'attente (72 %; n=181) ou d'attribution des reins des donneurs (68 %; n=171). Environ 20 % des répondants estimaient que les processus de liste d'attente et d'attribution n'étaient pas transparents. La sensibilisation à l'option de refuser une offre de rein de donneur décédé était élevée (69 %; n = 174), mais près de la moitié des répondants (46 %; n = 115) ont exprimé des préoccupations quant à la possibilité d'être désavantagés en refusant un rein de donneur décédé. Le tiers des participants (33 %; n = 83) étaient ouverts à accepter un rein moins idéal.

Limites: Par rapport à la population générale, les participants à l'étude étaient plus nombreux à être de race blanche, et étaient majoritairement instruits et à l'aise financièrement. Ceci limite la généralisabilité des résultats.

Conclusion: Une meilleure communication est nécessaire pour améliorer la connaissance et la transparence des processus d'attribution et d'inscription à la liste d'attente au Canada.

Keywords

patient education, expanded donor criteria, extended criteria, marginal, high Kidney Donor Profile Index, less-than-ideal kidneys

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Introduction

Transplantation has dramatically improved outcomes for people with kidney disease, yet patients continue to die on the waitlist and a concerning number of kidneys are discarded annually.[1,2] In the United States as many as 1 in 5 kidneys from deceased donors are not transplanted.[3] One strategy for potentially augmenting the pool of available deceased donor kidneys involves transplanting organs from donors with characteristics indicative of potentially suboptimal long-term graft survival.[4] Various labels and definitions have been used for such kidneys (i.e., expanded donor criteria [ECD], extended criteria, marginal, high Kidney Donor Profile Index [KDPI], or less-than-ideal [LTI] kidneys). These kidneys may be of particular benefit for some patients; especially those who are older or have multiple comorbidities.[5,6] When compared with remaining on dialysis, waitlisted patients have a survival advantage for accepting a LTI.[7,8] For example, in a retrospective study using administrative data in the United Kingdom (n = 47 917) lower-all cause mortality was noted for those who received an ECD kidney (defined as deceased donor kidneys aged ≥60 years or aged 50 to 59 years with 2 from the following 3; hypertension; raised creatinine and/or death from stroke) compared with dialysis.[7] In Canada, deceased donor kidneys are primarily allocated within individual provinces, except for highly sensitized patients—those with a calculated panel reactive antibody (cPRA) score over 95%—who can access a national pool of organs. Organ donation organizations oversee the processes of identifying donors, procuring organs, and allocating them, considering factors such as dialysis duration, medical urgency, and pediatric priority.[9]

The decision-making framework for transplant candidates regarding the acceptance or rejection of deceased donor kidneys—especially those that are LTI—necessitates a multifaceted approach encompassing ethical, medical, and personal considerations. This complex scenario requires an integrated strategy that emphasizes education, effective communication, and collaborative decision-making processes. Communication disparities can exist between healthcare providers and patients, supporting the call for improved dialogues to enhance patient comprehension of LTI kidneys.[10,11] Our previous qualitative studies with patients and clinicians have highlighted the crucial role of transparency with respect to the decision-making process and underscored the need for targeted educational resources concerning the risks and benefits associated with LTI kidneys.[10-12] Creating these resources, however, requires a thorough understanding of how patients and caregivers feel about decision making, LTI kidneys, and which patients would be interested in considering one. Moreover, we have a limited understanding on patient and caregiver perceptions of the current allocation and waitlisting process in Canada.

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The purpose of this study was to survey transplant recipients, candidates, and caregivers regarding their perceptions of the allocation and waitlist process in Canada and their impressions of LTI kidneys.

Methods

A bilingual (English and French) electronic national study was conducted by way of a self-reported survey and guided by the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) framework.[13] An advisory committee consisting of 7 members (5 healthcare providers/researchers and 2 patient-family advisors) oversaw the project design and methods and advised on participant recruitment. Approval for the study was obtained from the University of Saskatchewan Behavioural Ethics Board (Beh 4210), Saskatchewan Health Authority, and the Centre hospitalier de l'Université de Montréal (CE23-149).

Recruitment

The population of interest included transplant recipients, candidates, and caregivers. Participants in this convenience sample were recruited through social media posts by transplant and kidney advocacy groups and organizations such as the Canadian Transplant Association, Kidney Foundation of Canada, and the Canadian Donation and Transplantation Research Program. Patients who were listed for a kidney transplant at the Centre hospitalier de l'Université de Montréal (CHUM) and the Saskatchewan Transplant Program were also invited to participate by way of an email and invitation letter, respectively.

Survey Development

The survey was developed by the advisory committee in English and then translated to French by a professional translator. It was input into the Research Electronic Data Capture (REDCap) platform and tested on 2 laypeople to confirm the functionality and ease of use. Filter questions were included to specifically identify kidney transplant recipients, candidates, and caregivers, and to exclude pediatric patients (i.e., those younger than 18 years). Respondents were anonymous to the research team and completion of the survey was taken as evidence of informed consent.

Data Collection

Data collection occurred between January and March 2024. A $10 gift card and invitation to participate in future studies were offered to respondents who filled out the survey; contact information was obtained through a separate survey to preserve the anonymity of the participants. Respondents were briefed on the concept of LTI kidneys; kidneys may come from donors who are older, have underlying medical conditions such as diabetes or high blood pressure, or have slightly decreased kidney function. The questionnaire contained a section on demographics and clinical situation; questions to assess understanding of organ allocation and acceptance (20 items); questions about LTI kidneys (8 items); and educational preferences (8 items), with each appearing as a separate page on the internet survey. To promote interprovincial sharing and optimize the use of LTI kidneys, Canadian Blood Services is considering the creation of a national registry for patients interested in receiving an LTI kidney. The last section of the questionnaire aimed to assess the respondent's interest in joining a national LTI registry (Appendix A). A 5-point Likert scale was used to assess agreement with questions pertaining to organ allocation (i.e., how kidneys are offered and/or distributed when they become available) and decision making when a deceased donor kidney is offered. Adaptive questions were shown only to transplant candidates and recipients to assess the presence of dialysis, whether they preferred a support person to help with decision making, and for those who received a deceased donor kidney previously, whether they felt prepared and had enough time to decide (see Supplementary materials).

Data Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences Statistics version 29 to report descriptive statistics and frequencies. Only completed surveys were analyzed. Likert scale questions for assessing perceptions on allocation and waitlist were recoded to the categories of "agree," "neutral," and "disagree" and reported according to patient and caregiver. To further assess perceptions of those who had an opinion other than neutral, the neutral category was removed and chi-square test of Independence was used to calculate relationships between those who "agree" or "disagree" and the demographic variables: age ($\geq$50 or $<$50), location (Quebec versus the other locations combined), the highest level of education (up to high school completed or higher than high school), and annual income ($\geq$100 K or less than 100 K). For questions about whether the participant would consider accepting an LTI kidney or participating in a national LTI kidney registry, location was categorized according to geography. (West = AB, BC, SK, MB; East = NB, NL, NS, PEI; North = territories. Ontario and QB were left as independent provinces since their sample size was large enough to stand alone.) A P-value less than .05 was considered statistically significant.

Results

Of 380 people who opened the questionnaire, 311 began answering the survey. The final dataset included 251 respondents from 11 provinces and territories in Canada. Quebec had the highest number of respondents (65%, n = 162), with just over half (54%) completing the survey in French.

Approximately two-thirds of the respondents were patients (63%, n = 159), while the rest were caregivers (37 %, n = 92). Missing data primarily consisted of people who started or competed Section 1 (demographics) (42%, 25/60) or Section 2 (50%, 30/60).

Section 1: Demographics

Among the patient participants, the majority (68%, 108/159) had received a kidney transplant, with the remainder waiting (23%, 36/159) or considering a transplant (9%, 14/159). Approximately two-thirds of the patients with transplant (62%, 67/108) received their kidney from a deceased donor. Among the patients who were considering or waiting for a transplant, three-quarters of respondents were on dialysis (76%, 38/50), with hemodialysis being the most common modality (n = 24), followed by peritoneal dialysis (n = 13). Participant demographics are shown in Table 1.

Section 2: Questions to Assess Understanding of Organ Allocation and Acceptance

Respondents indicated a substantial level of understanding about both organ allocation and acceptance, with 74% (n = 186) and 65% (n = 162) agreeing they understood how patients are placed on the waitlist and how deceased donor kidneys are allocated, respectively. Nevertheless, a significant portion of respondents expressed a desire for more information about both the waitlist placement (72%, n = 181) and the allocation of deceased donor kidneys (68%, n = 171). Furthermore, less than half of the participants (41%, n = 103) knew where to find more information about listing and allocation criteria. Figure 1 presents perceptions on allocation and waitlist according to patient and caregiver.

Approximately 20% of the respondents felt that the waitlist (19%) and allocation processes (21%) in their province were not transparent. Free-form questions about whether the respondents had further questions about the waitlist and allocation processes indicated that they were seeking transparency, clarity, and efficiency. Some expressed frustration with the perceived slowness and lack of clear communication. Respondents had a broad variety of questions and comments about how the allocation criteria and the waitlist process work, which are presented in Table 2. Figure 2 presents perceptions of transparency according to patient and caregiver. Demographic variables including age, income, education level, and location were not associated with these questions.

The trust in physicians was notably high, with (72%, n = 180) of respondents trusting their physician to make decisions about accepting a deceased donor kidney (Figure 3). In contrast, almost half of the patient respondents (49%, n = 78/159) disagreed that they required help from a support person or caregiver to make this decision (Figure 4). When asked who the preferred individual was to have discussions about accepting or declining a deceased donor kidney with, respondents preferred the transplant team (28%) followed by the transplant nephrologist (18%). Respondents who were at least 50 years old (χ^2 (1, n = 195) = 7.5, P = .006) and respondents from Quebec (χ^2 (1, n = 195) = 9.5, P = .002) were more likely to agree that they trusted the physician to make the decision about whether to accept a deceased donor kidney.

Awareness about the option to refuse a deceased donor kidney offer was high (69%, n = 174), yet nearly half of respondents (46%, n = 115) expressed concern about being disadvantaged or removed from the waiting list if an offer for a deceased donor kidney was refused (Figure 5). This agreement of concern was higher in respondents from Quebec (χ^2 (1, n = 183) = 6.7, P = .01). For those who received a deceased donor kidney offer, only a small percentage felt unprepared (3%, n = 7) or needed more time to decide (2%, n = 6).

In terms of informed decision-making, respondents indicated a strong desire to be informed about the donor's medical conditions (86%), risk of infection (83%), age group (78%), lifestyles (61%), and duration of kidney function (56%) when receiving a kidney offer. In the free-form text box, 3 participants also added compatibility and cause of death. When asked whether the respondents had questions about shared decision making, the most common questions were about the implications of being offered a deceased donor kidney and then refusing it. When considering what details might change their decision to accept a kidney, respondents most frequently cited the risk of infection (65%), medical conditions (55%), duration of kidney function (45%) and the donor's age group (33%), as the critical factors in patients' decision-making processes.

Section 3: Questions About LTI Kidneys

Participants were surveyed on their knowledge and acceptance of LTI kidneys. Nearly half (46%, n = 116) indicated that their transplant team had discussed the concept of LTI kidneys, while the rest either had not had such discussions (42%, n = 106) or couldn't recall (12%, n = 29).

One-third of participants (33%, n = 83) were open to accepting an LTI kidney. A significant portion of respondents were either uncertain (30%, n = 76) or stated that their decision would depend on specific circumstances (20%, n = 50). Perceived risks of accepting an LTI kidney identified in free-form text included concerns about the functionality and potential complications (n = 88), fear of organ rejection and its implications (n = 24), concerns about a shortened lifespan of the kidney (n = 21), potential worsening of health and increased medical complications (n = 16), potentially having to return to dialysis if the kidney fails (n = 8), and inherent risks associated with undergoing transplant surgery (n = 8). When asked "Do you have any concerns about considering an LTI kidney transplant? If so, please describe," worry about potential complications and the longevity of the

Table 1. Participant Demographics.

Category	Characteristic	Number (n = 251)	Percentage (%)
Language	English	116	46.2
	French	135	53.8
Transplant Perspective	Patients	159	62.5
	Patient considering transplant	14	5.6
	Patient waiting for transplant	36	14.3
	Patient with a kidney transplant	108	43.0
	Caregivers	94	37.5
	Caregiver of patient considering transplant	27	10.8
	Caregiver of patient waiting for transplant	53	21.1
	Caregiver of patient with transplant	12	4.8
Location	Alberta	13	5.2
	British Columbia	7	2.8
	Manitoba	4	1.6
	New Brunswick	3	1.2
	Newfoundland and Labrador	6	2.4
	Nova Scotia	7	2.8
	Nunavut	1	0.4
	Ontario	35	13.9
	Prince Edward Island	3	1.2
	Quebec	162	64.5
	Saskatchewan	8	3.2
	Other	2	0.8
Age	18 to 30	25	10.0
	31 to 40	51	20.3
	41 to 50	53	21.1
	51 to 60	38	15.1
	61 to 70	61	24.3
	71 to 80	20	8.0
	80+	3	1.2
Gender	Man	123	49.0
	Woman	126	50.2
	Agender	2	0.8
Sex at Birth	Male	125	49.8
	Female	126	50.2
Education Level	Less than high school	5	2.0
	High school	32	12.7
	College	105	41.8
	University	106	42.2
	Prefer not to answer	3	1.2
Employment Status	Employed/self employed	151	60.2
	Unemployed	9	3.6
	Studying	4	1.6
	Retired	67	26.7
	Disability	9	3.6
	Other	4	1.6
	Prefer not to answer	7	2.8
Income	<$50K	46	18.3
	$50 to 100K	78	31.1
	$100 to 150K	83	33.1
	$150 to 200K	22	8.8
	>$200K	9	3.6
	Prefer not to answer	13	5.2

(continued)

Table 1. *(continued)*

Category	Characteristic	Number (n = 251)	Percentage (%)
Indigenous	Yes	2	0.8
	No	221	88.0
	Prefer not to answer	28	11.2
Ethnic Minority	Yes	28	11.2
	No	198	78.9
	Prefer not to answer	25	10.0
Population Group*	Arab	6	2.4
	Black	17	6.8
	Chinese	1	0.4
	Korean	1	0.4
	Latin American	2	0.8
	South Asian	2	0.8
	White	212	84.5
	Not listed above	3	1.2
	Prefer not to answer	6	2.4
First language learned as a child*	English	121	48.2
	French	136	54.2
	Another Language	17	6.8
	Prefer not to answer	1	0.4
Language currently spoken most often at home*	English	118	47.0
	French	133	53.0
	Another Language	12	4.8
	Prefer not to answer	1	0.4

*Answers may not add up to 100% because respondents could choose more than one answer

kidney was most commonly described (n = 48). Others expressed concern regarding how healthy the LTI kidney is (n = 26) or that the kidney may not last long or may be rejected (n = 16). Concerns were mentioned regarding donor's health leading up to their death (n = 8). Some respondents were looking for an assurance of a better quality of life (n = 20) or indicated they wanted to understand more before deciding (n = 6).

When asked about participating in a national registry for LTI kidneys, (45%, n = 113) of respondents indicated willingness. However (17%, n = 42) were against it, and a considerable number of participants (38%, n = 96) were unsure or indicated that their decision would depend on the circumstances. Statistically significant differences were noted in the respondents between above and below the cutoff of 50 and in location, but not education level or income. The results are shown in Tables 3 and 4.

Participants were asked to rate how important various factors were about decision making whether to accept an LTI kidney on a Likert scale ranging from 1 to 10, where 1 indicates an aspect is "not at all important" and 10 signifies it is "very important." Factors that were perceived to be the most important were current experience with dialysis or chronic kidney disease and donor factors. Responses are presented in Table 5.

Factors that would lead a respondent toward considering an LTI kidney were also derived from the free-form text. The most common responses were health status or how a person was managing on dialysis (n = 13), age (n = 8), quality or expected longevity of the LTI kidney (n = 7), and time spent waiting (n = 4). Perceived benefits of accepting an LTI kidney included the potential to stop dialysis (n = 53), improvements in quality of life (n = 20), the potential opportunity for a longer life without dialysis (n = 12), and a quicker match or only match for certain patients (n = 8). Some respondents expressed doubt and saw no benefits (n = 11).

Section 4: Questions About Educational Preferences on LTI Kidneys

Participants were asked about the information they would want if a new registry for LTI kidneys was created in free-formed text. Participants expressed a desire for information that allowed for comparison between LTI and standard kidneys (e.g., pros and cons of each option, advantages and risks (n = 25); the need to understand the possible problems post-transplant (n = 20); an interest in knowing the donor's history), including health and lifestyle (n = 19) and wanted answers about the success rates of transplants with LTI kidneys (n = 16).

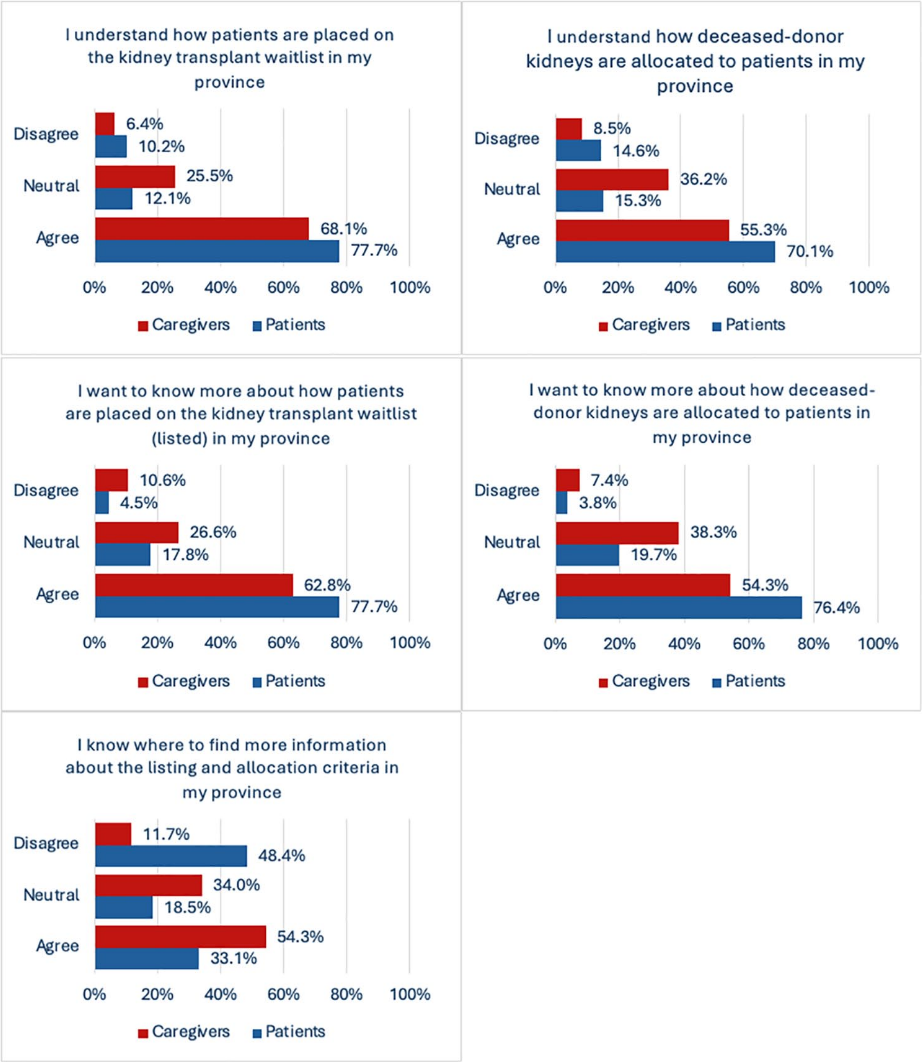

Figure 1. Perceptions on allocation and waitlist according to patient and caregiver.

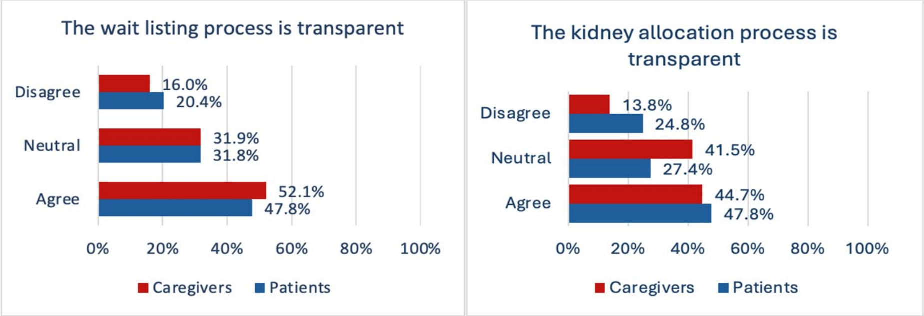

Figure 2. Perceptions on transparency according to patient and caregiver.

Table 2. Respondent Questions and Comments About the Waitlist and Allocation Criteria.

Do you have any questions about the allocation criteria in your province?	Do you have any questions about the way people are listed for a kidney transplant?
"I am curious to know how factors such as age, physical, mental, other possible health conditions influence the 'triage' of potential transplant recipients. (I assume gender and race aren't among factors that influence transplant decisions.)"	"Do I need to complete all the tests before I can be on the waiting list"
"I would like to know the criteria"	"How many profiles similar to mine were on the list when I was waiting?"
"What is the criteria for accepting or rejecting deceased donor?"	"What is the process exactly? What are the steps?"
"I would like to know how many people have been transplanted in a year in Quebec and what is the rate of organ loss"	"Do not know how people are listed definitely questions about when pre-emptive listing is possible. where do HSP patients rank inside my province (not just the national HSP Program)."
"Questions about the age of the donor and the recipient Questions about the donor's medical history (cancer, infectious diseases, HIV, malaria, hepatitis, etc.) Donor Lifestyle"	"What health conditions preclude transplant eligibility?"
"I'm not a 100% sure if the kidneys are first given to those Canada-wide who are harder to match (that would make sense) and then it goes to the first match in Saskatchewan."	"I would like to know how this list works I'd like to know the process"
"better understand the process because in most cases the patient has a general but rather vague idea of how the criteria for organ allocation work."	"What is the psychological criteria for accepting or rejecting patients for kidney transplant, the waiting list and how the clock in and out of the organ works"
"I have no idea how the kidney allocation criteria work. I didn't really need that information having received a kidney from a living donor. But, I'd like to know how it works."	"How do people get on the kidney transplant waiting list? Do I have any opportunities to be on the transplant list before I lose my graft?"
"Are there any differences between the provinces? Are age and potential survival criteria? Does the fact that you have already had a transplant allow you to access a new kidney more quickly to avoid going back to dialysis when the graft reaches its lifespan? Do we take into account the age of the patient vs. the age of the graft?"	"I don't really know how they're registered."
"I would like to know them precisely or even read this list of criteria intended for medical specialists, e.g. nephrologists, cardiologists, endocrinologists, oncologists"	"How are people put on the waiting list?"
"I would like to know them precisely or even read this list of criteria intended for medical specialists, e.g. nephrologists, cardiologists, endocrinologists, oncologists"	"What are the registration criteria?"
"I have rare blood. I am also hyper immune (100%). My chances of receiving offers are slim. I am a universal recipient (according to my blood type). Is it considered for transplantation? The doctors I've spoken to don't seem to know if the transplant team is taking this into account. This would help me tremendously if I were eligible for kidneys of any blood type."	"Are we speeding up the wait for tests to be taken before being able to access the transplant waiting list? Are neighbouring hospitals aware? Is this part of the criteria for getting in front of other patients?"
"What are the allocation criteria that are denied or unfavourable? e.g. donor who died of a heart attack in hospital or heart and/or lung failure. Can we receive this information?"	"I have always been told that the degree of kidney damage is the main factor in listing the list. Is that the case?"
"When there are several possible recipients, what are the criteria considered and the weight of each."	"Why does it take so long to be put back on the list when all the criteria are met and a nephrologist requests it?"
"My immune system is very strong, which puts me at a great disadvantage for another transplant. my doctor told me about a waiting time of 10 years. I risk losing my job, is there not a way to speed up the transplants or the distribution or the qualification of recipients to reduce the waiting time?"	"Yes—When and how are listed."
"would like to see both listing AND allocation criteria posted and available, similar to how Manitoba has done it"	"What are the criteria for being registered? What is the waiting time to be registered? How do I know how many people are ahead of me to have a transplant?"
"It's about being more transparent about the whole process."	"What influences the waiting time?"
"I do not have questions as much as would prefer to be provided with straightforward information."	"No question about signing up, but once on the list, why is there no tracking or information available for people waiting?"
"I never have a report on the results of transplants, in my case kidney transplants, from X better understand the process because in most cases the patient has a general but rather vague idea of how the criteria for organ allocation work"	"yes would like to be notified if, where I am on the list and what else must be done to get on the list"
"Understanding the Allocation Matrix"	"I'd like to know how the waiting list going to process and how long to get a kidney. I need total a explanation. Please"
	"Transparency and communication"
	"I'd like to know where I am on the waiting list"
	"Lack of communication"
	"All I know is that you have to be terminally ill with the graft and meet the allocation criteria that I would like to know in detail as specified in the answer above."
	"No question, but too long a process. It's impossible to test quickly. Still fighting. It is impossible to go to the private sector to do the tests required to be placed on the list. It took more than a year to get on the list."
	"I think that's important when you're waiting to see how this list is compiled. It helps to wait"
	"No. We had an information session at the hospital."

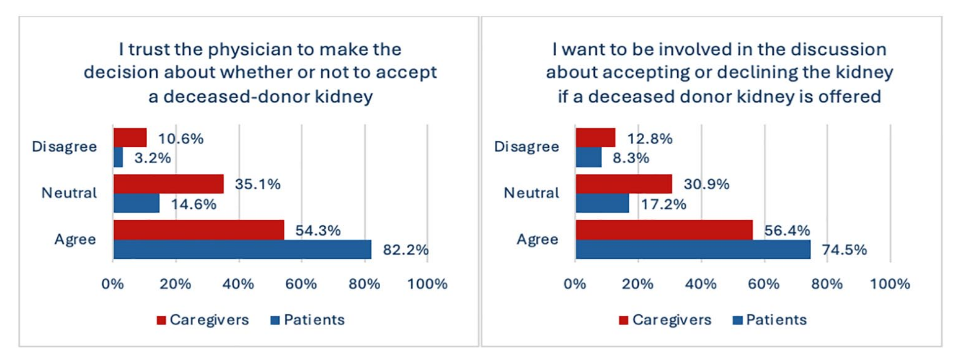

Figure 3. Perceptions on trust and involvement in decision-making according to patient and caregiver.

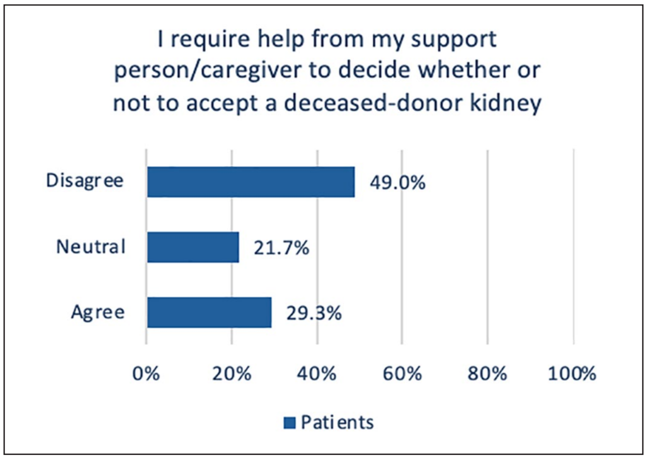

Figure 4. Patient perceptions on caregiver support with decision making.

The majority of respondents expressed a preference to learn more about LTI kidneys and a registry at their transplant clinic (54%, n = 136), followed by the dialysis clinic (30%, n = 75). Some suggested information on a website would also be helpful. Most respondents wished to learn about LTI kidneys as soon as they decided to have a kidney transplant (n = 6%, n = 167) or during the pre-transplant assessment (54%, n = 135). Discussions with the transplant team were the most preferred method of learning (75%, n = 187), and the transplant doctor was the most preferred source (49%, n = 124), followed by the nephrologist or dialysis doctor (14%, n = 35) (Table 6).

Discussion

This survey of patients and caregivers provided insight into the perceptions regarding organ allocation and acceptance. While most respondents (74%) indicated they understood how patients are placed on the kidney transplant waitlist, and how deceased donor kidneys are allocated (65%), nearly the same amount expressed a desire for more information. Less than half knew where to find more detailed information about these processes, highlighting a crucial gap in accessible resources or communication from transplant organizations.[14]

Transparency emerged as a critical concern, with approximately 20% of respondents perceiving the waitlist and allocation processes as lacking transparency. Such perceptions could arise from the complexities and variability inherent in the

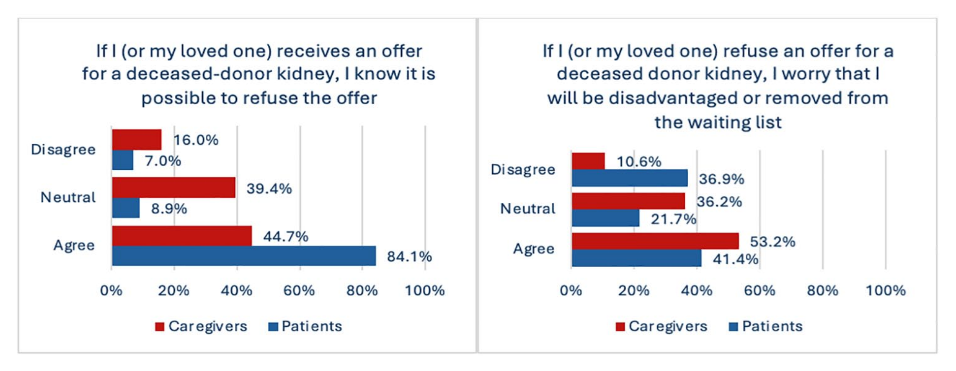

Figure 5. Perceptions on refusing a deceased donor kidney offer according to patient and caregiver.

Table 3. Perceptions on Accepting a Less-Than-Ideal and Participating in a National Registry According to Age.

		Response choices				
Question	Age category	Yes	No	I'm not sure	It would depend	*P*-value
Would you consider accepting an LTI kidney if it was offered to you (or your loved one)?	< 50 (n = 129)	59 (45.7%)	24 (18.6%)	31 (24.0%)	15 (11.6%)	<.001
	> 50 (n = 122)	24 (19.7%)	18 (14.8%)	45 (36.9%)	35 (28.7%)	
If there was a national registry for patients who would like to receive offers of LTI kidneys would you (or your loved one) consider participating?	< 50 (n = 129)	68 (52.7%)	25 (19.4%)	28 (21.7%)	8 (6.2%)	.007
	> 50 (n = 122)	45 (36.9%)	17 (13.9%)	45 (36.9%)	15 (12.3%)	

Table 4. Perceptions on Accepting a Less-Than-Ideal and Participating in a National Registry According to Location.

		Response choices				
Question	Location	Yes	No	I'm not sure	It would depend	*P*-value
Would you consider accepting an LTI kidney if it was offered to you (or your loved one)?	West (AB, BC, SK, MB, n = 32)	17 (53.1%)	4 (12.5%)	9 (28.1%)	2 (6.3%)	<.001
	ON (n = 35)	16 (45.7%)	10 (28.6%)	7 (20.0%)	2 (5.7%)	
	QB (n = 162)	39 (24.1%)	22 (13.6%)	55 (34.0%)	46 (28%)	
	East (NB, NL, NS, PEI, n = 19)	10 (52.6%)	5 (26.3%)	4 (21.1%)	0	
	North (Nunavet, n = 1)	1	0	0	0	
If there was a national registry for patients who would like to receive offers of LTI kidneys would you (or your loved one) consider participating?	West (AB, BC, SK, MB, n = 32)	20 (62.5%)	5 (15.6%)	6 (18.8%)	1 (3.1%)	N.S.
	ON (n = 35)	19 (54.3%)	5 (14.3%)	11 (31.4%)	0	
	QB (n = 162)	61 (37.7%)	27 (16.7%)	52 (32.1%)	22 (13.6%)	
	East (NB, NL, NS, PEI, n = 19)	12 (63.2%)	4 (21.1%)	3 (15.8%)	0	
	North (Nunavet, n = 1)	1	0	0	0	

AB = Alberta; BC = British Columbia; SK = Saskatchewan; MB = Manitoba; ON = Ontario; QB = Quebec; NB = New Brunswick; NL = Newfoundland; PEI = Prince Edward Island.

transplant system, which may not be fully communicated to patients and caregivers.[15] In a recent qualitative study in Quebec (n = 14), patients between 64 and 75 years with chronic kidney disease G4-5 generally perceived the allocation criteria to be fair.[16] However, in a cohort of waitlisted and kidney recipients in the United Kingdom (n = 36), some participants expressed concerns about how kidneys are allocated.[17] In the United States, concerns about the transparency of the transplant process were also identified by the general public.[18] Such concerns were not without consequence; participants who believed the allocation was "unfair" or were "unsure" about fairness were less willing to donate organs.[18]

In the present study, high awareness about the option to refuse a deceased donor kidney offer was reported (69%), yet nearly half of the respondents (46%) expressed concerns about potential repercussions, such as being disadvantaged or removed from the waiting list if they refuse an offer. This highlights the need for clearer policies or reassurances from transplant authorities to ensure patients feel secure in their ability to make informed choices without fear of penalty.

Despite the mixed perceptions, trust in physicians remained notably high, indicating a strong relationship between patients and their transplant physicians. Similar results were noted in our previous qualitative study with

Table 5. Perceived Importance of Factors Related to Decision Making on Whether to Accept a Less-Than-Ideal Kidney Rated on a Likert Scale of 1 (Not at All Important) to 10 (Very Important).

Factor	Mean ± SD
Your current experience with dialysis or chronic kidney disease	7.4 ± 2
Donor factors that impact kidney survival (e.g., donor age, high blood pressure, and how far away the kidney is coming from)	7.4 ± 2.3
Recipient factors that impact kidney survival	7.02 ± 2.3
Organ allocation process	6.7 ± 2.2
What to expect when you receive an offer	7.2 ± 2.1
Organ allocation criteria	6.8 ± 2.1
Type of deceased donors (donation after brain death or donation after cardiocirculatory death)	6.6 ± 2.3
Next steps if the organ is accepted	7 ± 2.3
Next steps if the organ is declined	7.1 ± 2.2
Other factors	5.7 ± 1.8

kidney transplant recipients and transplant candidates, where trust in the medical team emerged as a common theme.[11] Consistent with other literature, older respondents were more likely to trust their physician with decision-making,[19] and patients and caregivers wanted to be involved in the decision-making process about organ acceptance.[11,20,21] When it comes to making an informed decision about accepting a kidney offer, participants rated the donor's medical conditions (86%), risk of infection (83%), and the age group of the donor (78%) as the most important factors. This shows a well-considered approach, prioritizing health, and long-term outcomes in their decision-making process.

The willingness to accept LTI kidneys was notably low, with a third (33%) open to this option and another third being uncertain (30%). Less-than-ideal kidneys may benefit specific groups of patients such as those who are older or with multiple comorbidities and generally would not be a consideration for young transplant candidates. Interestingly, in the present study, participants who were younger than 50 were more likely to express an interest in LTI kidneys. This finding highlights the need for better educational materials that clearly articulate the risks and benefits associated with LTI kidneys and the populations that are most likely to benefit from them. Under half of the respondents (46%) indicated that their transplant teams had discussed the concept of LTI kidneys, which raises concerns about the consistency and effectiveness of communication practices across transplant centers. Enhancing uniformity in discussing all potential transplant options, including LTI kidneys is crucial for

Table 6. Educational Preferences for Education About Less-Than-Ideal Kidneys and a National Registry.

Category	Characteristic	Number (n = 251)	Percentage (%)
Where would you like to learn more about LTI kidneys and the new registry?	At the transplant clinic	136	54.2
	At the dialysis clinic	75	29.9
	At home	25	10.0
	On social media	5	2.0
	Other	10	4.0
When would you like to learn about LTI kidneys and the new registry?*	As soon I (or my loved one) decide to have a transplant	167	66.5
	Pre-transplant assessment	135	53.8
	Waiting list	94	37.5
	Other	13	5.2
How would you like to learn about LTI kidneys and the new registry?*	Video education	138	55.0
	Information booklets	146	58.2
	Discuss with team	187	74.5
	Group sessions	48	19.1
	Other	9	3.6
Who would you prefer to learn from about LTI kidneys?	The transplant doctor	124	49.4
	The transplant nurse	23	9.2
	The nephrologist or dialysis doctor	35	13.9
	The nephrology or dialysis nurse	5	2.0
	From another patient	8	3.2
	Other	56	22.3
What language(s) would you prefer educational materials to be created in?*	English	122	48.6
	French	135	53.8
	Prefer not to answer	3	1.2

*Totals will not add up to 100% since respondents could choose more than one response.

informed decision-making and facilitating trust in the transplant process. Second to discussions with the transplant team (i.e., transplant physician), respondents indicated a preference for information booklets and video education to learn about LTI kidneys. Standardizing educational materials across the country could facilitate uniformity in messaging.

The limitations of this work deserve consideration. We achieved responses from patients and caregivers across the country, but there was a higher representation of respondents from Quebec. Notable differences were found within Section 2 of the survey (questions about organ understanding and allocation) which suggests there may be regional differences and that results may not be generalizable across the country. Selection bias could also have played a role as some programs have lower rates of living donors, and there is an increased reliance on deceased donor kidney transplants. Eighty-five percent of the sample was white, and the majority were educated and financially at ease. This contrasts with our Canadian population, where approximately 70% reported being white[22]. Given the well-documented disparities in access to transplantation with marginalized populations[23,24] perceptions on kidney allocation, the waitlist, and LTI kidneys may vary. Furthermore, candidates who are ethnic minorities may not have access to social media and/or may not have been able to reply in French or English, which would have been missed in this study. We suggest a fulsome evaluation of this topic from the perspective of marginalized populations. For optimal contextualization of the responses, we opted to analyze only the complete surveys. However, this required the exclusion of 35 respondents who provided partial responses to sections 2 and 3 (12%). Finally, since the survey was anonymous and an incentive was offered through an unlinked survey, there is the possibility that surveys were completed more than once by the same respondent or by a respondent who was not a kidney transplant patient or care partner.

Conclusions

Patients and caregivers expressed a substantial level of understanding about organ allocation and acceptance, but many expressed concerns with the process, LTIs and an LTI registry. Enhanced communication is required to improve transparency about the allocation system and waitlist in Canada and facilitate decision making about deceased donor kidneys.

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Ethics Approval and Consent to Participate

Approval for the study was obtained from the University of Saskatchewan Behavioural Ethics Board (Beh 4210), Saskatchewan Health Authority, and the Centre hospitalier de l'Université de Montréal (CE23-149). Completion of the survey was considered implied consent.

Consent for Publication

Consent for publication was obtained from all authors.

Availability of Data and Materials

No primary data is presented in this publication.

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Supplemental Material

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