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How important is social support in determining patients' suitability for transplantation? Results from a National Survey of Transplant Clinicians

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Abstract

Background—National guidelines require programmes use subjective assessments of social support when determining transplant suitability, despite limited evidence linking it to outcomes. We examined how transplant providers weigh the importance of social support for kidney transplantation compared with other factors, and variation by clinical role and personal beliefs.

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Contributors KL conceived of the study and oversaw all aspects including writing. TAL oversaw the study design and statistical analysis and contributed to manuscript writing, JP and JE contributed to the study design and analysis; DWH contributed to data acquisition and to key elements of study design, EJG, ZB, ND contributed to the design of the experiment and to the manuscript development.

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Methods—The National survey of the American Society of Transplant Surgeons and the Society of Transplant Social Work in 2016. Using a discrete choice approach, respondents compared two hypothetical patient profiles and selected one for transplantation. Conditional logistic regression estimated the relative importance of each factor; results were stratified by clinical role (psychosocial vs medical/surgical providers) and beliefs (outcomes vs equity).

Results—Five hundred and eighty-four transplant providers completed the survey. Social support was the second most influential factor among transplant providers. Providers were most likely to choose a candidate who had social support (OR=1.68, 95% CI 1.50 to 1.86), always adhered to a medical regimen (OR=1.64, 95% CI 1.46 to 1.88), and had a 15 years life expectancy with transplant (OR=1.61, 95% CI 1.42 to 1.85). Psychosocial providers were more influenced by adherence and quality of life compared with medical/surgical providers, who were more influenced by candidates' life expectancy with transplant ($p<0.05$). For providers concerned with avoiding organ waste, social support was the most influential factor, while it was the least influential for clinicians concerned with fairness ($p<0.05$).

Conclusions—Social support is highly influential in listing decisions and may exacerbate transplant disparities. Providers' beliefs and reliance on social support in determining suitability vary considerably, raising concerns about transparency and justice.

INTRODUCTION

Kidney transplantation provides a unique example of rationing life-saving treatment in USA, requiring clinicians to consider multiple factors when deciding which patients to list for transplant. With growing organ scarcity and increasing oversight of outcomes, transplant centres must balance concerns for fairness and medical utility when selecting candidates.¹ To do so, transplant teams rely on guidelines that Centers for Medicare and Medicaid Policy (CMS) and professional societies promulgate to clarify the factors (medical, demographic, psychological and lifestyle) that should be used to determine eligibility.²⁻⁵ There is little information about how influential subjective criteria are compared with other factors when evaluating candidates for kidney transplantation, especially the requirement for adequate social support.^{6,7} Social support can be defined as the services, care or encouragement provided by social network members (eg, spouses or partners, family, and friends). Although no formal guidelines establish a threshold for social support, inadequate social support is designated as a relative contraindication to kidney transplantation in USA by CMS and professional transplant organisations.⁴ Accordingly, patients who cannot demonstrate sufficient social support may be excluded from kidney transplantation, resulting in differential access to care.

Compared with other evidence-based criteria used to determine transplant eligibility, social support remains controversial because of its subjectivity, lack of uniform standards for assessment⁷ and because its relationship to post-transplant outcomes remains uncertain.⁸ A 2017 meta-analysis found that social support was not predictive of post-transplant adherence, and was inconsistently associated with other post-transplant outcomes.⁸ Use of social support raises both procedural and distributive justice concerns. First, due to ambiguous guidance, clinicians may vary significantly in their reliance on social support in decision making. Inconsistent use of social support in patient evaluation and listing decisions

may significantly increase variation between as well as within centres, undermining uniformity and transparency in transplantation and raising procedural justice concerns. Second, use of social support may disproportionately affect vulnerable populations which are less able to identify caregivers with flexibility to leave work, with more strained support systems, and less able to self-finance home-based assistance. Further disadvantaging vulnerable populations by increasing barriers to transplantation raises distributive justice concerns, including the potential for exacerbating socioeconomic disparities.⁹¹⁰ Understanding how providers with diverse perspectives value different criteria and the relative importance of social support criterion is critical for minimising variation in clinical practice and socioeconomic disparities in access to care.

Clinicians' personal ethical beliefs may influence the extent to which they rely on the social support criterion. Recent increased scrutiny of outcomes by CMS may influence some clinicians to use social support in an attempt to prioritise outcomes above all else (utilitarian concerns). At the same time, the potential for contributing to disparities in access to the transplant waitlist may influence clinicians' against using social support (distributive justice/fairness concerns).¹¹⁻¹⁴ Clinical role may also contribute to attitudes about using social support in transplant evaluations, especially between clinicians directly involved in psychosocial evaluations (eg, social workers, psychologists, psychiatrists) and other medical or surgical clinicians (eg, nephrologists, transplant surgeons).

There is little information about how influential subjective criteria are compared with other factors when evaluating candidates for kidney transplantation, especially the requirement for adequate social support.⁶⁷¹⁵¹⁶ The absence of established definitions and thresholds for social support leaves significant discretion and interpretation to clinicians. Using a discrete choice experiment, this study examines which factors are most important to transplant clinicians when prioritising patients for kidney transplantation. We examine the relative importance of social support compared with other listing criteria, and assess whether use of social support varies based on clinical role in the transplantation process and ethical beliefs related to balancing fairness with utility.

METHODS

We developed a discrete choice experiment to examine how transplant clinicians rank the importance of social support when choosing a candidate for kidney transplantation, compared with other patient factors. The discrete choice experiment was included as part of a larger survey about transplant centres' ongoing social support evaluation practices, and clinicians' opinions about the evidence, importance and fairness of using social support in listing decisions. Discrete choice experiments are a well-established validated quantitative approach for eliciting preferences. They have been commonly used in the health policy context, especially in the context of complex medical decision making, where decision makers must consider multiple factors to arrive at a decision.¹⁷¹⁸ A typical discrete choice question elicits preferences by asking respondents to choose between multiple attribute-based scenarios. In our survey, we asked respondents to choose between two hypothetical candidates to receive a kidney transplant, based on differences in key patient attributes (figure 1).

Sample

We surveyed the American Society of Transplant Surgeons (ASTS) and Society for Transplant Social Work in October 2016 to gain diverse perspectives from clinicians with different roles in listing decisions and candidate evaluations. Participants received an email containing a description of the study, consent form and anonymous survey link.

Survey development

Following established guidelines for conducting discrete choice experiments (DCEs),¹⁹ we identified 20 possible attributes included in transplant listing decisions through a review of clinical guidelines and the literature. This attribute list was narrowed through iterative deliberations by a group of stake-holders (transplant surgeon, psychologist, social worker, ethicist and behavioural scientists; n=6) who ranked attributes by importance for transplant listing decisions and considered independence from other attributes.¹⁸ Rankings were qualitatively discussed until consensus was reached. In accordance with methodological recommendations to minimise respondents' cognitive burden,²⁰ seven attributes were selected: life expectancy with transplant, life expectancy without transplant, quality of life with transplant, adherence to medical regimen, time on the waiting list, social support and age (table 1). Attributes were defined and two to three, levels representing meaningful differences within attributes, were assigned following a literature review and discussion among stakeholders (ie, 20 years, 40 years and 60 years for the 'age' attribute)¹⁸ (table 1). We conducted cognitive pretests with transplantation experts (n=6) to ensure that respondents understood the survey questions as intended, and revised the DCE attributes and levels based on feedback.

Survey design

Respondents were presented with questions comparing two hypothetical transplant candidates described by varying levels of the seven attributes (hereafter 'candidate profiles'). For each question, respondents were instructed, 'Please imagine that one kidney is available for transplantation. We would like you to choose one patient to receive the organ for transplantation based on their listed attributes. Assume both patients are medically eligible for transplantation'. An example DCE question is shown in figure 1. Candidate profiles were generated using a fractional factorial design, selecting the subset of attribute and level combinations that ensured attribute balance and statistical efficiency.¹⁹ We identified the best orthogonal combination of attribute levels that minimised correlation between attributes and levels, and evaluated design efficiency using the relative D-efficiency Score in SAS.¹⁹ Using a simulation model prior to fielding, we tested the chosen design for balance, efficiency and to estimate needed sample size.²¹ Simulation results indicated a minimum sample of 270 respondents was needed. Respondents were evenly randomised into one of nine blocks of four discrete choice questions. To maintain statistical efficiency and design balance in subgroup analyses, randomisation was stratified by clinician involvement with psychosocial evaluation and familiarity with kidney transplantation.

Demographic information (organ transplant programme, United Network for Organ Sharing (UNOS) region, gender, years in practice) was collected. Personal beliefs related to social support were assessed based on disagreement with the following statements: 'Using social

support to determine transplant eligibility is fair'; and 'Social support is especially important in listing decisions because of the need to avoid wasting organs.' Responses were measured using a 5-point scale, from 'strongly disagree' to 'strongly agree'. These questions are based on measures widely used in surveys about ethical beliefs and rationing of healthcare.^{22–24} We assessed respondents' confidence in using social support to determine transplant eligibility; measured from 'extremely confident' to 'not at all confident'. We also included a free text field for comments. The survey was fielded using Qualtrics (2015, Provo, Utah, USA) and analyses were conducted using Stata V.14, College Station, Texas, USA.

Statistical analyses

We used conditional logistic regression to calculate the odds that a respondent would choose a particular candidate profile given the attribute levels presented, accounting for matched comparisons. The dependent variable was the profile chosen by the respondent and independent variables included attribute levels in the profiles. We used effects coding to represent the presence or absence of each attribute level. With effects coding, the estimated independent effects for each attribute level represent the incremental effect over the mean for respondents.²⁵ We adjusted for the within-subject correlation using bootstrapping with replacement methods.²⁶ Conditional attribute importance reflects the difference between the highest and lowest regression parameter estimates for each attribute, divided by the sum of all differences. This metric gives an estimate of the overall importance of each attribute.²⁷

We conducted stratified analyses based on clinical role (psychosocial provider vs not), belief that using the social support criterion is fair (agreed/disagreed), belief that social support is important to avoid wasting organs (agreed/disagreed) and confidence in the social support criterion (confident/not confident). Neutral responses were included into the disagree category for stratified regression analyses, and sensitivity analyses tested removing these responses from the analysis. Likelihood ratio tests were used to compare statistical differences in the importance of attributes between subgroups. Additional sensitivity analyses assessed the validity of responses from respondents who answered two or fewer discrete choice questions (n=96); those unfamiliar with kidney transplantation (n=73); and respondents who answered uniformly in the DCE (eg, always selecting 'Patient B'; n=47).

RESULTS

Survey sample

Overall, 627 people completed the survey (41% response rate) of whom 93% completed the DCE (n=584). Respondent characteristics are displayed in table 2. Approximately half (52.6%) of respondents were male, and 48.3% (n=282) were involved in psychosocial evaluation of transplant candidates (hereafter psychosocial providers). Of psychosocial providers, 66% were social workers and 29% were medical doctors (MDs). Medical/surgical providers that were not involved directly in psychosocial evaluation comprised 51.7% of the sample (n=302). Most respondents were involved in kidney transplantation (71.6%), followed by liver (52.9%), pancreas (38.7%), heart (14.4%) and lung (7.5%), with most involved in multiple programmes.

Most providers (88.7%) reported having used inadequate social support along with other factors when making listing decisions. Most (86.3%) agreed or strongly agreed that patients with inadequate support are evaluated less favourably for transplantation than similar patients with greater support. Most providers (71.4%) perceived social support was important for preventing organ waste (utility). Yet, a quarter of respondents (24.3%) thought using social support to determine transplant eligibility was unfair or were unsure about its fairness. Nearly half of respondents (42.4%) were only somewhat or not at all confident in using social support to determine transplant suitability.

Discrete choice experiment results

Overall, a candidate's life expectancy with transplant, adherence to medical regimen and social support were the most influential factors in transplant decision making (table 3; attribute importance estimates are shown as percentages and convey the overall influence each attribute had in the respondents' profile choice, conditioned on the particular attributes and levels in the survey, with higher numbers conveying more relative influence). Compared with the mean rate of choosing a profile, respondents were 1.68 times more likely to choose a profile of a transplant candidate that had social support (95% CI 1.50 to 1.86), 1.64 times more likely to select a profile of a candidate who always adheres to his/her medical regimen (95% CI 1.46 to 1.88) and 1.61 times more likely to select a profile of a candidate with a 15 years life expectancy (CI 1.42 to 1.85).

Importantly, short expected life expectancy following transplantation and lack of social support were similarly influential in providers' listing decisions. Respondents were less likely to select candidates who were expected to survive for only 5 years (OR=0.56; 95% CI 0.49 to 0.62) or who had no social support (OR=0.60; 95% CI 0.54 to 0.68). Life expectancy without transplant (a measure of urgency) and the age of the transplant candidate were the least influential attributes, and were not statistically significant. Sensitivity analyses with a more restricted sample yielded similar results.

Results by personal beliefs

The influence of social support in transplant decisions varied significantly based on clinicians' stated beliefs as well as their confidence in their centre's listing guidelines (table 4, figure 2). Social support was the *most* influential factor (24% attribute importance) among clinicians who believed that social support criterion was important to avoid organ waste (n=392), while it was the third *least* influential factor (12% attribute importance) in decision making among respondents who disagreed that social support was important for preventing organ waste (n=168; p<0.05 for statistical difference between groups). Social support was one of the *most* influential factors in decision making among clinicians who believed the use of social support was fair, (24% conditional attribute importance; n=422) but was one of the *least* influential factors in decisions among clinicians who did not believe that social support is fair (8% conditional attribute importance; n=135; p<0.05 for difference between groups). Social support was also significantly less influential in the decision making of clinicians who lacked confidence in their centre's listing guidelines compared with those who stated confidence in guidelines (table 4; 12% vs 26% conditional attribute importance, respectively; p<0.05 difference between groups).

Results by clinical role

When the sample was stratified by clinical role, comparing psychosocial providers and medical/surgical providers, differences emerged, although social support remained the second most influential attribute for both groups. Psychosocial providers were 1.69 times more likely (95% CI 1.41 to 1.92) and medical/surgical providers were 1.79 times more likely (95% CI 1.57 to 2.04) to select a candidate with social support (table 4). Overall, medical/surgical providers were most influenced by the candidate's life expectancy with transplant (24% attribute importance), followed by social support (20% attribute importance) and adherence to medical regimen (17% attribute importance) (table 4, full analysis results online supplementary appendices 1–5). Among psychosocial providers, the most influential attributes were adherence to medical regimen (attribute importance score: 25%), social support (21%) and quality of life with transplant (20%). Compared with medical/surgical providers, psychosocial providers were significantly more likely to prioritise medication adherence ($p<0.05$) and quality of life ($p<0.10$) in their choices. By contrast, medical/surgical providers were significantly more likely to prioritise life expectancy with transplant ($p<0.05$), compared with psychosocial providers.

DISCUSSION

Clinicians assign significant importance to objectively measured factors influencing patient and graft survival rates, in accordance with regulatory agencies that require minimum risk-adjusted outcomes.²⁸ Yet, little is known about how transplant clinicians consider subjective factors like social support when determining whether to waitlist patients for transplantation. Our findings reveal that social support is highly influential in shaping the opinions of medical/surgical providers and psychosocial evaluators alike. This finding is striking, given the limited evidence base confirming the impact of social support on transplant outcomes and its potential for increasing disparities.⁸ Vague, subjective criteria may result in shifting standards, and inconsistent treatment. Because reliance on social support is unpredictable, not evidence-based, and not always transparent, use of social support may contribute to unequal access to transplantation.

Social support was the second most important factor in listing decisions irrespective of clinical role, with psychosocial evaluators most influenced by adherence to medication, and medical/surgical providers most influenced by life expectancy post-transplant. Surgeons' preferences for life expectancy after transplant may stem from concerns over transplanting too many high-risk patients, which can lead to lower than expected patient and graft survival rates, jeopardising the transplant programme's status with regulatory agencies and payers, including centre of excellence designations. Preferences may also be affected by clinicians' awareness of the organ shortage and the imperative of avoiding futile transplants. By contrast, concern over adherence and quality of life may be more salient to social workers given the scope of their practice and their role in supporting patients following transplantation.

Clinicians' personal beliefs and confidence in their centre's evaluation guidelines strongly determined their reliance on social support in listing decisions. Clinicians who expressed more utilitarian values including perceived implications for organ waste were more likely to

use social support in listing decisions, whereas others more concerned about fairness seldom used social support in listing decisions. Specifically, among clinicians who perceived the social support criterion to be unfair, social support was among the least influential factors, compared with the most influential factor among those concerned with utility (preventing organ waste). Greater confidence in procedures related to social support evaluations was associated with greater reliance on social support in listing decisions. These findings underscore procedural justice concerns associated with subjective criteria because patients seeking life-saving transplants may receive radically different treatment depending on clinicians' personal beliefs and not on specified criteria.

Apparent discordance in use of social support by ethical beliefs and confidence in the social support criterion may result in significant variation in patient experiences and should be further examined in the context of persistent disparities in access to transplantation. Although the National Organ Transplant Act²⁹ mandates equal access to life-saving organs, vulnerable populations continue to face barriers in access to the waitlist.^{30,31} Persons of low socioeconomic status, racial and ethnic minorities, and those living in rural areas face disproportionate difficulty successfully completing transplant evaluations.^{12,13,15,32–36} Because demonstrating social support may be correlated with socioeconomic status, race, ethnicity and age, this criterion may increase and reinforce barriers to care for underserved populations.^{34,37} The family structure and marriage rates seen in particular groups, both of which may influence the ability to demonstrate social support, may contribute to this.⁹ For example, blacks (32%) are less likely than whites (56%) to be married, and this gap has increased significantly over time.³⁸ Patients in rural areas and those whose social network has limited job security or flexibility may also face greater difficulty demonstrating social support.^{11,39} Future research should examine differences in the ability of patients from undeserved backgrounds to meet the threshold for social support.

Lack of clarity about how to evaluate social support and its importance in determining listing status leaves this criterion increasingly susceptible to implicit bias and may also contribute to disparities. Implicit bias and subsequent reliance on stereotypes is particularly problematic when individuals face high levels of cognitive load and stress, as is the case in transplantation, limiting providers' ability to filter bias from their thoughts and interactions.⁴⁰ While attention is focused on the high stress, fast-paced medical environment and controlling explicit bias, physicians' are vulnerable to implicit bias.⁴¹ Implicit bias refers to *'the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favourable and unfavourable assessments, are activated involuntarily and without an individual's awareness or intentional control'*.⁴² Use of the social support criterion may reinforce implicit biases against people who are less socially connected, who do not have family or friends advocating on their behalf, and who may be part of a stigmatised population who often have fewer social contacts (ie, persons with persistent mental illness, history of substance abuse).⁴³ As such, the social support criterion may amplify existing biases and sanction them, entrenching unequal treatment as part of the transplant evaluation process, undermining both procedural and distributive justice.

The impact of implicit bias in medicine and surgery is documented in a growing literature, offering new explanations for the paradox that well-intentioned clinicians sometimes treat marginalised patients worse than others.^{40,44,45} For example, Green *et al* found that, even among physicians with no explicit racial bias, most displayed negative implicit bias towards black patients.⁴⁶ Moreover, while explicit bias did not affect behaviour, physicians with stronger implicit bias were less likely to recommend a preferred treatment for black compared with white patients, although both presented identical symptoms. Similarly, implicit bias has been associated with lower empathy towards marginalised patients, affecting care recommendations.⁴⁵ Taken together, these findings suggest that the social support criterion reinforces a blind spot among clinicians by sanctioning non-evidence-based and potentially stigmatising criterion that aligns with clinicians' implicit bias. Implicit bias operates on the subconscious level, making it difficult to recognise its existence and use. Studies linking bias to racial disparities in access to kidney transplantation illustrate the need for reviewing eligibility criteria and improving national standards, including those related to social support.^{47,48} Future studies should qualitatively examine how clinicians use social support to determine eligibility, and their beliefs around fairness, efficiency and equity to better understand the cognitive processes, emotions and organisational factors contributing to waitlisting decisions. Further exploration of the mechanisms by which clinicians legitimise the use of a criterion which they believe may be unfair is also needed to effectively tailor interventions to improve equity in evaluations.

Our study is not without limitations. Although our sample is balanced nationally, the ASTS membership did not include a sufficient number of nephrologists, and as such, we cannot examine whether they hold different preferences. However, although the medical/surgical providers and psychosocial providers in our sample have distinct roles, training and preferences for many factors, they did not differ with respect to their prioritisation of social support. Future work should examine preferences of nephrologists. While our study includes questions about ethical beliefs commonly discussed in the context of organ transplantation, our survey did not define fairness to avoid biasing providers' responses. Future studies should examine differences in ethical ideologies more comprehensively to determine how these influence other aspects of clinical decision making. Finally, patient perspectives were not included in this paper. Future studies should examine public perceptions about using social support to determine transplant eligibility.

Our findings should be considered in conjunction with recent and proposed changes to regulatory oversight of solid organ transplantation in USA. Some suggest that greater regulatory scrutiny of transplant programmes with poorer than expected outcomes is harmful, and may lead to risk aversion on the part of transplant programmes.⁴⁹ Risk averse programmes may undertake fewer high-risk transplants, turning away patients who could benefit, and resulting in unnecessary organ waste. While studies have examined potential harms of increased regulatory scrutiny on organ waste, the potential impact for vulnerable patients seeking transplantation remains unclear. One consequence of heightened scrutiny and lack of clear guidelines for using social support to determine eligibility for transplantation is greater susceptibility to implicit bias and lack of uniformity in care. Given the poor evidence base, lack of transparency and potential to increase disparities, the transplant community should re-examine use of social support in patient evaluation and

improve definitions and assessments to ensure transparency and equity in access to transplantation.

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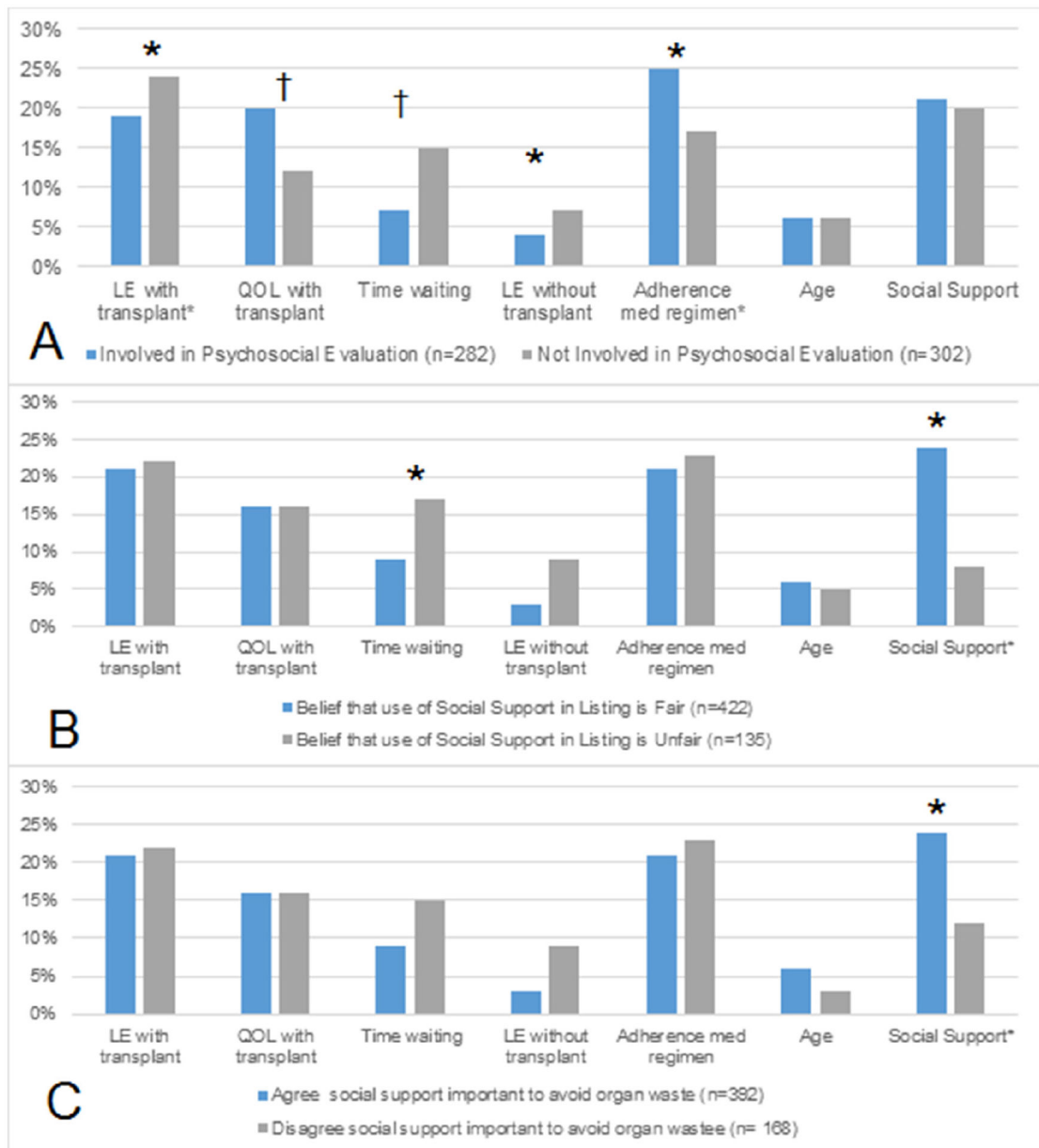
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In this question, please imagine that one kidney is available for transplantation. We would like you to choose one patient to receive the organ for transplantation based on their listed attributes. Assume both patients are medically eligible for transplantation.

Patient A	Patient B
Age: 60 years old	Age: 45 years old
Life expectancy with transplant: 5 years	Life expectancy with transplant: 15 years
Life expectancy without transplant: 1 year	Life expectancy without transplant: 2 years
Quality of life with transplant: No/minor improvement following transplant	Quality of life with transplant: Significant improvement following transplant
Social Support: No	Social Support: Yes
Adherence to medical regimen: Always adheres to medical advice (e.g., never misses a medication)	Adherence to medical regimen: Sometimes adheres to medical advice (e.g., misses a medication once a week)
Time Waiting: 8 years	Time Waiting: 5 years

Figure 1.
Sample discrete choice question.



The likelihood ratio test was used to compare the difference in attribute estimates between the subgroups (i.e. involved in psychosocial evaluation versus not involved). *Represents a significant difference in importance ranking between subgroups for the specified attribute, with likelihood ratio test $p < 0.05$. †Represents a significant difference in importance ranking between subgroups for the specific attribute, with likelihood ratio test $p < 0.1$.

Figure 2.

Graphs of conditional logistic regression model results, stratified by clinical role (A), belief in fairness of using social support criteria (B), agreement with importance of avoiding organ waste (C). QOL, Quality of life; LE, Life expectancy.

Table 1

Discrete choice experiment: transplant candidate profile attributes and levels

Attribute	Definition	levels
Life expectancy with transplant	Number of years patient is expected to live posttransplant	5 years 10 years 15 years
Quality of life with transplant	Level of functioning achieved with transplant in the long term	No/slight improvement Significant improvement
Time on waiting list	Time already spent waiting on the transplant list (time since candidacy for transplant)	3 years 5 years 8 years
Life expectancy without transplant	Number of years patient is expected to live if he or she does not receive the organ	3 years 2 years 1 year
Adherence to medical regimen	How well a patient follows medical advice for transplant medications	Sometimes Often Always
Age	Patient's age at the time of transplant	60 years 40 years 20 years
Social support	Whether a patient has someone to look after him/ her after organ transplantation and assist with needed post-transplant care	No Yes

Table 2

Sample descriptive statistics

	Full sample		Involved In psychosocial evaluation		Not involved in psychosocial evaluation	
	N	Per cent	N	Per cent	N	Per cent
Total	584		282	48.3	302	51.7
Gender (n=489)						
Male	257	52.7	82	14.4	175	30.0
Female	232	47.4	160	27.4	72	12.3
UNOS region (n=462)						
Region 1	49	10.6	23	3.9	26	4.5
Region 2	54	11.7	22	3.8	32	5.5
Region 3	25	5.4	12	2.1	13	2.2
Region 4	36	7.8	24	4.1	12	2.1
Region 5	62	13.5	31	5.3	31	5.3
Region 6	23	4.8	10	1.7	12	2.1
Region 7	40	8.6	19	3.3	21	3.6
Region 8	33	7.2	13	2.2	20	3.4
Region 9	29	6.3	15	2.6	14	2.4
Region 10	48	10.4	26	4.5	22	3.8
Region 11	63	13.7	36	6.2	27	4.6
Organ programme*						
Kidney	418	71.6	180	30.8	238	40.8
Liver	309	52.9	114	19.5	195	33.4
Heart	84	14.4	65	11.1	19	3.3
Lung	44	7.5	26	4.5	18	3.1
Pancreas	226	38.7	81	13.9	145	24.8
Other	54	9.3	28	4.8	26	4.5
Confident in listing guidelines (n=419)						
Confident	178	30.5	176	30.1	134	22.9
Not confident	241	41.3	94	16.1	144	24.7
Believe using social support in listing is fair (n=562)						

	Full sample		Involved In psychosocial evaluation		Not involved in psychosocial evaluation	
	N	Per cent	N	Per cent	N	Per cent
Agree	422	72.3	214	36.6	200	34.2
Disagree	79	13.5	24	4.1	55	9.4
Neutral	61	10.5	34	5.8	35	6.0
Believe using social support in listing is important to avoid organ waste (n=560)						
Agree	392	67.1	193	33.0	197	33.7
Disagree	54	9.2	26	4.5	28	4.8
Neutral	114	19.5	51	8.7	63	10.8
	Mean	SD	Mean	SD	Mean	SD
Years in practice (n=484)	16.5	11.2	16.1	10.9	16.9	11.4
Years in transplantation (n=486)	13.5	10.4	11.3	9.8	16.1	10.4
Average psychosocial evaluations per month (n=238)	19.9	20.2	20.0	20.4	0	N/A

Percentages are of full sample (n=584) and may add up to <100% as responses to questions were not required. Remaining respondents did not answer the question.

* Percentage may add up to >100%, as respondents were allowed to select multiple organs.

Table 3

Results from the discrete choice experiment conditional logistic regression

Attribute	Level	or	P value	95% CI	Conditional attribute importance
Life expectancy with transplant	5 years	0.56	<0.001	0.49 to 0.62	21%
	10 years	1.10	<0.001	1.00 to 1.24	
	15 years	1.61	<0.001	1.42 to 1.85	
Quality of life with transplant	No/slight improvement	0.66	<0.001	0.49 to 0.62	16%
	Significant improvement	1.51	<0.001	1.38 to 1.64	
Time waiting	3 years	0.76	<0.001	0.68 to 0.87	11%
	5 years	0.99	0.698	0.87 to 1.10	
	8 years	1.33	<0.001	1.18 to 1.50	
Life expectancy without transplant	3 years	0.86	0.011	0.76 to 0.97	5%
	2 years	1.07	0.312	0.95 to 1.17	
Adherence to medical regimen	1 year	1.09	0.134	0.97 to 1.25	
	Sometimes	0.57	<0.001	0.50 to 0.64	21%
	Often	1.07	0.329	0.94 to 1.19	
Age	Always	1.64	<0.001	1.46 to 1.88	
	60 years	0.87	0.010	0.78 to 0.97	5%
	40 years	1.01	0.746	0.91 to 1.14	
Social support	20 years	1.13	0.036	1.01 to 1.27	
	No	0.60	<0.001	0.54 to 0.68	20%
	Yes	1.68	<0.001	1.50 to 1.86	

Modelled with effects coding. N = 497. Pseudo R2 = 0.2406. Attribute importance estimates are shown as percentages and convey the overall influence each attribute had in respondents' profile choice, conditioned on the particular attributes and levels in the survey, with higher numbers conveying more relative influence.

Table 4

Conditional attribute importance: subgroup results by involvement in psychosocial evaluation, belief in fairness of listing, agreement with importance of avoiding organ waste and guideline confidence

	Involvement in psychosocial evaluation		Believe social support in listing is fair		Believe social support is important in listing to avoid organ waste		Confidence in listing guidelines	
	Involved	Not involved	Agree	Disagree	Agree	Disagree	Confident	Not confident
N	282	302	422	135	392	168	178	241
Pseudo R ²	0.244	0.265	0.259	0.244	0.260	0.236	0.267	0.247
Attribute	% Importance		% Importance		% Importance		% Importance	
Life expectancy with transplant	19*	24*	21	22	21	22	19	24
Quality of life with transplant	20 [†]	12 [†]	16	16	16	16	16	16
Time waiting	7 [†]	15 [†]	9*	17	9	15	9	15
Life expectancy without transplant	4*	7*	3	9	3	9	2	8
Adherence to medical regimen	25*	17*	21%	23	21	23	22	20
Age	6	6	6	5	6	3	5	5
Social support	21	20	24*	8	24*	12*	26*	12*

Attribute importance estimates are shown as percentages and convey the overall influence each attribute had in respondents' profile choice, conditioned on the particular attributes and levels in the survey, with higher numbers conveying more relative influence. The likelihood ratio test was used to compare the difference in attribute estimates between the subgroups (ie, involved in psychosocial evaluation versus not involved).

* Represents a significant difference in importance ranking between subgroups for the specified attribute, with likelihood ratio test $p < 0.05$.

[†] Represents a significant difference in importance ranking between subgroups for the specific attribute, with likelihood ratio test $p < 0.1$.