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Willingness of the United States general public to participate in kidney paired donation

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Abstract

Background—Availability of kidney paired donation (KPD) is increasing in the United States, and a national system through UNOS is forthcoming. However, little is known about attitudes toward KPD among the general public, from which donors (particularly non-directed) are drawn.

Methods—In a national study, we assessed the public's attitudes regarding participation in KPD.

Results—Among 845 randomly selected participants, 85.2% of respondents were either “extremely willing” or “very willing” to participate in KPD. Experiences with the medical or organ transplant systems, such as undergoing surgery, having a primary medical provider, a living will, a friend who donated or received an organ, and considering donation after death, were associated with increased willingness. However, increased age, male sex, African American race, Hispanic ethnicity, distrust of the medical system, and not understanding organ allocation were associated with less willingness.

Conclusions—We identify strong support for KPD but some important potential barriers to participation which should be considered as KPD programs are implemented.

Keywords

kidney exchange; kidney transplantation; public attitudes

Kidney paired donation (KPD) is an emerging modality through which potential transplant recipients with incompatible live donors can obtain transplants by participating in matches

with other donor–recipient pairs with reciprocal incompatibilities (1, 2), non-directed donors (3), or other compatible pairs (4). Use of KPD has doubled yearly in the last several years (5), and KPD programs throughout the United States are consolidating to form a single national KPD program through the United Network for Organ Sharing (UNOS), which is currently being developed. Yet, KPD remains underutilized in the US compared with predictions (6) and experience from other countries (7). Furthermore, disparities exist in access to KPD, with greater representation of Caucasians and college-educated patients among KPD recipients when compared with traditional live donor recipients (5) or the deceased donor waiting list (8).

Potential donor attitudes toward KPD could affect future utilization of and access to this donation mechanism. Waterman et al. (9) have shown a high willingness to participate in KPD among 174 donors who were found to be incompatible with their recipients. In a study of 87 minority patients with end-stage renal disease (ESRD), Ackerman et al. (10) have shown a high willingness to participate in KPD among patients in need of a kidney transplant. However, incompatible donors and patients with ESRD are highly motivated to pursue KPD and may not accurately reflect the opinions of the general public. Furthermore, these studies were not powered to detect subgroup differences that might inform potential target groups for education.

Identification of public attitudes toward KPD could yield particularly valuable insight into the success of future public programs, as their success will likely depend on the awareness and approval of potential donors from diverse socio-demographic backgrounds and varied levels of exposure to the transplant or health care systems. This is particularly relevant as the proportion of unrelated donors (friends, co-workers, acquaintances, and friends-of-friends) has significantly increased in the last several years; the opinions of unrelated donors are likely to be much more similar to those of the general public than those of close relatives who either live with or around the dialysis-bound recipients. Furthermore, these programs are also likely to involve participation from non-directed donors (NDDs) who are drawn from the general public rather than from pairs with needy recipients. Identifying factors associated with decreased willingness to participate in KPD may aid in the successful implementation of sustainable programs.

In a national study, we assessed attitudes toward KPD among the United States general public and factors associated with decreased willingness to participate in KPD.

Methods

Study design and population

We performed a national, cross-sectional study of persons living in households in the continental United States from May 2004 to August 2005 to assess attitudes regarding various aspects of life and deceased organ donation. Households were identified via random digit dialing with oversampling to enhance responses from African American and Hispanic participants, as previously described (11). Within each household, participants were randomly selected to participate using the next-birthday method (12, 13), and those who agreed to participate were interviewed by a trained telephone interviewer using a

standardized questionnaire administered in English or Spanish languages. The study was approved by the Institutional Review Board at the Johns Hopkins Medical Institutions.

Questionnaire content

Questions assessed willingness to participate in KPD as well as several factors that could be related to willingness including their socio-demographic characteristics, religiosity and spirituality, experiences with the medical system, experiences with the organ transplant system, willingness to donate deceased organs, perceived understanding of US transplant organ allocation, and trust of the medical system. To assess willingness to participate in KPD, we presented participants with the following hypothetical scenario and question:

Please imagine that your family member has developed kidney failure, and you have volunteered to donate one of your kidneys to them as a living donor. Unfortunately, your kidney is not a good match for your family member and it cannot be used. In another family, whom you do not know, there is a similar problem. In that family, the kidney of the person who wants to donate is not a good match for the person who needs the kidney. The transplant team has discovered that your kidney would work well for the person in the other family who needs a kidney, and the kidney from the other family would, in turn, work well for your family member who needs a kidney. In this situation, how willing would you be to “swap kidneys,” so that your family member could receive a kidney from the other family, and the other family could receive your kidney?

Answers regarding willingness could be *extremely*, *very*, *moderately*, *slightly*, and *not willing*. We assessed self-reported age, sex, race, ethnicity, marital status, education level, and household income as delineated in Table 1.

To assess religiosity and spirituality, we asked in separate questions: “To what extent do you consider yourself a religious [or spiritual] person?” Answers could be *very*, *moderately*, *slightly*, or *not at all* and were dichotomized as *very* vs. others given the distribution of the responses.

To assess experience with the medical system, we asked four *yes/no* questions: (i) “Have you ever had to stay overnight in a hospital?” (ii) “Have you ever had to stay overnight in a hospital for surgery?” (iii) “Do you have a primary care physician?” and (iv) “Do you have a living will or advanced directive?” We asked two *yes/no* questions to assess experiences with the organ transplant system: (i) “Do you have a friend or relative who has donated an organ?” and (ii) “Have you ever had a relative or friend who has received an organ, such as a kidney, lung, or liver?”

We assessed willingness to become a deceased organ donor with two questions: (i) “Would you consider donating organs after death?” (*yes/no/not sure*) and (ii) “On your driver's license, are you an organ donor?” (*yes/no/not applicable (do not have a driver's license)/don't know*). For these questions, responses other than yes or no were dropped from analysis.

We assessed understanding of US transplant organ allocation by asking agreement with the statement: “I understand the way in which donated organs are distributed to people who

need them in the United States.” To assess trust of physicians, health insurance plans, and hospitals, we asked agreement with the following statement (asked separately): “I trust my physician [or my health insurance plan] [or hospitals] to put my medical needs above all other considerations.” Answers to the above questions could be completely agree, mostly agree, somewhat agree, agree a little, and not agree at all.

Statistical analysis

Willingness to participate in KPD was measured on a five-level ordered categorical scale, as shown in Fig. 1. As such, odds ratios (ORs) were obtained using ordered logit regression models and are interpreted as the relative odds of a one-level increase in willingness to participate in KPD per unit change of the independent variable. For dichotomous independent variables, ORs are interpreted as the relative odds of a one-level increase in willingness to participate in KPD for those with a given characteristic (or answering yes to a given question) vs. those without (or answering no). For independent variables using five-level agreement scales (such as trust of physicians), ORs are interpreted as the relative odds of a one-level increase in willingness to participate in KPD for each increasing or decreasing level of agreement with the given question.

Initial analyses demonstrated strong associations between willingness to participate in KPD and age, race, and sex. To address this potential confounding, all associations between independent variables and willingness to participate in KPD were analyzed using multivariable models adjusting for age (per decade over 30), race (African American vs. non-African American), and sex (men vs. women) and are reported as adjusted odds ratios (AORs).

Demographics are shown based on the sample population. Proportions describing willingness to participate in KPD are shown weighted based on the distribution of households in the census regions used as sampling frames. In this way, proportions and regression model coefficients do not represent those from within the sample population, which was purposefully oversampled to adequately capture minority participants, but rather they represent estimates from the general population. All statistical analysis was performed using STATA 11.0/MP for Linux (StataCorp, College Station, TX, USA).

Results

Overall, willingness to participate in KPD among the general population was high, with 85.2% of respondents indicating that they would either be *extremely willing* or *very willing* to participate in KPD. Only 4.0% indicated that they would not be willing to participate (Fig. 1). Willingness to participate in KPD varied according to age, sex, and race, but not in terms of marital status, education, household income, or insurance (Table 1).

In multivariable models adjusted for age, sex, and race, several factors were associated with statistically significantly decreased willingness to participate in KPD, including socio-demographic factors, mistrust of the medical system, and perceived lack of understanding of organ allocation in the United States (Table 2). Among socio-demographic factors, older (vs. younger) age, male (vs. female) sex, African American (vs. non-African American) race,

and Hispanic (vs. non-Hispanic) ethnicity were associated with decreased willingness to participate in KPD. The adjusted odds of willingness to participate in KPD (per level on the five-level scale, see Methods) decreased by 15% per decade over age 30 (AOR, 0.85; 95% CI, 0.75–0.96; $p = 0.01$), was 45% lower in African Americans compared with non-African Americans (AOR, 0.55; 95% CI, 0.37–0.83; $p = 0.004$), was 38% lower in Hispanics compared with non-Hispanics (AOR, 0.62; 95% CI, 0.40–0.96; $p = 0.031$), and was 30% lower in men compared with women (AOR, 0.70; 95% CI, 0.51–0.94; $p = 0.019$). Along the five-level scale (ranging from high to low levels of trust) used to assess trust in physicians, each one-level decline in physician trust was associated with 30% lower odds of willingness to participate in KPD (AOR, 0.70; 95% CI, 0.60–0.81; $p < 0.001$). Similarly, each one-level of decreased perceived understanding of the US transplant organ allocation system was associated with 22% lower odds of willingness to participate in KPD (AOR, 0.88; 95% CI, 0.80–0.97; $p = 0.014$).

Several factors were associated with statistically significantly increased willingness to participate in KPD, including religiosity/spirituality, greater experience with the medical system, experience with the organ transplant system, and willingness to donate deceased organs. Participants reporting themselves to be *very* spiritual had 52% greater odds of willingness to participate in KPD compared with their counterparts reporting themselves to be less than *very* spiritual (AOR, 1.52; 95% CI, 1.13–2.05; $p = 0.006$). Participants reporting having ever stayed in a hospital for surgery, having a primary medical provider, and having a living will/advance directive had 54%, 68%, and 87% greater odds of willingness to participate in KPD compared with their counterparts without these experiences (AORs, respectively, 1.54, 95% CI, 1.13–2.11; 1.68, 95% CI, 1.16–2.43; and 1.87, 95% CI, 1.34–2.62; all $p < 0.01$). Participants reporting their friend or relative had ever donated an organ or received a transplant had 54% and 70% greater odds of willingness to participate in KPD (AORs, 1.54, 95% CI, 1.03–2.31; 1.70, 95% CI, 1.16–2.48; both $p < 0.05$). Finally, willingness to donate deceased organs was strongly associated with willingness to participate in KPD, with persons reporting they would consider donating their organs after death having three-fold greater odds of willingness to participate in KPD compared with those reporting they would not consider donating (AOR, 3.74; 95% CI, 2.26–6.18; $p < 0.001$) and persons reporting they were an organ donor on their license having nearly twofold greater odds of willingness to participate in KPD (AOR, 1.88; 95% CI, 1.38–2.48; $p < 0.001$).

Discussion

In this national study, we found high levels of willingness to participate in KPD among the US general public. In addition, we identified several factors associated with less willingness to participate in KPD among the public, including socio-demographic factors, mistrust of the medical system, and perceived lack of understanding of US transplant organ allocation. Factors associated with improved willingness to participate in KPD included religiosity/spirituality, prior experiences with the medical system, experiences with the transplant system, and willingness to donate deceased organs. Overall findings of generally favorable attitudes toward KPD are encouraging for policy makers currently developing regional and national programs. Findings regarding factors associated with greater or less willingness to

participate in KPD may provide insight into mechanisms through which the potential success of future KPD programs could be enhanced.

Our findings provide needed information regarding the general public's views of the potential acceptability of future large-scale KPD programs and are corroborated by similar findings in smaller studies of select patient populations. Waterman and colleagues (9) reported that 63.8% of donors who were ruled out for ABO-incompatibility or positive cross-match with their intended recipients were willing to participate in KPD, and Ackerman and colleagues (10) reported that 100% of a convenience sample of minority patients with ESRD supported KPD. However, both groups studied patients directly involved in live donor kidney transplantation, namely donors with intended recipients and ESRD patients seeking kidney transplantation. Our findings expand on these prior studies by demonstrating high levels of willingness to participate in KPD among potential unrelated and non-directed donors, who have played a major role in recent KPD success and have who have not been represented in prior studies of willingness to participate in KPD.

Potential barriers to successful implementation of KPD warrant consideration as current programs are being developed. Demographic differences in willingness to participate in KPD could contribute to disparities in access to this procedure, particularly for groups such as ethnic/race minorities, who are already less likely to utilize live kidney transplant as a treatment modality (15). Further elucidation of why these groups may be hesitant to participate in KPD may be needed to identify the appropriate strategies to enhance willingness to participate. While trust in medical care may be difficult to improve on a population basis, efforts to enhance the transparency of the KPD process may aid persons who are both less trusting as well as persons reporting poor understanding of the US transplant organ allocation system. Previous studies have identified perceived knowledge and transparency of organ allocation to be strongly associated with willingness to become a deceased organ donor (11). Study findings regarding factors associated with enhanced willingness to participate in KPD may also provide insight into mechanisms through which the success of future programs could be enhanced. For example, high interest in KPD among persons stating they would consider becoming deceased organ donors suggest efforts to pair campaigns to raise awareness of newly developed KPD programs with existing campaigns focusing on raising awareness of deceased organ donation might enhance the success of KPD. Similarly, findings of favorable attitudes toward KPD among persons considering themselves highly religious or spiritual suggest KPD may have appeal among groups, such as ethnic/racial minorities, typically less willing to participate in organ donation for religious or spiritual reasons (16).

Limitations of our study deserve mention. First, we assessed participant responses to a hypothetical situation rather than their true behaviors. It is possible persons reporting favorable attitudes toward KPD in a hypothetical situation might not be willing to participate in KPD if faced with a real situation. However, the exponential growth of KPD in the United States over the last 10 yr suggests that those faced with the dilemma of incompatibility do indeed pursue KPD (5). In our hypothetical situation, we also could not account for factors such as relationship to the recipient or age of the recipient. It is possible that potential donors with close relationships to the intended recipients might be more willing to participate in

KPD. We also did not specify any costs, or lack thereof, associated with donation, nor did we provide respondents with information about their own potential future health risks associated with KPD.

In addition, despite our evidence showing widespread interest in KPD, our question asked participants about a donation between parties related to the intended kidney recipients and did not probe whether KPD programs would make non-directed donation seem more attractive to potential donors in the general public. Indeed, rates of non-directed donation have increased as more centers have begun to utilize these donors in KPD programs (8). Large-scale, highly regulated programs enhancing the likelihood of a successful match between non-directed donors and potential recipients could enhance its appeal for persons inclined to pursue non-directed donation. Second, the cross-sectional nature of this study limits our ability to draw causal inferences regarding findings of association between characteristics of study participants and willingness to participate in KPD. Finally, we assessed only general willingness to participate in KPD. A more detailed understanding of attitudes regarding the various options and logistical challenges of KPD (dominos, chains, travel, organ transport, etc.) would further inform the development of KPD policies.

In conclusion, a great majority of the US general public expressed willingness to participate in KPD programs. However, importantly, men, ethnic/racial minorities, and participants expressing mistrust in physicians or perceived lack of understanding of the US transplant organ allocation system were less willing to participate in KPD. Further work to identify in more detail potential reasons for decreased willingness among these demographic subgroups could yield insight into ways in which KPD programs currently being developed can address concerns of these groups. Efforts to enhance transparency of the KPD process may address concerns among persons less trusting or with less understanding of the US transplant organ allocation system.

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Fig. 1. Willingness to participate in kidney paired donation (KPD) among study participants, weighted to account for oversampling so that proportions represent estimates from the general population rather than the study population.

Table 1

Characteristics of study participants, stratified by willingness to participate in kidney paired donation (KPD)

	<u>Willingness to participate in KPD</u>			
	Less (n = 124)	Very (n = 192)	Extremely (n = 494)	p-Value
Socio-demographic				
Age (%)				
18–40	31.5	38.5	38.7	0.002
41–59	44.4	41.1	46.4	
60–75	24.2	20.3	15.0	
Sex (%)				
Men	41.1	35.1	31.4	0.006
Women	58.9	64.9	68.6	
Race (%)				
White or Caucasian	66.1	65.6	73.1	0.029
Black or African American	16.9	14.1	9.9	
Asian or other	16.9	20.3	17.0	
Ethnicity (%)				
Non-Hispanic	85.2	83.6	85.4	0.2
Hispanic	14.8	16.4	14.6	
Marital status (%)				
Married or living with a partner	54.0	60.9	58.7	0.3
Separated, divorced, widowed	27.4	20.3	20.9	
Never married	18.5	18.8	20.4	
Education (%)				
High school or less	35.2	27.9	25.7	0.2
2 yr of college	19.7	23.7	23.9	
College	23.8	24.2	31.4	
Graduate or professional school	21.3	24.2	19.0	
Household income (%)				
\$0–\$20 000	16.2	14.4	14.5	0.5
\$20 000–\$40 000	22.2	20.4	22.8	
\$40 000–\$60 000	23.1	23.2	16.2	
\$60 000–\$80 000	15.4	13.8	15.8	
\$80 000–\$10 0000	6.0	7.7	8.7	
over \$100 000	12.0	16.6	17.0	
Don't know	5.1	3.9	5.0	
Insurance (%)				
Uninsured	10.6	11.0	8.9	0.6
Insured	89.4	89.0	91.1	
Religiosity and spirituality				
Religious person (%)				
Very religious	30.1	25.1	32.0	0.3

	Willingness to participate in KPD			p-Value
	Less (n = 124)	Very (n = 192)	Extremely (n = 494)	
Moderately religious	42.3	42.9	37.9	
Slightly religious	13.8	19.9	14.0	
Not religious at all	13.8	12.0	16.0	
Spiritual person (%)				
Very spiritual	36.6	43.2	49.0	0.004
Moderately spiritual	39.8	40.0	35.4	
Slightly spiritual	16.3	13.7	8.7	
Not spiritual at all	7.3	3.2	6.9	
Experience with the medical system				
Ever stayed in a hospital (%)				
No	22.6	22.0	17.2	0.5
Yes	77.4	78.0	82.8	
Ever stayed in a hospital for surgery (%)				
No	42.3	45.3	35.8	0.1
Yes	57.7	54.7	64.2	
Has primary medical provider (%)				
No	16.9	20.7	13.4	0.1
Yes	83.1	79.3	86.6	
Has a living will/advanced directive (%)				
No	74.2	70.3	63.5	0.036
Yes	24.2	29.2	35.9	
Not sure	1.6	0.5	0.6	
Experience with the organ transplant system				
Friend/relative has donated an organ (%)				
No	78.0	81.3	75.1	0.5
Yes	15.4	14.1	20.4	
Not sure	6.5	4.7	4.5	
Friend/relative has received a transplant (%)				
No	76.5	82.7	72.6	0.1
Yes	23.5	17.3	27.4	
Willingness to donate deceased donors				
Consider donating organs after death (%)				
No	22.6	12.0	6.1	<0.001
Yes	68.5	78.6	88.2	
Not sure	8.9	9.4	5.7	
Organ donor on license (%)				
No	50.0	39.6	29.1	<0.001
Yes	42.7	53.1	67.6	
N/A	4.8	2.1	2.2	
Don't know	2.4	5.2	1.0	
Perceptions of transplant organ allocation				

	<u>Willingness to participate in KPD</u>			
	Less (n = 124)	Very (n = 192)	Extremely (n = 494)	p-Value
Don't understand organ distribution (%)				
Completely agree	17.9	13.5	24.6	0.002
Mostly agree	10.6	16.1	13.0	
Somewhat agree	19.5	26.6	22.8	
Agree a little	8.9	14.1	9.6	
Not agree at all	43.1	29.7	29.9	
Trust of the medical system				
Don't trust doctor to prioritize medical needs (%)				
Completely agree	34.4	40.7	59.2	<0.001
Mostly agree	27.9	33.9	23.3	
Somewhat agree	29.5	18.5	12.2	
Agree a little	5.7	4.8	1.8	
Not agree at all	2.5	2.1	3.4	
Don't trust insurance co. to prioritize medical needs (%)				
Completely agree	13.2	9.6	15.7	<0.001
Mostly agree	10.7	16.5	14.7	
Somewhat agree	33.1	36.2	27.0	
Agree a little	16.5	21.8	11.0	
Not agree at all	26.4	16.0	31.5	
Don't trust hospital to prioritize medical needs (%)				
Completely agree	18.9	13.6	25.5	<0.001
Mostly agree	21.3	30.9	28.1	
Somewhat agree	37.7	38.7	27.9	
Agree a little	11.5	9.9	5.3	
Not agree at all	10.7	6.8	13.2	

Demographics are calculated based on the sample population of survey respondents (unweighted). p-Values are chi-square tests-of-trend based on the entire five-point scale. "Less" column represents *Not*, *Slightly*, and *Moderately* willing.

Table 2

Association between willingness to participate in kidney paired donation (KPD) and respondent characteristics

	Multivariate odds ratio (adjusted for age, sex, and race)	p-Value
Socio-demographic characteristics		
Age (per decade over age 30)	0.85 (0.75–0.96)	0.01
Sex (men vs. women)	0.70 (0.51–0.94)	0.019
Race (African American vs. Caucasian)	0.55 (0.37–0.83)	0.004
Ethnicity (Hispanic vs. non-Hispanic)	0.62 (0.40–0.96)	0.031
Marital status (married vs. not)	1.01 (0.74–1.38)	0.9
Education (any school after high school)	1.29 (0.93–1.80)	0.1
Income (per category of \$20 000 annual)	1.04 (0.95–1.13)	0.4
Insurance (insured vs. uninsured)	1.40 (0.87–2.25)	0.2
Religiosity and spirituality		
Religious person (very religious vs. others)	1.34 (0.97–1.87)	0.078
Spiritual person (very spiritual vs. others)	1.52 (1.13–2.05)	0.006
Experience with the medical system		
Ever stayed in a hospital	1.36 (0.93–2.00)	0.1
Ever stayed in a hospital for surgery	1.54 (1.13–2.11)	0.007
Has primary medical provider	1.68 (1.16–2.43)	0.006
Has a living will/advanced directive	1.87 (1.34–2.62)	<0.001
Experience with the organ transplant system		
Friend/relative has donated an organ	1.54 (1.03–2.31)	0.037
Friend/relative has received a transplant	1.70 (1.16–2.48)	0.006
Willingness to donate deceased donors		
Consider donating organs after death	3.74 (2.26–6.18)	<0.001
Organ donor on license	1.88 (1.38–2.56)	<0.001
Perceptions of transplant organ allocation		
Don't understand organ distribution	0.88 (0.80–0.97)	0.014
Trust of the medical system		
Don't trust doctor to prioritize medical needs	0.70 (0.60–0.81)	<0.001
Don't trust insurance company to prioritize medical needs	0.98 (0.88–1.09)	0.7
Don't trust hospital to prioritize medical needs	0.91 (0.80–1.02)	0.1

Odds ratio were calculated using ordered logistic regression, weighted for representation of respondents within the general population, so that odds ratios represent estimates from the general population rather than those from the study population and are interpreted as the relative odds of a one-level increase in willingness to participate (as categorized in Fig. 1). The 95% confidence intervals are shown in parentheses.