

Dialysis Patients' Social Networks and Living Donation Offers



Avrum Gillespie, Jonathan Daw, Riley Brown, Jamie Cappiello, Briana Eugene Lee, Edward L. Fink, Heather M. Gardiner, Peter P. Reese, Crystal A. Gadegbeku, and Zoran Obradovic

Rationale & Objective: Most living kidney donors are members of a hemodialysis patient's social network. Network members are divided into core members, those strongly connected to the patient and other members; and peripheral members, those weakly connected to the patient and other members. We identify how many hemodialysis patients' network members offered to become kidney donors, whether these offers were from core or peripheral network members, and whose offers the patients accepted.

Study Design: A cross-sectional interviewer-administered hemodialysis patient social network survey.

Setting & Participants: Prevalent hemodialysis patients in 2 facilities.

Predictors: Network size and constraint, a donation from a peripheral network member.

Outcomes: Number of living donor offers, accepting an offer.

Analytical Approach: We performed egocentric network analyses for all participants. Poisson regression models evaluated associations between network measures and number of offers. Logistic

regression models determined the associations between network factors and accepting a donation offer.

Results: The mean age of the 106 participants was 60 years. Forty-five percent were female, and 75% self-identified as Black. Fifty-two percent of participants received at least one living donor offer (range 1-6); 42% of the offers were from peripheral members. Participants with larger networks received more offers (incident rate ratio [IRR], 1.26; 95% CI, 1.12-1.42; $P = 0.001$), including networks with more peripheral members (constraint, IRR, 0.97; 95% CI, 0.96-0.98; $P < 0.001$). Participants who received a peripheral member offer had 3.6 times greater odds of accepting an offer (OR, 3.56; 95% CI, 1.15-10.8; $P = 0.02$) than those who did not receive a peripheral member offer.

Limitations: A small sample of only hemodialysis patients.

Conclusions: Most participants received at least one living donor offer, often from peripheral network members. Future living donor interventions should focus on both core and peripheral network members.

Complete author and article information provided before references.

Correspondence to
A. Gillespie (avrum.gillespie@tuhs.temple.edu)

Kidney Med. 5(6):100640.
Published online April 15, 2023.

doi: 10.1016/j.xkme.2023.100640

© 2023 The Authors.
Published by Elsevier Inc.
on behalf of the National
Kidney Foundation, Inc. This
is an open access article
under the CC BY-NC-ND
license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Living donor kidney transplantation is underutilized despite being the optimal treatment for kidney failure.¹ Epidemiologic factors and social determinants of health such as age,² race,³ sex,⁴ income,³ and education⁵ are associated with decreased utilization of living donor kidney

study demonstrated that kidney transplant candidates with a larger network size (Table 1), the number of members in the network, made more living donation requests probably because they have a larger pool of potential living donors.¹⁰ However, this study did not measure the interconnectedness of the candidates' networks. Network density and network constraint are both measures of interconnectedness but differ in that network constraint incorporates network size, a factor associated with living donor requests,¹⁰ whereas density does not. Network density, the percent of network members connected to each other, may be important. For example, one study found that hemodialysis patients with densely interconnected networks were less likely to have a kidney transplant evaluation.¹¹ This may have occurred because densely connected network members tend to share the same information and enforce behavioral norms, potentially limiting access to transplant information.^{6,11} Densely connected network members, referred to as core network members, also tend to be the network members with whom patients discuss their important matters. In contrast, peripheral network members are attached less densely (fewer relationships) to the core

Editorial, ● ● ●

transplantation. One social determinant that has not been thoroughly studied is the dialysis patient's social network.^{6,7} Most living donors are the patients' social network members (eg, family members, spouse, or friends).^{8,9} There are data about the network members who are evaluated and eventually donate,⁸ but little is known about a critical antecedent step wherein network members offer to donate and patients decide whether to accept these offers. Is living donor kidney transplantation underutilization a matter of having members who are not willing to donate or is it that the recipient is unwilling to accept their offers?

Differences in dialysis patients' social networks may affect the number of living donor offers they receive. One

PLAIN LANGUAGE SUMMARY

Hemodialysis Patient Social Networks and Offers of Living Donor kidney transplantation (LDKT) is underutilized despite being the optimal treatment for kidney failure. The social networks of patients with kidney failure may provide important insights into the underutilization of LDKT, because most living donors are members of the patient's social network. A 2-center network survey of hemodialysis patients found that half of the patients had received living donor offers. Many of these offers came from network members who were neither close to the patient nor to the other members of the patient's network. As a result, patients with larger and weakly interconnected networks received more living donor offers. Network-based interventions should focus on both strongly connected and weakly connected network members.

network and, as a result, tend to have information, norms, and behaviors not shared by the core network.^{11,12} Network constraint measures the percent of network members that potentially share the same information/norm. Constraint decreases as the networks get larger; however, if there are many mutual relationships in the network, constraint increases.^{7,11-13} Thus, the more peripheral members, the lower the constraint. The core-peripheral network member distinction has not been well studied and may be critical for living kidney donation promotion efforts¹⁰: if patients receive more living donor offers from core network members, these efforts can continue to focus on core network members such as nuclear family, spouses, and friends; if patients receive more offers from peripheral network members, these efforts should be expanded throughout the patient's social network.

The 2 aims of the study are (1) to explore associations between social network size, density, constraint, and the number of network members who offer to donate a kidney, and (2) to examine the network factors associated with patients' accepting or refusing living donation offers. To accomplish these aims, we conducted a social network survey (Fig 1) of hemodialysis patients in 2 facilities, asking patients with whom they discussed important matters (core network), who among them has offered to donate, anyone outside of the core network (peripheral members) who had offered to donate, and how interconnected were the patients' network members. By characterizing the social networks of dialysis patients, we seek to identify barriers to living donation and potential network interventions that address these barriers and promote living kidney donation effectively and ethically.

METHODS**Study Design, Setting, and Participants**

Data were collected between October 2018 and February 2020 as a baseline analysis for a social network intervention clinical trial for in-center hemodialysis to determine how hemodialysis clinic networks affect transplant information and behaviors. This study was conducted in 2 hemodialysis facilities in southeastern Pennsylvania and central New Jersey. This was designed to be a census of both hemodialysis facilities with an anticipated recruitment of 200 participants (Fig 2). Patients were eligible to participate if they had kidney failure, spoke English, and were 18 years old or older. Patients were approached to participate during their hemodialysis sessions. Patients were excluded if they declined to participate, were unable to give consent (eg, cognitive, severe visual, or hearing impairment), were hospitalized, switched to peritoneal dialysis, received a transplant, transferred out, died before they could be surveyed, or were asleep during the

Table 1. Glossary of Network Terms

Term	Description
Egocentric Network Analysis	An analysis mapping and measuring participant's (ego) relationships with their network members (alters).
Network Measures	
Size	The number of network members in the network. This can be weighted by the strength of the relationships with the network members, in which stronger relationships contribute to the size more than weaker relationships.
Density	A measurement of how interconnected the participant's network members are to each other.
Constraint	A measurement of how information and behaviors are contained or constrained. It is a summary measurement of the size of the participant's network (smaller networks more constraining), the density of the network (denser networks are more constraining), the strength of relationships in the network (stronger relationships more constraining).
Network Members	
Core Network Members	People who have strong relationships with the participant as well as the other core network members. They discuss important matters with each other, have the same information, and enforce behavioral norms.
Peripheral Network Members	People who are have weaker relationships with the participant as well as the core network members. They tend to have novel information, norms, and behaviors compared with core network members.

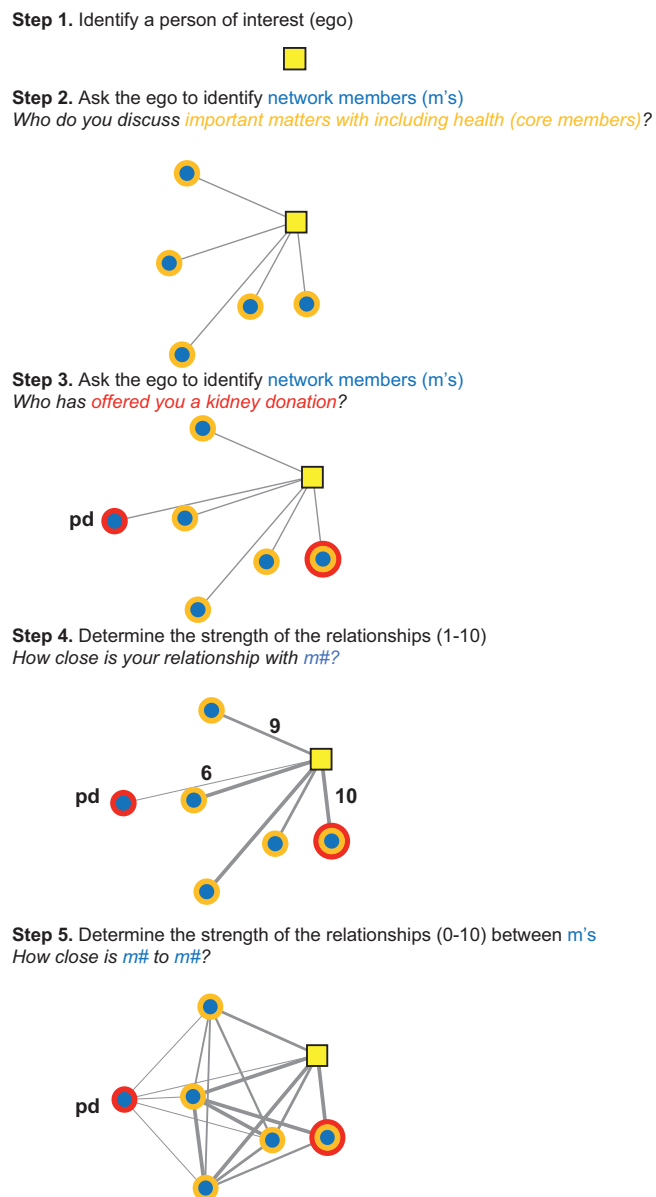


Figure 1. Egocentric network survey. The egocentric network methods used in this study are illustrated. Step 1. First, a person of interest, in this case a hemodialysis patient (ego) was approached to participate. The ego is represented by a yellow square. The participant was then asked to identify network members (m) represented by a blue circle. Step 2. We asked participants about who they discuss important matters and health with (core network members), highlighted in orange. Step 3. We then asked about which network members offered to donate (highlighted in red) both within in the core network and those who may not be core network members; these network members are called peripheral donors and is indicated by the initials **pd**. Step 4. We then asked the participant of the strength of the relationships on (1-10) scale with 1 being not very close and 10 the closest. The strength of the relationships in this figure is indicated by the thickness of the line connecting the ego to the network members. In this figure, to help with this interpretation, the strength of the relationship is also indicated as a number above the corresponding relationship. Step 5. Determine the strength of the relationships (links) between the other network

recruitment period. Participants were not excluded because of age or self-identified comorbid conditions that would be contraindications to kidney transplantation because we are interested in all hemodialysis patients' attitudes and behaviors toward kidney transplantation. Participants received a \$10 gift card on completion of the survey. The Temple University Institutional Review Board approved the study protocol (IRB #11648); written informed consent was obtained from all participants. The clinical and research activities being reported here are consistent with the Principles of the Declaration of Istanbul as outlined in the "Declaration of Istanbul on Organ Trafficking and Transplant Tourism" as well as adherence to the Declaration of Helsinki.^{14,15}

Variables

The primary outcome was the number of living donor offers a participant reported receiving. The secondary outcome was whether the participant accepted a network member's transplant offer (yes or no). The independent variables included network size, density, constraint, the size of the core network, and whether the transplant offer originated from a core or a peripheral network member. Confounding variables included age, sex, race, income, marital status, education, dialysis vintage, and self-reported waitlist status.¹⁶⁻¹⁸

Data Sources, Measurement, and Bias

We used an interviewer-administered computer-based questionnaire for data collection. The questionnaire, which combined previously validated questionnaires,^{4,19,20} identified and quantified hemodialysis patients' social network relationships. The questionnaire also assessed participants' attitudes and communication skills regarding their health and kidney disease and demographic variables including age, sex, race, income, education level, and marital status.

The 3-component social network questionnaire (Items S1-3, Fig 1) used egocentric methods: the name generator, the name interpreter, and the who-to-whom matrix.¹⁹ The name generator included multiple questions to identify up to 12 social network members outside of the hemodialysis clinic, which is generally the limit of accurate recall while minimizing cognitive burden.²¹ Core network members were members with whom patients discuss important matters including health. One question generated names of network members who offered to donate a kidney, including those who were not core network members.

members. The strength of these relationships is also indicated by the thickness of the line. After these data are collected, we then calculated the network metrics. For example, in this network, the network size is 6 because they identified 6 other members. The network density is 80%, indicating that 80% of the network members are connected with each other. The network constraint is 54%, indicating that 54% of the network likely has redundant information and behaviors.

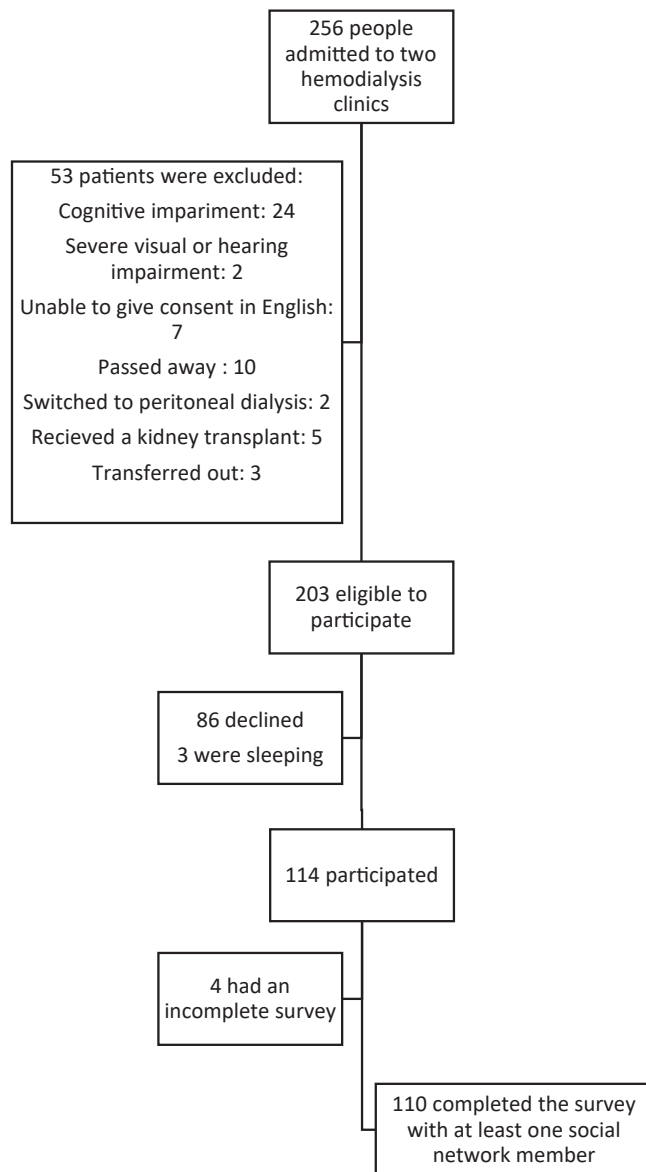


Figure 2. Enrollment scheme.

Network members' names could be generated by more than 1 question.

The name interpreter collected the network member's sex and relationship to the participant (eg, sibling, child, spouse) using a closed-question format with an open-ended "other" category. The "other" category was coded into romantic partners (including spouse); in-laws; extended family members (eg, aunts, uncles, cousins); and community members (eg, neighbors, church members, caretakers). The patient-alter relationship strength was measured using a 10-point emotional closeness scale, with 10 indicating the closest. For network members who offered to donate, participants were asked whether they declined or accepted the offer, and, if accepted, whether the member was evaluated for donation at a transplant center, and if so, what happened subsequently.

The who-to-whom matrix questions were used to assess relationship closeness between each network member pair. Participants were asked to rate how close network members were to each other on a 0 (total strangers) to 10 (especially close) scale. Network variables (size, density, and constraint) were calculated using the relationship closeness data from the name interpreter and the who-to-whom matrix. Network size is the sum of the participants' relationships.²² Density and Constraint were weighted for relationship closeness (see [Item S4](#) for a detailed description). Density and constraint are reported as percentages.

Descriptive Statistics

χ^2 and Fisher exact tests were used to test the statistical significance of independent variables' association with categorical dependent variables, and the t test was used for dependent continuous variables.

Modeling Participant and Network Characteristics and Number of Living Donor Offers

We used both negative binomial regression and Poisson regression to test the association of the network size, core network size, density, constraint, and the number of living donor offers. Participants' sex, race, age, marital status, income, and hemodialysis vintage were included in the model.¹⁶⁻¹⁸ Age and the network variables were mean-centered to facilitate model interpretation. A negative binomial regression or a Poisson regression model was selected based on information criterion statistics.²³

Modeling Participant and Network Characteristics With Accepting a Living Donor Offer(s)

We used logistic regression models for the associations of network factors and accepting a living donor offer among the subset of participants who received a living donor offer(s).

Sensitivity Analyses and Statistical Software

The Stata `-countfit-` procedure was used to examine observed versus predicted counts for the number of offers count models.²³ To test the Poisson regression's sensitivity to outliers, we examined the residuals of the model and excluded cases with leverage > 0.3 , Cook's distance > 0.5 , or influence > 0.04 , then re-estimated the model.²⁴ Additionally, the number of offers and constraint model was re-estimated after excluding participants potentially unlikely to receive a living donor offer; age ≤ 75 years, history of malignancy, and reporting never being evaluated for a transplant. For the logistic regression model of accepting an offer, the model was re-estimated after removing significant outliers (dfbeta values > 0.5).²⁵

Questionnaire data were collected and managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at Temple University Hospital.^{26,27} SPSS version 25 was used for data processing and descriptive analyses.²⁸ Stata version 15 was used for the

Table 2. Demographic Variables Associated With Receiving an Offer

Demographics	Did Not Receive Offer n=55 (50%)	Received Offer n=55 (50%)	Total N=110	P
Age, y (SD)	64 (13)	57 (12)	60 (13)	0.005
Sex				0.85
Female	24 (44)	25 (45)	49 (45)	
Male	31 (56)	30 (55)	61 (55)	
Race				0.48
Black	41 (75)	40 (73)	81 (74)	
White	12 (22)	10 (18)	22 (20)	
Other	2 (4)	5 (9)	7 (6)	
Hispanic	1 (2)	4 (7)	5 (5)	0.17
Married	18 (33)	23 (42)	41 (37)	0.32
Religiosity				0.69
Attends religious ceremonies	33 (60)	35 (64)	68 (62)	
Never Attends	22 (40)	20 (39)	42 (38)	
Education ^a				0.81
High school or Less	26 (48)	26 (47)	52 (48)	
Some college	15 (28)	18 (33)	33 (30)	
Bachelor's degree or higher	13 (24)	11 (20)	24 (22)	
Employment				0.02
Employed	5 (9)	4 (7)	9 (8)	
Unemployed	2 (4)	5 (9)	7 (6)	
Retired	31 (56)	16 (29)	47 (43)	
Disabled	17 (31)	30 (55)	47 (43)	
Annual income				0.06
\$ 0-19,000	13 (24)	21 (38)	34 (31)	
\$ 20,000-39,000	14 (25)	6 (11)	20 (18)	
\$ 40,000-79,000	9 (16)	7 (13)	16 (15)	
\$ 80,000 or more	3 (5)	9 (16)	12 (11)	
NR	16 (29)	12 (22)	28 (25)	
Facility Location				0.55
Facility 1	36 (65)	33 (60)	69 (63)	
Facility 2	19 (35)	22 (40)	41 (37)	
Clinical Variables				
Dialysis vintage				0.14
< 1 y	9 (16)	6 (11)	15 (14)	
1-5 y	31 (55)	24 (44)	55 (50)	
> 5 y	15 (27)	25 (45)	40 (36)	
History of cancer	9 (16)	6 (11)	15 (14)	0.41
Undergoing transplant evaluation	26 (54)	36 (65)	62 (63)	0.07
Self-reported on the transplant waitlist	17 (31)	24 (44)	41 (39)	0.17
Previous kidney transplant	4 (7)	4 (7)	8 (7)	1.00

Note: Table 2 shows the demographic and clinical differences between the participants who received at least one living donor offer and those who did not. Abbreviations: NR, no response; SD, standard deviation.

^aOne patient did not report their highest level of education.

negative binomial and logistic regression.²⁹ egor²² and igraph³⁰ were used for social network calculations and visualizations.

Missing Data

Participants' surveys were excluded from these analyses if the survey was <90% complete. Weighted network constraint was imputed for 1 missing case using constraint without weighting. For 4 participants, network density could not be calculated because the participant had only 1 network member.

RESULTS

Response Rate by Clinic

Figure 2 shows the enrollment scheme of the study. The reasons for nonparticipation were declining to participate (n=86) or sleeping during hemodialysis (n=3). The most common reason for exclusion was cognitive impairment (n=24). Fifty-seven percent of eligible participants at facility 1 (Philadelphia, n=71) and 53% at facility 2 (central New Jersey, n=43) participated in the study. Of the 114 who participated, 110 completed the survey and 106 identified a

social network member. There were no significant age or sex differences between participants and the population of the facilities (Tables S1-S2). The survey took on average 38 minutes to complete (range 12-70 minutes).

Participant Demographic and Clinical Characteristics

The participants' mean age was 60 ± 13 years; 45% were female and 74% self-identified as Black, 20% self-identified as non-Hispanic White, 5% identified as Hispanic White, and 1% identified as Asian in the Other category (Table 1). Eighty-six percent had been on hemodialysis for more than 1 year. Thirty-nine percent of patients reported being on the kidney transplant waitlist.

Demographic and Clinical Variables of Participants Who Did and Did Not Receive Living Donation Offers

Fifty percent of participants reported receiving at least one living donation offer from a network member (range 1-6; see Table 2). Participants who received an offer were younger (57 ± 12 vs 64 ± 13 , $P = 0.005$, Table 2) and were less often retired than those who did not receive an offer (29% vs 56%, $P = 0.02$). Eight participants had previously received a kidney transplant (1 received a living donor and 7 received a deceased donor transplant).

Defining and Describing the Core and Peripheral Network Members Who Offered to Donate

Participants identified 4.8 ± 1.9 network members, with a weighted network size of 4.3 ± 1.8 (Table S3, range 1-10 members, Fig 3). The mean network density was $70\% \pm 25\%$, indicating that 70% of a participant's network members were interconnected. The mean network constraint was $67\% \pm 20\%$, indicating that 67% of a participant's network would likely have the same information/norms, and that 33% of their network could potentially provide novel information/norms. Figure 3 shows examples of participants' networks of similar size and how they differ by density and constraint.

In the aggregate, 504 network members were identified. Most (90%, $n=456$) of these network members were core network members with whom participants discussed important matters. The mean participant core network member relationship strength was 9.1 ± 1.5 . These core members were connected to $72\% \pm 26\%$ of the other network members. Only 14% ($n=62$) of the core network members offered to donate. They tended to be the participants' children (28%), siblings (17%), extended family members (16%), friends (16%), spouses or partners (10%), parents (7%), and community members (5%; Table 2).

Forty-two percent ($n=44$) of the network members who offered to donate did not discuss the participant's important matters (hereinafter peripheral donors; Table 3, Fig 1). These peripheral donors accounted for 9% of identified network members. In contrast to core network

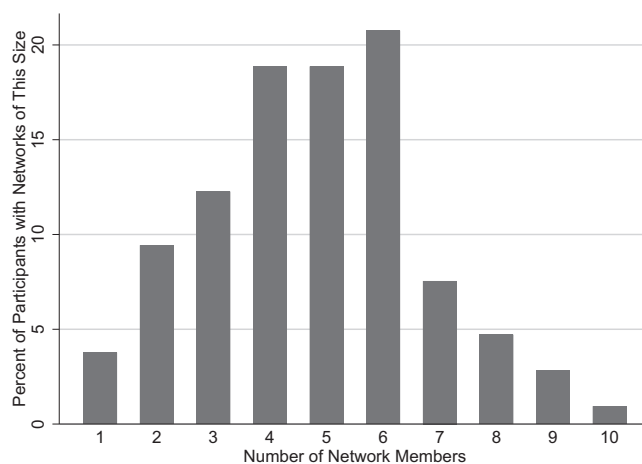


Figure 3. Size of the networks. This figure shows the distribution of the total number of network members in a participant's network on the x-axis and the percentage of participants with that many network members on the y-axis.

members, peripheral donors had significantly weaker relationships with the participant (7.6 ± 2.7 vs 9.1 ± 1.5 , $P < 0.001$) and were less densely connected to the other network members ($49\% \pm 31\%$ vs $72\% \pm 26\%$, $P < 0.001$). These peripheral network members tended to be extended family (34%), siblings (21%), friends (18%), and community members (16%, $P < 0.001$; Table 3).

Participant Demographics, Clinical Variables, Network Constraint, and Number of Living Donor Offers

Participants with larger networks received more offers (incident rate ratio [IRR], 1.26; 95% confidence interval [CI], 1.12-1.42; $P = 0.001$; Table 4, Model 1). For every 4 additional network members, a patient would likely receive 1 additional offer. Participants with greater network constraint received fewer living donor offers (IRR, 0.97; 95% CI, 0.96-0.98; $P < 0.001$; Table 4, Model 4, Figs. 4 and 5). A participant with a constraint of 30% is likely to receive 2 to 3 offers, whereas a participant with a constraint of 60% will likely receive one offer, and a participant with 100% constraint may not receive any offer at all (Figs. 4 and 5). Younger participants received more living donor offers (Table S4). Participants whose self-identified race was Black or African American received fewer offers than participants who identified themselves as White or Asian (Table S4). Participants with a dialysis vintage greater than a year received more offers than participants who had been on hemodialysis less than a year (Table S4). Self-reported listing status was not associated with the number of offers (Table S5). There were no significant interactions among the demographic and network variables (Table S6).

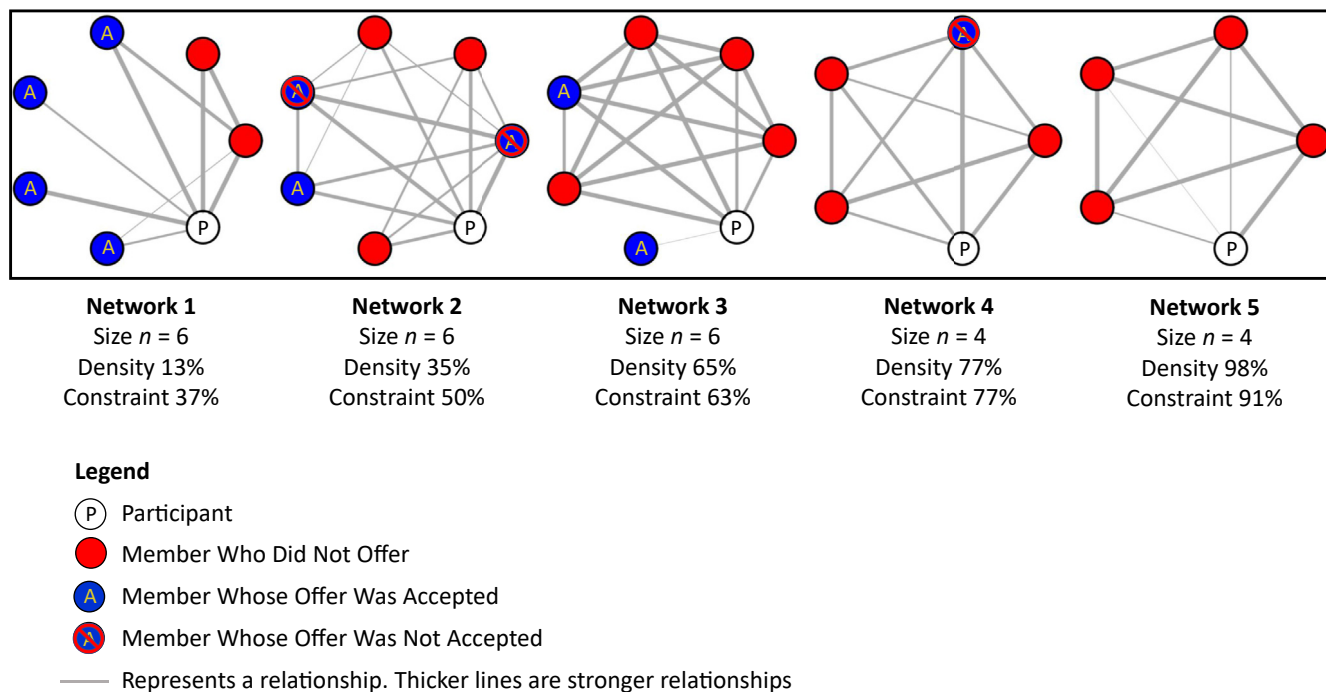


Figure 4. A sample of 5 networks and the differences in size, density, constraint, living donor offers, and whether the offer was accepted. This figure shows 5 patient networks of similar size but of different constraint to visualize how change in constraint is associated with which network members offered to donate as well as to visualize which offers were accepted. The participants are the white circles labeled “P” and their network members are red circles if they did not offer to donate or blue circles if they offered to donate. If a blue circle has an “A,” that means that network member offer was accepted. If blue circle has an “A” with a line through it, that means the offer was not accepted. Gray lines between the circles represent the relationships. The thicker the line, the stronger the relationship. Underneath each network is the number of network members, the density of the network, and the constraint of that network. Network 1 has the lowest constraint of 37% and also has an example of 3 peripheral donors, 2 not being connected to any other network members (peripheral donors) and another network member who offered and is only weakly connected to another network member. Network 3 has a higher constraint of 63% and also has an example of both a core network member who offered to donate as well as peripheral donor who is not connected to other members of the network. Note that Networks 4 and 5 have lower constraint because of the strength of connections among the network members and their networks are smaller. Network 5 has the highest constraint because it has the strongest relationship among its members.

Factors Associated With Accepting a Living Donor Offer

Fifty-three percent ($n=29$) of the participants who received a living donation offer accepted the offer, with 72% accepting only 1 offer. Participants with larger core networks were less likely to accept offers of living donation (odds ratio [OR], 0.71; 95% CI, 0.51-1.01; $P = 0.05$; Table 5). Participants receiving offers from peripheral network members had 3.6 times the odds (OR, 3.56; 95% CI, 1.15-10.8; $P = 0.02$) of accepting a living donor offer than those who only received a core network member offer. Table S7 shows the multivariable adjustment for demographics and clinical variables. Twenty-five percent of the network members whose offers were accepted were evaluated for donation (Table 1). Although one of these network members had previously donated, none of the network members donated within the study period. The main reasons were the member not being a match (24%), the member losing interest (24%), and the participant’s ineligibility for health reasons (15%).

Sensitivity Analysis

Sensitivity analyses performed on the number of offers models showed that network constraint remained a significant predictor of the number of offers received (Table S5, S8), and core network size remained significantly associated with accepting a living donor offer (Table S9).

DISCUSSION

In this study of hemodialysis patients’ social networks, we found that many of the network members who offered to donate were peripheral to the participant’s densely interconnected core network. Thus, the participants with the least constrained networks received the most offers. Further, participants who received an offer from these peripheral donors were more likely to accept a living donor offer. Unfortunately, despite over half of the participants receiving a living donor offer, and half of those offers being accepted, very few were evaluated, and none

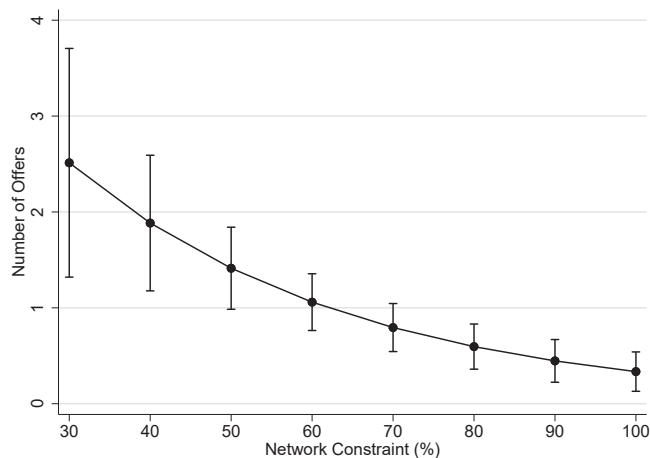


Figure 5. Number of offers and network constraint. This figure is a marginal prediction plot with 95% confidence interval that shows the predicted number of offers based on the constraint of the network. This plot was estimated on the Network Constraint model (Model 5) with vintage set to 1-5 years. All other variables are at their means.

resulted in a living donor transplant during the study period.

Network constraint, previously linked to access to diverse information streams,^{12,13} has recently been shown to be an important social determinant of health. Dhand et al³¹ found that stroke patients with less constrained networks were more likely to get a timely evaluation for their stroke symptoms than those with constrained networks. The proposed mechanism is that peripheral network members have a greater propensity to encourage the patient to seek immediate treatment and not to minimize the stroke symptoms. In our study, although

we did not collect participants' or network members' knowledge about kidney transplantation, it is possible that the peripheral donors may have offered to donate because they had positive information about living donation that was not shared by the core network. Additionally, the peripheral network members may be less affected by paralyzing group decision dynamics³² about which family member is going to donate and make a quick decision about donation with minimal consequences to the patient's network.³³

Our previous study¹⁰ found that waitlist candidates, who were unsuccessful at obtaining a living donor transplant, were more likely to request a living donation from a strongly connected network member. We proposed that it may be better to request a living donation from a weakly connected peripheral member. In comparison, this study found that prevalent hemodialysis patients, regardless of their transplant eligibility status, prefer accepting offers from peripheral donors. They may prefer peripheral network members because if that donor fails to donate, it would be easier for the participants to distance themselves from the peripheral donor compared with a core network member whom they will see more frequently and are connected to mutual core network members.³⁴ Similarly, perceived debt to a core network donor could be more easily enforced by mutual core network members than perceived debts to peripheral donors who lack mutual connections.³⁵⁻³⁷

A scalable version³⁸ of our survey could be adapted for clinical use in hemodialysis facilities and transplant centers to inform evidence-based interventions.^{20,39-42} First, the survey could show if network members' offers were being declined because their relationship exaggerates the risks of donation.^{20,39-42} Communication/education interventions can teach about living kidney donation's benefits and

Table 3. Demographics and Outcomes of Core Network Members and Disconnected Donors

Variable	Core Network n=456	Peripheral Donors n=44	P
Female sex	288 (63%)	23 (52%)	0.67
Related			
Spouse/partner	46 (10%)	0 (0%)	0.009
Parent	33 (7%)	2 (5%)	<0.001
Sibling	80 (17%)	9 (20%)	
Child	126 (28%)	2 (5%)	
Extended family	75 (16%)	16 (36%)	
Friend	71 (16%)	8 (18%)	
Community member	25 (5%)	7 (16%)	
Relationship strength, mean (SD)	9.1 (1.5)	7.6 (2.7)	<0.001
% Connected with other network members, mean (SD)	72 (26)	49 (31)	<0.001
Offered to donate	n=62 (14%)	n=44 (100%)	
Accepted offer	20 (32%)	22 (50%)	0.07
Ever evaluated at a transplant center	8 (40%)	3 (14%)	0.08
% connected with other potential donors, mean (SD) ^a	91 (27)	70 (42)	0.01

Note: Comparison of the demographic differences and outcome between members of the important matters or core network and network members who were not part of the core network who offered to donate (peripheral donors). One percent of network members were missing information about offers.

^a50 core network members who offered to donate and 34 peripheral donors were in a network that another member also offered to donate.

Table 4. Associations Network Variables and the Number of Living Donor Offers

	Model 1 Network Size, N=106, R ² = 0.14 IRR (95% CI), P	Model 2 Core Network Size, N=106, R ² = 0.06 IRR (95% CI), P	Model 3 Network Density, N=102, R ² = 0.06 IRR (95% CI), P	Model 4 Network Constraint, N=106, R ² = 0.16 IRR (95% CI), P	Model 5 Full Model, N=102, R ² = 0.23 IRR (95% CI), P
Network size	1.26 (1.12-1.42), 0.001	—	—	—	1.05 (0.76-1.46) 0.75
Core network size	—	1.03 (0.89-1.18), 0.71	—	—	0.67 (0.56-0.80), <0.001
Density	—	—	1.00 (0.99-1.01), 0.40	—	1.02 (1.00-1.03) 0.07
Constraint	—	—	—	0.97 (0.96-0.98), <0.001	0.95 (0.91-0.98), 0.006
Constant	0.61 (0.27-1.36), 0.23	0.56 (0.21-1.49), 0.25	0.54 (0.20-1.44), 0.22	0.43 (0.19-0.97), 0.04	0.56 (0.24-1.33), 0.19
Model type	Poisson	Negative Binomial	Negative Binomial	Poisson	Poisson

Note: Table 4 shows the results of the count models examining the IRRs associations between demographic, network variables, and number of living donor offers. All models were adjusted for participants' age, self-reported race, marital status, income, and dialysis vintage. Full table reporting demographic coefficients is in the supplement (Table S4). Abbreviations: IRR, incident rate ratio; R², pseudo R².

risks,^{20,39-42} increasing the participants willingness to discuss kidney transplantation and accept network members' living donation offers. Second, this survey could also identify the network members' barriers to donating, which is critical because ~25% of accepted offers were reportedly evaluated for donation. These may not be all serious offers, but efforts must be made to improve access to living donor evaluation by streamlining the evaluation process, eliminating financial hardships,⁴³ and by educational interventions for the donor including paired donation for incompatible matches.^{39,41} This may also increase equity for those from minority groups who experience more barriers to accessing and completing the donor medical evaluation.^{8,40} Last, as more people use online social networks to recruit living donors, they are more likely to recruit people peripheral to their core network.⁴⁴

These findings must be evaluated in the context of their limitations. First, our sample is limited to 2 Middle Atlantic urban and suburban facilities, and our response rate was just over 50%. Although we included patients who were potentially ineligible for transplant, it is possible that those who did not want to participate had a negative attitude toward transplant and were less likely to receive living donor offers. Our sample included predominantly Black hemodialysis patients, limiting the generalizability to other facilities and other ethnic minority groups. Second, because this study was a baseline analysis of participants in an in-center hemodialysis social network living donor intervention, we only enrolled in-center hemodialysis patients and cannot generalize our findings to patients receiving peritoneal dialysis or successful living donor transplant recipients. Third, only a small subset of network members was reported to have been evaluated for donation, which was not confirmed with the centers, limiting our ability to analyze the network factors associated with potential donors completing their evaluation. Fourth, this study relies on participants' recollections and perceptions of their relationship with network members and the relationships between network members, and it is possible that peripheral donors were more connected to the network than the participants realized.⁴⁵ Finally, because our survey selected 5 different name generators to map out the relevant social connections in terms of living donor offers and not living donation requests,⁹ we did not generate all potential peripheral network members, which has been estimated to be between 9-150.^{39,46} Thus, it is possible that participants who did not receive living donor offers could have also had low constraint networks in which none of these peripheral network members wanted to or were able to donate a kidney.

In conclusion, many people with kidney failure treated by hemodialysis received living donor offers, and many of these offers were from network members who are not tightly connected with their core network. Future research and interventions should use a network-based strategy to help facilitate the living donation process for patients and their potential living donors.

Table 5. Demographic and Network Variables and Their Association With Accepting an Offer

	Descriptive χ^2 Analysis			Univariate Logistic Regression	
	Declined Offer N=26 (48%)	Accepted Offer N=29 (52%)	P	Odds Ratio (95% CI)	Average Marginal Effects (95% CI)
Demographic and Clinical Variables					
Age, y, mean (SD)	59 (10)	55 (13)	0.19	0.97 (0.93-1.02)	-0.7 (-1.7 to 0.3)
Black race, n (%)	20 (77%)	20 (69%)	0.51	0.67 (0.20-2.22)	-10 (-39 to 19)
Female sex, n (%)	11 (42%)	14 (48%)	0.66	1.27 (0.44-3.69)	-6 (-20 to 32)
Partnered, n (%)	14 (54%)	18 (62%)	0.54	0.71 (0.24-2.09)	-8 (-34 to 18)
Income > \$40,000, n (%)	11 (42%)	10 (34%)	0.55	0.72 (0.24-2.14)	-8 (-35 to 18)
Vintage			0.76		
<1 y	3 (12)	3 (10)		Reference	
1-5 y	10 (38)	14 (48)		1.4 (0.23-8.42)	8 (-36 to 53)
>5 y	13 (50)	12 (42)		0.92 (0.16-5.49)	-2 (-47 to 43)
Network Variables					
Offer from a peripheral network member, N (%)	10 (38%)	20 (69%)	0.02	3.56 (1.15-10.84)	29 (8-49)
Weighted network size, mean (SD)	4.8 (1.3)	4.6 (2.0)	0.56	0.91 (0.66-1.25)	-2 (-10 to 5)
Core network size, mean (SD)	4.8 (1.3)	3.9 (1.9)	0.05	0.71 (0.5-1.01)	-7 (-15 to -1)
Density, mean (SD)	71 (21)	60 (28)	0.11	0.98 (0.96-1.00)	0.4 (-0.9 to 0.1)
Constraint, mean (SD)	60 (11)	61 (17)	0.92	1.02 (0.71-1.46)	0.5 (-8 to 9.4)
Number of offers, mean (SD)	1.8 (1.06)	2.03 (1.5)	0.52	1.15 (0.75-1.77)	4 (-7 to 14)

Note: Table 5 compares the demographic and network variables among participants who received at least one and declined it to participants who received at least one offer and accepted at least one offer. Percentages in parentheses are column percentages. Abbreviations: CI, confidence interval; SD, standard deviation.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Item S1. Name Generator

Item S2. Sample of Name Interpreter

Item S3. Sample of Who-to-Whom Questions (Matrix)

Item S4. Calculating Network Measures

Table S1. Age and Sex Differences Among Participants and the Census of the Facilities

Table S2. Differences in Demographics and Network Variables Between the Two facilities

Table S3. Differences in Network Variables and Receiving the Living Donor Offer

Table S4. Associations Between Demographic and Network Variables and the Number of Living Donor Offers

Table S5. Linear and Non-linear Interaction Effects for Network Constraint and Number of Offers Model

Table S6. Multivariable Logistic Regression for Accepting an Offer

Table S7. Sensitivity Analysis of Network Constraint and Number of Offers Model

Table S8. Sensitivity Analysis of Network Constraint and Number of Offers Model for Those Who Are 75 Years Old or Younger, No History of Cancer, and Report Being Evaluated for a Kidney Transplantation.

Table S9. Sensitivity Analysis of Core Network Size with and without Significant Outliers Removed

ARTICLE INFORMATION

Authors' Full Names and Academic Degrees: Avrum Gillespie, MD, Jonathan Daw, PhD, Riley Brown, MS, Jamie Cappiello, MPH,

Briana Eugene Lee, BA, Edward L. Fink, PhD, Heather M. Gardiner, PhD, MPH, Peter P. Reese, MD, MSCE, Crystal A. Gadegbeku, MD, and Zoran Obradovic, PhD

Authors' Affiliations: Division of Nephrology, Hypertension, and Kidney Transplantation, Department of Medicine, Lewis Katz School of Medicine, Temple University (AG, RB, BEL), Philadelphia, Pennsylvania; Department of Sociology and Demography, College of Liberal Arts, Penn State (JD), Philadelphia, Pennsylvania; Department of Social & Behavioral Sciences, College of Public Health, Temple University (JC, HMG), Philadelphia, Pennsylvania; Department of Communication and Social Influence, Klein College of Media and Communication, Temple University (ELF), Philadelphia, Pennsylvania; Renal-Electrolyte and Hypertension Division, Department of Medicine, Perelman School of Medicine, University of Pennsylvania (PPR), Philadelphia, Pennsylvania; Glickman Urological and Kidney Institute, Cleveland Clinic (CAG), Cleveland, Ohio; and Center for Data Analytics and Biomedical Informatics, Temple University (ZO), Philadelphia, Pennsylvania.

Address for Correspondence: Avrum Gillespie, MD, 3440 N Broad St. Kresge West Suite 100, Philadelphia, PA 19140. Email: avrum.gillespie@tuhs.temple.edu

Authors' Contributions: Research area and study design: AG, ELF, HMG, PPR, CAG, ZO; data acquisition: AG, RB, JC; data analysis and interpretation: AG, JD, RB, JC, ELF, BL, HMG, PPR, CAG, ZO; statistical analysis: AG, JD, ELF, ZO; and supervision or mentorship: ELF, HMG, PPR, CAG, ZO. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

Support: This research was funded by National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health under the award K23 DK111943 (AG) and R01 DK114888 (JD). The content is solely the responsibility of the

authors and does not necessarily represent the official views of the National Institutes of Health.

Financial Disclosure: The authors declare that they have no relevant financial interests.

Peer Review: Received September 20, 2022. Evaluated by 2 external peer reviewers, with direct editorial input from the Statistical Editor and the Editor-in-Chief. Accepted in revised form February 26, 2023.

REFERENCES

- Port FK, Dykstra DM, Merion RM, Wolfe RA. Trends and results for organ donation and transplantation in the United States, 2004. *Am J Transplant*. 2005;5(4 Pt 2):843-849. doi:10.1111/j.1600-6135.2005.00831.x
- Segev DL, Kucirka LM, Oberai PC, et al. Age and comorbidities are effect modifiers of gender disparities in renal transplantation. *J Am Soc Nephrol*. 2009;20(3):621-628. doi:10.1681/ASN.2008060591
- Gill J, Dong J, Rose C, Johnston O, Landsberg D, Gill J. The effect of race and income on living kidney donation in the United States. *J Am Soc Nephrol*. 2013;24(11):1872-1879. doi:10.1681/ASN.2013010049
- Gillespie A, Hammer H, Kolenikov S, et al. Sex differences and attitudes toward living donor kidney transplantation among urban black patients on hemodialysis. *Clin J Am Soc Nephrol*. 2014;9(10):1764-1772. doi:10.2215/CJN.12531213
- Dageforde LA, Petersen AW, Feurer ID, et al. Health literacy of living kidney donors and kidney transplant recipients. *Transplantation*. 2014;98(1):88-93. doi:10.1097/TP.0000000000000027
- Arthur T. The role of social networks: a novel hypothesis to explain the phenomenon of racial disparity in kidney transplantation. *Am J Kidney Dis*. 2002;40(4):678-681. doi:10.1053/ajkd.2002.35672
- Ladin K, Hanto DW. Understanding disparities in transplantation: do social networks provide the missing clue? *Am J Transplant*. 2010;10(3):472-476. doi:10.1111/j.1600-6143.2009.02963.x
- Kumar K, Tonascia JM, Muzaale AD, et al. Racial differences in completion of the living kidney donor evaluation process. *Clin Transplant*. 2018;32(7):e13291. doi:10.1111/ctr.13291
- Song MK, Paul S, Plantinga L, Henry C, Turberville-Trujillo L. Social networks of self-care and perceived treatment burden among patients on in-center hemodialysis. *Kidney Med*. 2019;1(3):97-103. doi:10.1016/j.xkme.2019.04.001
- Gillespie A, Gardiner HM, Fink EL, Reese PP, Gadegbeku CA, Obradovic Z. Does sex, race, and the size of a kidney transplant candidate's social network affect the number of living donor requests? A multicenter social network analysis of patients on the kidney transplant waitlist. *Transplantation*. 2020;104(12):2632-2641. doi:10.1097/TP.0000000000003167
- Browne T. The relationship between social networks and pathways to kidney transplant parity: evidence from black Americans in Chicago. *Soc Sci Med*. 2011;73(5):663-667. doi:10.1016/j.socscimed.2011.06.031
- Burt RS. *Structural Holes: The Social Structure of Competition*. Harvard University Press; 1992.
- Burt RS. Structural holes and good ideas. *Am J Sociol*. 2004;110(2):349-399. doi:10.1086/421787
- No author listed. The declaration of Istanbul on organ trafficking and transplant tourism. Istanbul summit April 30-May 2, 2008. *Nephrol Dial Transplant*. 2008;23(11):3375-3380. doi:10.1093/ndt/gfn553
- World Medical Association. World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bull World Health Organ*. 2001;79(4):373-374.
- Ayanian JZ, Cleary PD, Weissman JS, Epstein AM. The effect of patients' preferences on racial differences in access to renal transplantation. *N Engl J Med*. 1999;341(22):1661-1669. doi:10.1056/NEJM199911253412206
- Reese PP, Shea JA, Berns JS, et al. Recruitment of live donors by candidates for kidney transplantation. *Clin J Am Soc Nephrol*. 2008;3(4):1152-1159. doi:10.2215/CJN.03660807
- Weng FL, Dhillon N, Lin Y, Mulgaonkar S, Patel AM. Racial differences in outcomes of the evaluation of potential live kidney donors: a retrospective cohort study. *Am J Nephrol*. 2012;35(5):409-415. doi:10.1159/000337949
- Perry BL, Pescosolido BA. Social network activation: the role of health discussion partners in recovery from mental illness. *Soc Sci Med*. 2015;125:116-128. doi:10.1016/j.socscimed.2013.12.033
- Traino HM, West SM, Nonterah CW, Russell J, Yuen E. Communicating about choices in transplantation (COACH). *Prog Transplant*. 2017;27(1):31-38. doi:10.1177/1526924816679844
- Manfreda KL, Vehovar V, Hlebec V. Collecting ego-centered network data via the Web. *Metodol Zvezki*. 2014;1(2):295.
- Krenz T, Krivitsky PN, Vacca R, et al. egor version 1.21.7. Accessed April 29, 2022. <https://cran.r-project.org/web/packages/egor/index.html>
- Long JS, Freese J. *Regression Models for Categorical Dependent Variables Using Stata*. 3rd ed. Stata Press; 2014.
- Banghart M, Dimond R. Regression diagnostics with R. Accessed April 29, 2022. <https://sscc.wisc.edu/sscc/pubs/RegDiag-R/>
- Chatterjee S, Hadi AS. Influential observations, high leverage points, and outliers in linear regression. *Stat Sci*. 1986;1(3):379-393. doi:10.1214/ss/1177013622
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010
- Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform*. 2019;95:103208. doi:10.1016/j.jbi.2019.103208
- IBM SPSS Statistics for Windows. version 25.0. IBM Corp; 2017.
- StataCorp. *Stata Statistical Software: Release 15*. StataCorp LLC; 2017.
- Csárdi G, Nepusz T. The igraph software package for complex network research, InterJournal. *Complex Syst*. 2006;1695(5):1-9. <https://igraph.org>
- Dhand A, Luke D, Lang C, Tsiaklides M, Feske S, Lee JM. Social networks and risk of delayed hospital arrival after acute stroke. *Nat Commun*. 2019;10(1):1206.
- Darley JM, Latané B. Bystander intervention in emergencies: diffusion of responsibility. *J Pers Soc Psychol*. 1968;8(4 Pt 1):377-383. doi:10.1037/h0025589
- Valapour M, Kahn JP, Bailey RF, Matas AJ. Assessing elements of informed consent among living donors. *Clin Transplant*. 2011;25(2):185-190.
- Reese PP, Allen MB, Carney C, et al. Outcomes for individuals turned down for living kidney donation. *Clin Transplant*. 2018;32(12):e13408.
- Fox RC, Swazey JP. *Spare Parts*. Oxford University Press; 2002:40.

36. Waterman AD, Stanley SL, Covelli T, Hazel E, Hong BA, Brennan DC. Living donation decision making: recipients' concerns and educational needs. *Prog Transplant*. 2006;16(1):17-23.
37. Granovetter M. The strength of weak ties: a network theory revisited. *Sociol Theory*. 1983;1:201-233. doi:10.2307/202051
38. Dhand A, White CC, Johnson C, Xia Z, De Jager PL. A scalable online tool for quantitative social network assessment reveals potentially modifiable social environmental risks. *Nat Commun*. 2018;9(1):3930. doi:10.1038/s41467-018-06408-6
39. Rodrigue JR, Paek MJ, Schold JD, Pavlakis M, Mandelbrot DA. Predictors and moderators of educational interventions to increase the likelihood of potential living donors for black patients awaiting kidney transplantation. *J Racial Ethn Health Disparities*. 2017;4(5):837-845. doi:10.1007/s40615-016-0286-0
40. Patzer RE, Paul S, Plantinga L, et al. A randomized trial to reduce disparities in referral for transplant evaluation. *J Am Soc Nephrol*. 2017;28(3):935-942. doi:10.1681/ASN.2016030320
41. Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis*. 2013;61(3):476-486. doi:10.1053/j.ajkd.2012.08.039
42. Patzer RE, McPherson L, Basu M, et al. Effect of the iChoose Kidney decision aid in improving knowledge about treatment options among transplant candidates: A randomized controlled trial. *Am J Transplant*. 2018;18(8):1954-1965. doi:10.1111/ajt.14693
43. Klarenbach S, Gill JS, Knoll G, et al. Economic consequences incurred by living kidney donors: a Canadian multi-center prospective study. *Am J Transplant*. 2014;14(4):916-922. doi:10.1111/ajt.12662
44. Kumar K, King EA, Muzaale AD, et al. A smartphone app for increasing live organ donation. *Am J Transplant*. 2016;16(12):3548-3553.
45. Gillespie A. Together we can improve outcomes in kidney failure: examining social networks in hemodialysis. *Kidney Med*. 2019;1(3):79-82. doi:10.1016/j.xkme.2019.05.002
46. Dunbar RIM, Shultz S. Evolution in the social brain. *Science*. 2007;317(5843):1344-1347. doi:10.1126/science.1145463