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Critical Factors Associated With Missing Follow-Up Data for Living Kidney Donors in the United States

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Follow-up care for living kidney donors is an important responsibility of the transplant community. Prior reports indicate incomplete donor follow-up information, which may reflect both donor and transplant center factors. New UNOS regulations require reporting of donor follow-up information by centers for 2 years. We utilized national SRTR data to evaluate donor and center-level factors associated with completed follow-up for donors 2008–2012 (n = 30 026) using multivariable hierarchical logistic models. We compared center follow-up compliance based on current UNOS standards using adjusted and unadjusted models. Complete follow-up at 6, 12, and 24 months was 67%, 60%, and 50% for clinical and 51%, 40%, and 30% for laboratory data, respectively, but have improved over time. Donor risk factors for missing laboratory data included younger age 18–34 (adjusted odds ratio [AOR] = 2.03, 1.58–2.60), black race (AOR = 1.17, 1.05–1.30), lack of insurance (AOR = 1.25, 1.15–1.36), lower educational attainment (AOR = 1.19, 1.06–1.34), >500 miles to center (AOR = 1.78, 1.60–1.98), and centers performing >40 living donor transplants/year (AOR = 2.20, 1.21–3.98). Risk-adjustment moderately shifted classification of center compliance with UNOS standards. There is substantial missing donor follow-up with marked variation by donor characteristics and centers. Although follow-up has improved over time, targeted efforts are needed for donors with selected characteristics and at centers with higher living donor volume. Adding adjustment for donor factors to policies regulating follow-up may function to provide more balanced evaluation of center efforts.

Abbreviations: AOR, adjusted odds ratio; HRSA, Health Resources and Services Administration; ICC, intraclass correlation; OPTN, Organ Procurement and Transplantation Network; SRTR, Scientific Registry of Transplant Recipients; UNOS, United Network for Organ Sharing

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Introduction

Follow-up care for living kidney donors is an important responsibility of the transplant community. Despite relatively reassuring data regarding the long-term health of donors, follow-up care is essential to monitor progress, identify morbidity, and facilitate any potential need for interventions (1–6). In addition, there has been an increased rate of living donors with complex medical conditions, rendering vigilant monitoring for any potential health consequences of donation increasingly important (7–10). Prior reports have indicated a lack of complete reporting of kidney donor follow-up on standard United Network for Organ Sharing (UNOS) forms (11–13). Explanations for incomplete follow-up included concerns related to resources required by centers to track donor outcomes and potential reluctance or inability among some donors to receive regular follow-up care (12,13). These incomplete follow-up data may reflect a variety of factors that are reflective of both donor and transplant center characteristics. Transplant centers have variable infrastructure and resources to continually monitor donors as well as varying geographic distribution from which donors travel (12–15). Donors have variable access to healthcare, health literacy, and motivation to seek medical care among other factors which may impact the ability of a center to capture donor follow-up data (16–20). For example, roughly one-fifth of donors are reported to have no health insurance at the time of donation which may impact access to follow-up care (21).

UNOS regulations established in 2013 require complete and timely follow-up data for donors at 6, 12, and 24 months following donation (22). The specific clinical and laboratory parameters that are required are listed in Table 1. For donors in 2014, these standards included 70% timely completion of follow-up forms for selected clinical parameters and 60% completion of follow-up forms for selected laboratory data for all living kidney donors at each time

Table 1: Proportion of complete clinical and lab parameters by follow-up period

Donor variable	Follow-up period		
Donor status and clinical data	6 months	1 year[3]	2 years[4]
Patient status	96%	89%	79%
Working for income	70%	64%	54%
Donor readmitted	89%	79%	68%
Kidney complications	89%	79%	68%
Maintenance dialysis	89%	79%	67%
Donor developed hypertension requiring medication	85%	74%	63%
Donor diabetes	88%	78%	66%
Donor cause of death (if applicable)[2]	100%	100%	100%
All donor status and clinical data	**67%**	**60%**	**50%**
Kidney laboratory data	6 months	1 Year	2 Years
Serum creatinine	69%	53%	42%
Urine protein[1]	52%	42%	32%
All kidney laboratory data	**51%**	**40%**	**30%**

[1]Urine protein based on completing either urinalysis results by urine protein or protein–creatinine ratio.
[2]Assumes no deaths among living donors with no completed form.
[3]Excludes donors in 2012.
[4]Excludes donors in 2011–2012.

point (22). For donors in 2015, these standards increased to 80% and 70% for clinical and laboratory data, respectively (22). Of note, these standards for compliance are unadjusted and, therefore, do not account for any variations in characteristics of donors between transplant centers.

The primary aim of this study is to simultaneously evaluate donor and center-level factors associated with follow-up reporting for living kidney donors. In addition, given potential heterogeneity of donor characteristics between transplant centers, we investigated the degree to which center compliance with follow-up data standards is affected by donor factors and consistent after adjusting for donor characteristics. These results may provide information to enable development of interventions to improve follow-up, identify patients at high risk for loss of follow-up and inform policy regarding the regulation of center compliance with follow-up standards.

Methods

We utilized SRTR data for living kidney donors from January 2008 to December 2012 with follow-up through November 2013. The SRTR data system includes data on all donor, waitlisted candidates, and transplant recipients in the United States, submitted by the members of the Organ Procurement and Transplantation Network (OPTN), and has been described elsewhere (23). The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors. The study was approved by the Cleveland Clinic Institutional Review Board.

In order to allow for sufficient follow-up time to assess completeness of forms, we utilized cohorts relative to the year of donation. For models assessing 6 months follow-up, we used all available donors during the study period (2008–2012). For analyses assessing 1-year follow-up, we restricted the study population to donors between 2008 and 2011 and for models assessing 2-year follow-up, we restricted the data set to donors between 2008 and 2010 to account for additional lag in receipt of follow-up forms. Donors with an indicated death prior to the follow-up period were excluded from the applicable analyses. The specific parameters of interest and definitions for complete clinical and laboratory follow-up data are based on UNOS policies. For the primary analysis regarding center compliance, we used 2014 standards for complete laboratory and clinical data.

We evaluated the association of donor demographic characteristics, educational attainment, working status, distance to center (based on residence and transplant center zip code), marital status, donor–recipient relationship, history of cigarette use, year of donation, history of hypertension, citizenship (U.S. vs. non-U.S.), donor body mass index, and estimated glomerular filtration rates (based on the Modification of Diet in Renal Disease equation). We also evaluated the association of community risk score which has been described in prior studies and shown to be significantly associated with transplant candidate and recipient outcomes (24,25). Finally, we examined the impact of center-level factors on the proportion of complete living donor follow-up information including centers' annual number of living donor transplants and the proportion of kidney transplants at centers from living donors relative to the combination of living and deceased donors.

Given the potential that both donor and center-level characteristics may affect completeness of living donor follow-up data, we used multivariable logistic model with transplant centers considered as a random effect (proc glimmix in SAS) to evaluate the joint impact of donor and center factors. Based on these models, we calculated the intraclass correlation (ICC), estimating the proportion of variation of missing data at the center level and evaluated the independent association of center and donor factors with missing data. We also generated adjusted models for estimating the proportion of missing data at each center. As center effects were the focus of these models, we excluded center-level characteristics and included only the set of donor characteristics. We compared the adjusted and unadjusted proportion of missing data by center to estimate the effect of risk adjustment on donor follow-up attributed to centers and in addition, evaluate the number of centers that would change their qualitative rating of compliance based on the current UNOS standards. In order to calculate the adjusted proportion of missing data by center, we first used the point estimates for missing data attributable to each center generated from the model adjusted for donor characteristics. The adjusted proportion was then based on the difference of

the center effect without donor characteristics (an intercept-only model) accounting for the intercept effect. All analyses were conducted in SAS (v.9.2., Cary, NC).

Results

The study included 30 026 living kidney donors in the United States from 2008 to 2012. The average age of donors was 42 years (standard deviation = 11.6). Sixty-two percent of donors were female, 70% were white (non-Hispanic), 14% Hispanic, and 12% black. Table 1 depicts the proportion of donors with completed follow-up parameters that are required by UNOS at 6, 12, and 24 months postdonation. For donors throughout the study period, 67% of donors had complete clinical data and 51% had complete laboratory data at 6 months follow-up. Patient status (alive or dead) was the most often completed parameter (96%) on forms. In contrast, information regarding donors working status (70%), serum creatinine (69%), and urine protein (52%) was the least likely to have complete information. Among donors between 2008 and 2011, complete 1-year follow-up clinical data were available for 60% of donors and complete 1-year laboratory data were complete for 40% of donors. Among donors from 2008 to 2010, complete 2-year clinical data were available for 50% of donors and complete laboratory data were available for 30% of donors. The proportions of complete clinical and laboratory follow-up forms by year of donation are displayed in Figure 1. As indicated, there has been significant improvement in completed follow-up including 76% 6-month clinical data and 61% 6-month laboratory data for donors in 2012.

Completion of follow-up information varied significantly by both donor and center characteristics. Table 2 displays the proportion of completed data based on both donor and center characteristics at each follow-up period for clinical and laboratory information. Differences in complete follow-up information were most dramatic by donor age, race, educational attainment, distance between donors' residence and the transplant center and size of the living donor programs. Results of the multivariable model for 1-year clinical and laboratory data are displayed in Table 3. As indicated, donors 18–34 were independently more likely to have missing clinical (adjusted odds ratio [AOR] = 1.66, 95%CI 1.30–2.12) and laboratory follow-up data (AOR = 2.03, 95%CI 1.58–2.60) as compared to donors aged 65 years and older. Black donors had significantly higher likelihood of missing clinical (AOR = 1.24, 95%CI 1.11–1.37) and laboratory (AOR = 1.17, 95%CI 1.05–1.30) data as compared to non-Hispanic whites. Donors without health insurance had 21% and 25% increased adjusted likelihood for missing 1-year follow-up clinical and laboratory data, respectively. Donors residing more than 500 miles from the transplant center had 38% and 78% increased likelihood of missing clinical and laboratory data, respectively, as compared to donors within 30 miles of the center. Donors at centers performing more than 40 living donor transplants per year had over twofold greater likelihood of

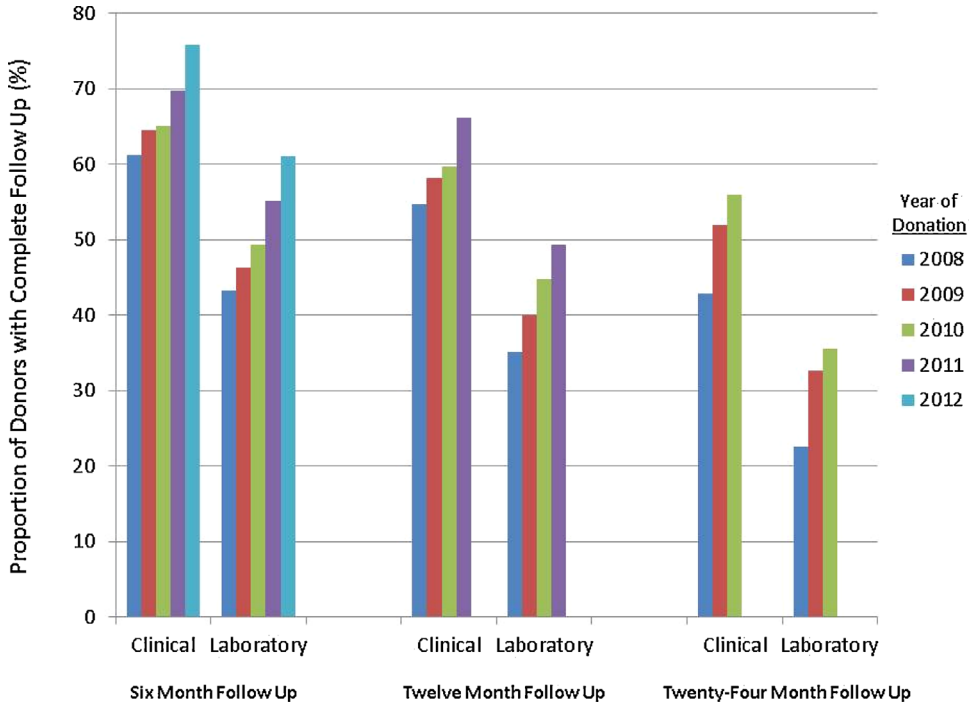

Figure 1: Proportion of compliant completed clinical and lab parameters by year of donation.

Table 2: Proportion of complete clinical and lab data by donor and transplant characteristics[1]

Donor and transplant characteristics		Clinical data			Lab data		
		Follow-up period			Follow-up period		
	Level (% of study population)	6 months	1 year[1]	2 years[2]	6 months	1 year[1]	2 years[2]
Gender	Female (62)	67%	60%	52%	52%	41%	32%
	Male (38)	67%	59%	48%	49%	38%	28%
Donor age	18–34 (30)	63%	54%	44%	48%	35%	25%
	35–54 (55)	68%	61%	52%	52%	40%	31%
	55–64 (13)	72%	65%	56%	54%	46%	38%
	65+ (2)	72%	63%	64%	56%	49%	41%
Donor race/ethnicity	White, Non-Hispanic (70)	68%	61%	52%	51%	40%	31%
	Black (12)	63%	54%	46%	50%	36%	27%
	Hispanic (14)	65%	57%	48%	51%	41%	33%
	Asian (4)	66%	56%	48%	52%	38%	30%
	Other (1)	65%	58%	43%	46%	39%	32%
History of hypertension	No (97)	67%	60%	50%	51%	39%	30%
	Yes (3)	70%	63%	55%	55%	44%	38%
Working for income[1]	No (17)	63%	56%	49%	51%	39%	31%
	Yes (83)	69%	61%	52%	51%	40%	31%
Recipient primary insurance	Private (59)	67%	60%	51%	50%	39%	30%
	Medicare (36)	67%	59%	50%	52%	40%	30%
	Other (6)	64%	58%	46%	50%	42%	31%
Marital status[1]	Single (27)	65%	55%	46%	49%	37%	29%
	Married/Life partner (63)	69%	62%	53%	52%	41%	32%
	Divorced/Separated (9)	68%	61%	50%	52%	40%	29%
	Widowed (1)	67%	58%	51%	54%	44%	36%
Donor relationship to recipient	Parent (8)	68%	62%	54%	51%	40%	30%
	Child (16)	66%	59%	47%	51%	39%	30%
	Other, Biological (29)	66%	58%	49%	49%	37%	28%
	Non-Biological (46)	68%	60%	52%	52%	41%	32%
History of cigarette use	No (75)	67%	60%	51%	51%	40%	31%
	Yes (25)	66%	58%	48%	51%	37%	29%
Donor health insurance	No/Unknown (30%)	61%	54%	46%	44%	34%	28%
	Yes (70)	70%	62%	53%	54%	42%	32%
Educational attainment[1]	Graduate degree (12)	71%	65%	55%	55%	44%	34%
	College degree (28)	71%	65%	55%	55%	44%	35%
	Attended college (29)	68%	59%	51%	50%	40%	31%
	High school or less (31)	66%	57%	48%	51%	40%	30%
Citizenship	United States (95)	68%	60%	51%	51%	40%	31%
	Non-US (5)	59%	52%	42%	47%	35%	27%
Distance to center[1]	<30 miles (43)	71%	63%	54%	55%	44%	36%
	31–150 miles (32)	67%	59%	50%	50%	39%	29%
	151–500 miles (13)	63%	56%	45%	45%	33%	23%
	>500 miles (12)	62%	56%	47%	44%	32%	24%
Transplant center annual number of living donor kidney transplants	≤10 (8)	76%	67%	60%	58%	46%	37%
	11–20 (11)	76%	70%	61%	54%	41%	35%
	21–40 (27)	73%	66%	53%	64%	50%	36%
	>40 (54)	61%	53%	45%	42%	33%	26%
Percent of all kidney transplants at center that were deceased donors	<50% (25)	67%	58%	48%	43%	32%	26%
	50–67% (47)	65%	59%	50%	52%	42%	32%
	>67% (28)	70%	63%	54%	55%	42%	32%
Estimated GFR prior to donation[1]	≥100 mL/min/kg/m^2 (37)	66%	59%	48%	51%	40%	30%
	80–99 mL/min/kg/m^2 (41)	69%	61%	51%	52%	41%	31%
	<80 mL/min/kg/m^2 (22)	67%	60%	52%	51%	39%	31%
Body mass index[1]	13–20 kg/m^2 (4)	66%	56%	51%	51%	40%	30%

(*Continued*)

Table 2: Continued

Donor and transplant characteristics	Level (% of study population)	Clinical data: Follow-up period 6 months	Clinical data: Follow-up period 1 year[1]	Clinical data: Follow-up period 2 years[2]	Lab data: Follow-up period 6 months	Lab data: Follow-up period 1 year[1]	Lab data: Follow-up period 2 years[2]
	20–25 kg/m^2 (32)	68%	61%	51%	52%	41%	31%
	26–30 kg/m^2 (42)	68%	61%	52%	52%	40%	32%
	31–35 kg/m^2 (20)	67%	60%	48%	50%	39%	28%
	36+ kg/m^2 (3)	64%	56%	48%	46%	33%	26%
Community risk	0–9	69%	62%	52%	50%	39%	31%
Score (0–40 scale with 0 equal to the lowest risk)	10–19	68%	62%	53%	52%	42%	33%
	20–29	65%	57%	48%	50%	38%	30%
	30–40	66%	56%	47%	49%	37%	27%
OVERALL	N = 30 023	67%	60%	50%	51%	40%	30%

[1]Excludes donors in 2012 to allow for adequate follow-up.
[2]Excludes donors in 2011–2012 to allow for adequate follow-up.

missing clinical and laboratory data as compared to centers performing less than 10 living donor transplants. The largest living donor programs also had the highest proportion of donors traveling more than 500 miles (13%) as compared to 7% of donors at the smallest living donor programs. Completed follow-up varied by center, the ICC for follow-up forms ranged from 40% (6-month laboratory) to 30% (12-month clinical) indicating a substantial proportion of variation in follow-up was at the center-level. Results of the multivariable model for 2-year follow-up were very similar with each of the significant variables in the 1-year models also significant for 2-year follow-up. In addition, for clinical data, males were statistically significantly more likely than females to have missing data at 2 years.

The proportion of centers that were noncompliant (based on 2014 UNOS standards) with follow-up clinical and laboratory data over the study period is displayed in Figure 2. As indicated, 87 (37%) centers had inadequate clinical follow-up data (more than 30% missing complete data) and 118 (49%) centers had inadequate laboratory follow-up (more than 40% missing complete data). The proportion of centers that had noncompliant follow-up data increased with duration of follow-up including 159 (69%) of centers for 2-year clinical data and 193 (84%) centers for 2-year laboratory data. Figure 2 also depicts the proportion of centers that met the same threshold of missing data based on models adjusted for donor characteristics. The overall proportion of centers with noncompliant follow-up was similar as the unadjusted models (as expected). However, there was a moderate reclassification of centers, such that between 2% and 6% of centers shifted above or below the applicable threshold of performance with risk adjustment. Most centers had relatively minor shifts in the estimated proportion of follow-up with adjusted versus unadjusted models; however, estimates dramatically shifted for several centers. For example, for 12-month laboratory follow-up data, the difference in adjusted to unadjusted proportions ranged from −15% to +10% but the 25th and 75th percentile differences were −1% and +2% (median = 0%). Similarly, for 12-month clinical follow-up data, the minimum change in the proportion of follow based on adjusted models was −15%, 25th percentile = −1%, median = 0%, 75th percentile = +2% and maximum +7%. To illustrate the shift further, Figure 3 depicts the relationship between centers' unadjusted proportion of missing 1-year clinical data (x-axis) and adjusted proportion of missing data (y-axis). As indicated on the graph, most centers had minor shifts in estimates; however, 12 (5%) centers were reclassified for performance with adjustment for donor characteristics.

Discussion

There are several principal findings of our study. First, as previously documented, the study confirms relatively high rates of missing follow-up data for living donors, particularly for laboratory parameters. However, the completion rate of follow-up data is improving in more recent years. Missing follow-up data are highly variable by donor characteristics and more common among younger and black donors, donors without health insurance and lower educational attainment and donors that reside further distance from the transplant centers. There is significant variation in completion of follow-up data by individual transplant centers, and on average, missing data are more common among larger living donor programs. Finally, risk adjustment for donor characteristics has a moderate effect on identifying centers with noncompliant levels of missing data based on current UNOS standards. Cumulatively, these results suggest that despite improvements in reporting follow-up data, further efforts to collect data are needed. Furthermore, targeted interventions may be needed to monitor patients with selected characteristics. Lastly, regulation of transplant center compliance for living donor follow-up may consider

Table 3: Adjusted likelihood of missing 1-year clinical and lab parameters among living donors[1]

		Clinical information at 1 year			Lab information at 1 year		
Donor characteristic (reference group)	Level	Adjusted odds ratio	95%CI	p-value[2]	Adjusted odds ratio	95%CI	p-value[2]
Gender (female)	Male	1.05	0.99–1.12	0.14	1.11	1.04–1.19	0.001
Donor age (65+)	18–34	1.66	1.30–2.12		2.03	1.58–2.60	
	35–54	1.28	1.01–1.62	<0.001	1.58	1.24–2.00	<0.001
	55–64	1.07	0.84–1.37		1.21	0.95–1.55	
Donor race/ethnicity (White, non-Hispanic)	Asian	1.25	1.05–1.48		1.12	0.94–1.35	
	Black	1.24	1.11–1.37		1.17	1.05–1.30	
	Hispanic	1.03	0.93–1.14	<0.001	0.84	0.76–0.94	<0.001
	Other	0.99	0.74–1.33		0.82	0.59–1.13	
History of hypertension (no)	Yes	1.05	0.87–1.28	0.60	1.03	0.84–1.25	0.79
Year of donation (2011)	2008	1.80	1.65–1.96		2.14	1.95–2.34	
	2009	1.54	1.42–1.68	<0.001	1.79	1.64–1.95	<0.001
	2010	1.41	1.30–1.54		1.34	1.23–1.47	
Working for income (yes)[1]	No	1.18	1.09–1.29	<0.001	1.05	0.96–1.15	0.18
Recipient primary insurance (Medicare)	Private	0.97	0.91–1.03	0.59	0.97	0.90–1.03	0.06
	Other	0.97	0.84–1.12		0.84	0.72–0.97	
Marital status (married/life partner)[1]	Single	1.13	1.04–1.22	0.002	1.07	0.98–1.16	0.08
	Divorced/Separated	1.11	1.00–1.23		1.12	1.00–1.25	
	Widowed	1.33	1.04–1.69		1.32	1.00–1.75	
Donor relationship to recipient (parent)	Child	0.91	0.80–1.05	0.31	0.85	0.73–0.98	0.03
	Other biological	0.97	0.86–1.09		0.94	0.83–1.07	
	Non-biological	0.99	0.89–1.12		0.88	0.78–0.99	
History of cigarette use (no)	Yes	1.19	1.10–1.27	<0.001	1.22	1.13–1.31	<0.001
Health insurance (yes)	No	1.21	1.12–1.31	<0.001	1.25	1.15–1.36	<0.001
Educational attainment (post-college graduate degree)[1]	College degree	0.93	0.83–1.03		0.96	0.85–1.07	
	Attended college	1.19	1.06–1.33	<0.001	1.12	1.00–1.26	<0.001
	High school or less	1.23	1.10–1.37		1.19	1.06–1.34	
Citizenship (United States)	Other	1.19	1.01–1.40	0.04	1.08	0.91–1.29	0.39
Distance to center (<30 miles)[1]	31–150 miles	1.14	1.06–1.23	<0.001	1.22	1.13–1.32	<0.001
	151–500 miles	1.22	1.11–1.35		1.47	1.32–1.64	
	>500 miles	1.38	1.25–1.53		1.78	1.60–1.98	
Transplant center annual number of living donor transplants (≤10)	11–20	0.87	0.56–1.35	0.004	1.26	0.73–2.17	0.03
	21–40	1.21	0.80–1.84		0.94	0.56–1.58	
	>40	2.12	1.32–3.42		2.20	1.21–3.98	
Percent of all transplants at center that were deceased donors	per 10%	1.05	0.94–1.17	0.43	0.98	0.86–1.13	0.80
Estimated GFR prior to donation (>100 mL/min/kg/m^2)[1]	80–99	0.96	0.90–1.03	0.59	0.99	0.91–1.06	0.87
	<80	0.97	0.89–1.06		0.97	0.89–1.07	
BMI (20–25 kg/m^2)[1]	13–20	1.19	1.01–1.40	0.001	1.09	0.91–1.29	0.08
	26–30	0.99	0.92–1.06		1.06	0.99–1.14	
	31–35	0.99	0.91–1.08		1.07	0.97–1.17	
	36+	1.10	0.92–1.31		1.28	1.05–1.55	
Community risk score	Per unit	1.00	0.99–1.00	0.84	1.00	0.99–1.00	0.81

[1]Missing levels of baseline variable not displayed.
[2]p-value reflects tests of the overall association of the donor characteristic with missing levels with adjustment for other covariates in the model.

risk adjustment in order to provide a fair representation of center efforts to collect data.

Perhaps the most important findings of the study indicate significant variation of follow-up data attributed to donor characteristics. Based on the nature of the analysis, these factors are independent of individual transplant centers or selected center-level characteristics. There is a strong association of donor age with capture of follow-up information, which may be associated with generally better

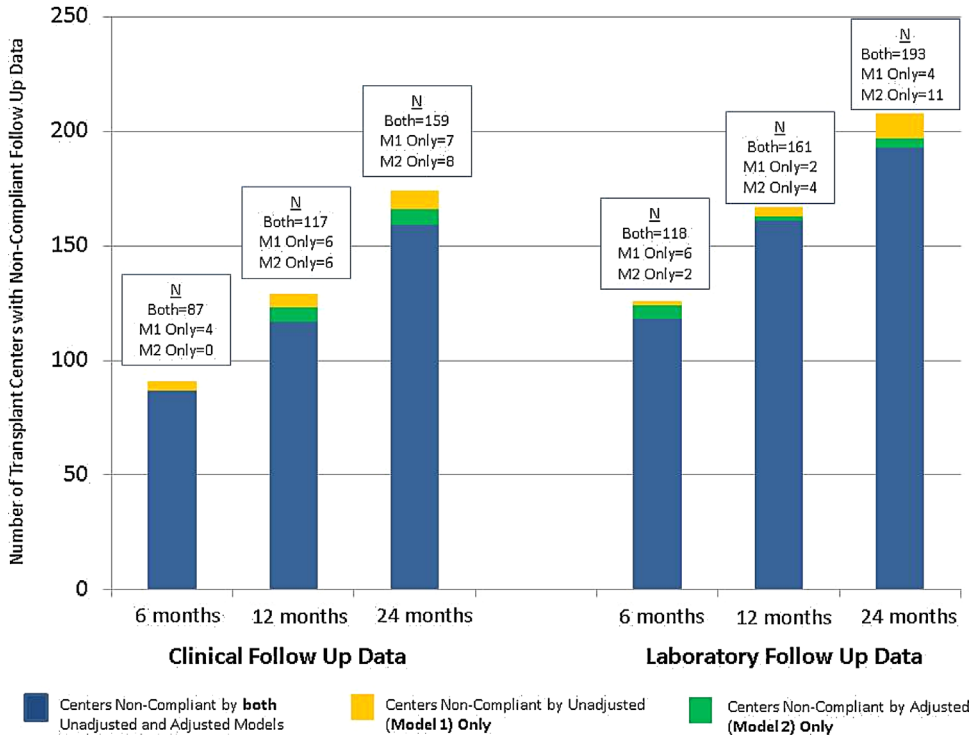

Figure 2: Noncompliant centers by follow-up period and adjusted versus unadjusted models. Low rating based on 2014 standards which stipulate 60% complete laboratory information and 70% complete clinical information; n = 246 transplant centers. Models adjusted for donor demographic characteristics, history of hypertension, year of donation, recipient insurance, donor marital status, donor–recipient relationship, donor working for income, donor history of cigarette use, donor health insurance, donor educational attainment, donor citizenship, donor estimated glomerular filtration rate, donor body mass index, community risk score, and donors' distance to transplant center from primary residence.

health for younger donors, relatively increased mobility and less inclination and/or aptitude for seeking medical care. Despite this, identifying early markers of morbid conditions for younger donors is vitally important and results suggest that interventions to incentivize ongoing monitoring are needed. Importantly, donors that report lack of health insurance have lower educational attainment and donors not working for income are significantly more likely to have missing follow-up data which may be directly impacted by poorer access to healthcare. This is despite the fact that at least for donors with health insurance, reimbursement for follow-up care is similar to recipient follow-up care (26). These results reinforce the need to consider funding mechanisms for donor follow-up and eliminate logistical impediments for follow-up care based on financial need (27,28). Of note, the National Living Donor Assistance Center does provide funding for donor follow-up to those who qualify for financial assistance for at least 2 years and it is likely that not all eligible donors and centers take advantage of this mechanism to support ongoing care (29). Given the recent decline in living donor kidney transplantation and lower incidence of living donation in lower socioeconomic regions, establishing coordinated follow-up care for donors with financial impediments is vitally important for both current donors and to reassure comprehensive care for prospective donors (18,28).

Unlike findings which illustrated an association between community risk factors and transplant candidate and recipient outcomes, there was no evidence of an association of community risk level and donor follow-up (24,25). This may suggest that risks for missing follow-up information are particular to individuals and cannot be more generally ascribed to donors from higher risk communities. The interpretation for the elevated risk of missing data for donors with reported cigarette use is not entirely clear, but may reflect behavioral attributes or disinclination to receive general healthcare among these donors. The study also demonstrates that black donors are less likely to have documented follow-up information despite reports that this population has relatively increased risks of morbidity related to donation (5,16,30–32). Interestingly, widowed donors also are associated with higher rates of missing data, which potentially could be related to relatively lower social support or psychological conditions (33,34). Finally, there was no association of follow-up with estimated GFR, potentially suggesting that rigor of follow-up is not directly related to perceived risk of renal dysfunction. Another interesting

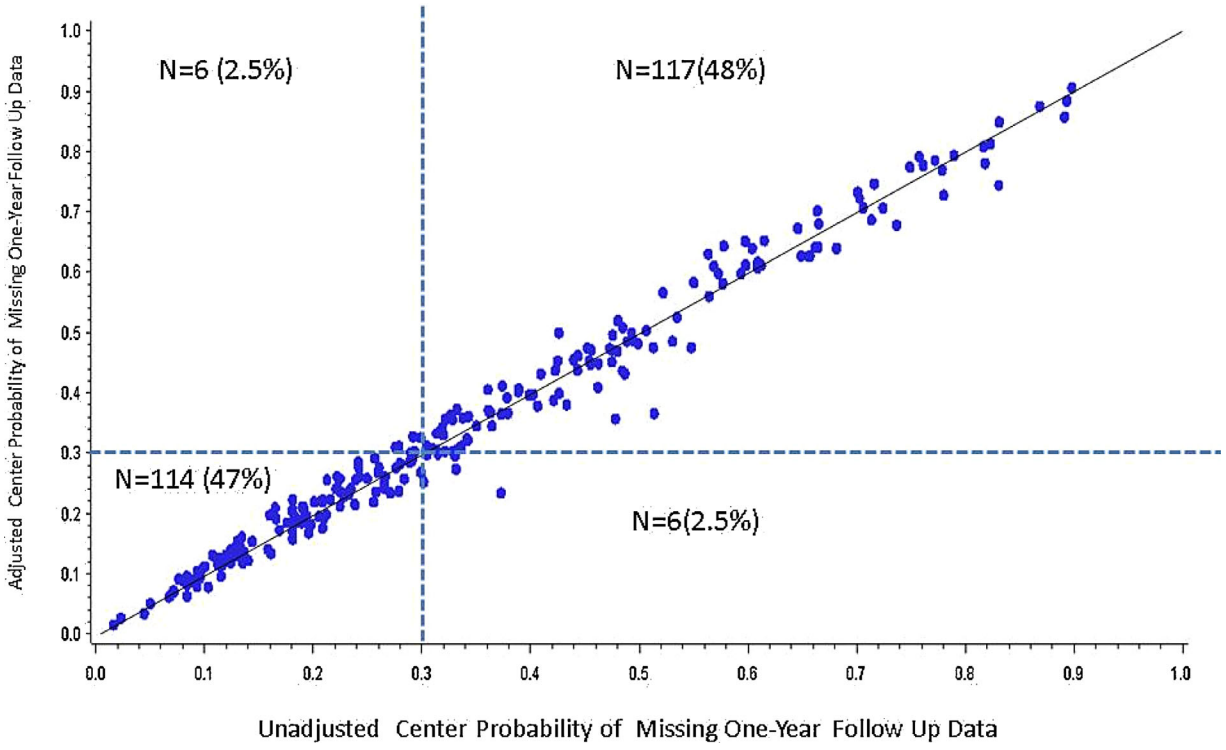

Figure 3: Agreement of adjusted and unadjusted proportions of missing 1-year clinical follow-up data by transplant center. Based on 2014 standards of no more than 30% missing follow-up clinical data, 95% of centers would receive similar ratings (48% of centers with excessive missing and 47% of centers with compliant level of missing clinical data), while 5% of centers would have a different qualitative rating with adjusted versus unadjusted estimates.

situation to evaluate for donor follow-up may be paired exchanges. Evaluation of the effect of these transplants was beyond the scope of the current study, but understanding whether follow-up was similar for these donors will be important to monitor prospectively. Cumulatively, further efforts are needed to identify barriers to follow-up care for at-risk donors and potentially expedite interventions in circumstances in which complications of donation arise.

Presence of follow-up data was highly variable by individual transplant center. In fact, model estimates from this study indicate that 30–40% of known variation in missing data is explained at the center level. As depicted visually in Figure 2 for 1-year clinical data, the range in ascertainment of follow-up by centers is almost 0–100%. These results clearly suggest that processes and protocols among centers are strongly associated with follow-up, which may, in part, be attributed to variable resources and lack of reimbursement for centers to attain information about donor health following discharge (12,20). Not surprisingly, missing follow-up was strongly associated with donors that resided longer distances from the center. These results reinforce the notion that the capacity to acquire follow-up data is, in part, affected by either direct access to donors' care or coordination with caregivers in the community. Interestingly, higher rates of missing data were associated with larger living donor programs, which counterintuitively may have more infrastructure for the program. However, this result may also illustrate that the overall volume of patients and the capacity for any center to monitor a large number of donors that may be outside of the transplant center's health system. Another contribution for higher levels of missing data among larger living donor programs is a higher proportion of donors traveling greater distances to the center and the additional impediments for monitoring health for these donors.

Use of risk adjustment to identify noncompliant centers (based on current UNOS standards) had a moderate impact on simulated center performance evaluations. Although risk-adjustment may provide a more fair assessment of center efforts to obtain follow-up information between centers with diverse donor populations, our study indicates that most centers would receive similar qualitative rating for compliance with and without risk adjustment. Regardless, risk-adjustment should be considered to evaluate center compliance which may also have the benefit of dissuading conscious or subconscious disinclination to accept donors with risk factors for loss to follow-up.

There are many compelling reasons to monitor living donor outcomes, most prominently to carefully evaluate the health of this population and to ensure that there no groups of donors who appear to be at undue risk associated with the procedure. The current follow-up information provides some insights into the health of the population but is limited due to the high level of missing data and the potential that these data are systematically different than donors with follow-up information. Thus, a more comprehensive assessment, ideally with outcomes beyond 2 years, would provide a more broad and reliable assessment of the health of the living donor population and identify any potential concerns more rapidly. The improvements in capturing living donor follow-up data are likely associated with documentation and more broad recognition of the relatively high rate of missing data in conjunction with new UNOS regulations to require follow-up by transplant centers (12,35). Despite the importance of center compliance of living donor follow-up, the impact of these new regulations should also be carefully monitored. Given mixed effects of regulatory oversight that have been observed for monitoring posttransplant outcomes, careful examination and development of policy to avoid unintended consequences are crucial (36–41). For example, a potential consequence of rigid oversight of living donor follow-up may be to generate disincentives for programs to accept donors that are at relatively higher risk for lack of capture of follow-up information. From one perspective, for these donors in which capture of follow-up information may be more challenging, there may be questions of whether they should be considered a viable donor. On the other hand, despite failure to capture follow-up information, it could be argued that donor autonomy ought to be respected as many of these donors may inevitably be uninterested in routine monitoring and in good health and as such stifling donation among these individuals may not lead to diminished health among these donors but a deleterious impact on transplant candidate outcomes. More generally, the transplant community may benefit from more effective strategies to share resources and align efforts to capture donor follow-up information and include integration of existing data that does not require unwieldy and resource-intensive efforts from transplant centers (42).

In summary, there is clear recognition that continual monitoring of living kidney donor health is an important priority for the transplant community. The study indicates that despite improvements in documentation regarding donor health through standard UNOS follow-up forms, additional progress for monitoring donor health is needed. These efforts may be strategically targeted for donors with selected characteristics and larger living donor transplant programs. Policy efforts to remove financial barriers for ongoing care among donors, as well as facilitating access to current programs may also be highly effective at facilitating capture of donor follow-up information. Regulation of living donor follow-up among centers may be effective, but should also be balanced with consideration of potential unintended consequences. Evaluation of center compliance may benefit by adjusting for donor characteristics, yet wide disparities in follow-up between centers exist independent of variation in donor populations. Further demonstration of effective and cost-effective practice patterns and interventions by centers to acquire living donor follow-up data are needed.

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Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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