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Kidney Transplant Candidate Acceptance Of Live Donor Esrd Risk

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Abstract

Background: We recently found that potential living kidney donors (LKDs) are willing to accept high levels of end stage renal disease (ESRD) to donate. Since receipt of a living donor kidney is also contingent recipient attitudes, we sought to explore potential recipients' acceptance of risks to potential LKDs and their attitudes on risk acceptance.

Methods: We conducted a mixed methods prospective study of ESRD patients undergoing transplant evaluation. Using a novel 10,000 dot diagram, participants indicated the highest chance of a LKD getting ESRD they were willing to accept. Participants also completed demographic, risk taking, and health surveys. Ordinal logistic regression assessed factors associated with willingness to accept living donor ESRD risk. Qualitative analysis sought to understand rationale and justification of risk acceptance.

Results: 57 potential kidney transplant recipients participated in the study. A third of transplant candidates accepted a maximum risk below the current level of 0.9%. In unadjusted analysis, having an interested potential LKD was associated with willingness to assume a higher chance of donor ESRD (OR 5.74, p=0.002). Adjusting for covariates, having a potential donor remained significantly associated with increased willingness to accept donor ESRD risk (OR 5.88, p=0.008). Qualitative analyses identified four main reasons for willingness to accept higher risk, and four main reasons for willingness to limit donor risk.

Discussion: We found that two thirds of potential recipients accept at least the current level of ESRD risk for potential LKDs. Future work should explore why potential recipients are willing to accept greater risks if they have a potential LKD. The use of the visual aid was described as helpful and could be developed into an educational tool to explain risks associated with living donation. The visual aid may also help transplant candidates start

the conversation and ask someone to consider being a living donor. Understanding recipient attitudes about risks to LKDs will enhance informed consent and facilitate dialogue between potential donors and recipients.

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Background

End-stage renal disease (ESRD) and chronic kidney disease are a growing burden on health world-wide. In the US, 20 million people suffer from chronic kidney disease.[1] There are two treatment options for individuals suffering from ESRD: dialysis or transplantation. Kidney transplantation is currently viewed as the best treatment option for ESRD patients due to improved quality of life, and cost effectiveness compared to dialysis.[2-4] Most importantly, kidney transplantation provides improved survival outcomes compared to dialysis.[5] Due to the known association of dialysis exposure and mortality, those patients who can obtain a living donor transplant earlier have improved survival versus dialysis patients.[6] In addition, living kidney donation has lower rates of delayed graft function and has a lower chance of rejection because of the genetic similarity between donor and recipient.[3 4]

Although living kidney transplantation is the preferred treatment option for ESRD patients, there has been a decline and subsequent plateau of the number of living kidney donors (LKDs) in the US. This trend is a concern for health care workers and researchers across the United States.[7] Those who do not have a living donor are placed on the national organ transplant waiting list, managed by the United Network for Organ Sharing (UNOS). Depending on a variety of factors, the average wait time for a kidney can be 3-5 years[1].

Patients with ESRD are typically referred by their nephrologist or dialysis unit to a transplant center for an extensive evaluation to determine candidacy for transplantation. At Yale-New Haven Hospital Transplant Center, patients interested in receiving a kidney transplant from a living or deceased donor come into new patient clinic for a comprehensive one-day evaluation.[8] During this visit, patients meet with a transplant surgeon, nephrologist, social worker, pharmacist, dietician, and transplant coordinator. Not all potential transplant recipients are approved to move to the waiting list. Members of the transplant team evaluate potential transplant recipients that present to clinic, and the transplant team makes a decision about whether or not to approve an individual for transplantation. Even though the transplant team is ultimately responsible for the decision, transplant candidates' attitudes towards living donation may shape their willingness to ask people to consider donating and have a significant impact on the chances of identifying a living donor.

After the evaluation takes place, a series of decisions are made to move forward with transplantation. The transplant team must decide if the transplant candidate is eligible, and transplant recipient must decide if they want to pursue living transplantation. The recipients may or may not be comfortable asking potential donors after they learn what living transplantation involves. However, equally important is understanding how potential transplant recipients gauge risks to LKDs. Even if a LKD is highly motivated and willing to take higher levels of risk to donate, the transplant recipient must be willing to accept that risk to the donor.

Current research on how kidney transplant candidates' think about this decision is limited. A previous study evaluated risk-taking for potential kidney transplant recipients, potential LKDs, and transplant professionals.[9] The study measured how willing these groups were to take risks for long-term donor hypertension, cardiovascular disease, and ESRD. About half the recipients in the study had stage 5 kidney disease requiring transplant or dialysis, and the other half had stage 3 or 4; only a small group had actually been evaluated for transplantation. However there are a number of limitations to this study. The authors noted they excluded people who were not interested in living kidney donation because their inclusion would exacerbate differences between potential donors and recipients willingness to accept post-donation complications of donors.[9] In addition, the questions asked by investigators were closed-ended and had pre-determined responses with little clinical relevance. Furthermore, the data used in the paper did not reflect the most current risks to LKDs.[10] Background information such as requirements of dialysis, and physical and mental health of recipient need were not measured.

Therefore we sought to identify the maximum chance of ESRD that kidney transplants candidates were willing to accept for their potential living kidney donors by applying the latest data and recent literature on risk education. Additionally, we sought to identify characteristics of individuals who were risk averse and those who were willing to take high levels of risk. We predicted that individuals who were more educated, had a higher income, were in worse health, were on dialysis, had higher social capital, and had higher scores on risk-taking measurements would be more likely to take higher risks for their donors.

Methods

Study Design

We conducted a prospective, mixed methods study of patients with ESRD who presented to clinic to be evaluated as a potential kidney transplant recipient. Study recruitment occurred between August to November 2015. Eligible and interested participants were recruited during their new clinic visit.

We recruited individuals at the Yale New Haven Hospital Transplant Center new patient clinic. In a one year period from July 2014 – June 2015, the center performed 64 deceased donor transplants and 43 living donor transplants (Figure 1).[11] In this time period 273 individuals were added to the kidney waiting list.[11] As of June 2015, 874 individuals were on the kidney transplant waiting list.[11] The center is located in UNOS Region 1 (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and eastern Vermont), where the median waiting time for a deceased donor kidney transplant is 49.7 months.[12]

Exclusion criteria included: not speaking English, previous evaluation at another center or listing for a transplant, prior solid-organ transplant, intended kidney/pancreas or kidney/liver transplants, and low health literacy based on a simple screening question. In addition, individuals with poor eyesight who were unable to adequately see the visual instruments were not included in the study. Individuals who left the clinic before being

approached for study eligibility were unable to participate.

Survey instruments included: demographic questionnaire (including a question asking if they were receiving hemodialysis or peritoneal dialysis), survey regarding perceived health and wellbeing (12-Item Short Form Health Survey, SF12), and scale of attitudes toward risks from the decision sciences literature.[13] Participants also took the Domain Specific Risk Taking Scale (DOSPERT), a validated measure of attitudes toward risk. The outcomes of the DOSPERT include overall risk taking propensity score, and subscales for ethical, financial, health, recreational, and social risk taking.[13] In addition, participants completed a novel instrument evaluating understanding and willingness to accept health risks to living kidney donors, the Donor Specific Risk Questions for Recipients (DSRQ-R).

The DSRQ-R is a visual aid designed to educate transplant candidates about donor risks and to assess their willingness to accept risk. This approach was selected because recent literature suggests that visual aids reduce common cognitive biases associated with interpreting risk literature[14,15]. In the DRSQ-R, risk information is presented using a 10,000 dot visual array to represent risks. Participants are given a practice question to orient themselves to the visual instrument. Information about risk of ESRD to the general population, risk of ESRD to healthy individuals who do not donate, and risk to living donors. Then respondents are presented with a blank diagram and prompted the respondents to specify how much risk they would be willing to accept for a living donor for the risk of kidney failure following the kidney donation surgery. Following completion of the DSRQ-R, a research team member asked follow-up questions to confirm selection of response and open-ended probes to better understand the rationale behind the answer and motivations for taking certain levels of risk. This brief interview was audio-recorded and transcribed for qualitative data analysis purposes.

The DSRQ-R was pilot tested among six previously transplanted individuals and two individuals on the transplant waiting list. The instrument was examined for clarity in the descriptions and instructions. Pilot participants were interviewed about the wording of the questions and their understanding of the instrument.

Participants received a $50 Visa gift card. This study was approved by the Yale University Institutional Review Board.

Statistical Analysis
Participant characteristics were analyzed by dialysis status using Chi Square test and Fisher's exact test to assess between-group differences.

The primary outcome was maximum willingness to accept risk of ESRD (possible range: 0 – 100% by hundredths of a percent). Willingness to accept risk of donor ESRD was non-normal. Attempts to transform the variable were unsuccessful. The variable ESRD was analyzed by tertiles. Recipients in the lowest tertile were willing to take a level of risk that was at or below the current level of risk (0 – 0.90%). The recipients in the

middle tertile were willing to take a level of risk between 1 - 3%. The third tertile included recipients who were willing to take a level of risk between 3 - 100%.

Cumulative ordinal logistic regression was performed treating ESRD as an ordinal variable in tertiles, with the most risk averse as the reference group. Univariate analyses were conducted between increased willingness to accept risk of ESRD with demographic variables (sex, age, race, marital status, education, income, religion, receipt of disability insurance), dialysis requirements (receiving dialysis, number of months on dialysis), perceived physical and mental health (SF-12), and baseline risk-taking propensity (DOSPERT), and whether the candidate had identified a potential LKD. Variables significant at the univariate level were included in the multivariate model. An interaction term with age and African American race was included based on the demographics of the older population in the sample.

Statistical analyses were completed using SAS 9.3 (Cary, NC).

Qualitative Analysis
The interviews following completion of the DSRQ-R helped to better understand the rationale for willingness to take higher or lower levels of risk. Codes were created using an inductive approach via iterative review of the data. Two independent researchers applied major and minor coding for identified themes.[16] Coding discrepancies were resolved by a third tie-breaker coder.

Qualitative data analysis was completed with qualitative coding methods from NVivo 11 (Victoria, Australia).[17] Associations were made between willingness to accept risk and major and minor themes using Fisher's exact test in SAS.

Results

Quantitative
The study includes 57 individuals undergoing evaluation to be wait-listed for a kidney transplant (response rate 67%, Figure 2).

Table 1 presents the participant characteristics for the sample and by dialysis status. Participants were 56% male; 51% completed some college; the mean age was 55 years. More than a third were African American (36%), and there were few Hispanics (9%). Sixty-five percent were retired or not employed for wages, and 30% were receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). Nearly one quarter of the participants (23%) had an annual household income under $35,000. Of the individuals on dialysis, half were receiving peritoneal dialysis and half were receiving hemodialysis. More than half of the participants (60%) had a potential LKD interested in donating to them. There were significant difference in income; a greater percentage of potential recipients who were on dialysis had a household annual income of under $35,000 (41%) compared to 7% of the potential recipients who were not yet on dialysis (p= 0.013). Nearly half of individuals on dialysis (48%) were receiving SSI or SSDI, while 13% of individuals not receiving dialysis were

receiving SSI or SSDI (p= 0.008). Physical and mental health composite scores did not differ significantly by dialysis status.

The majority of transplant candidates (67%) were willing to accept a level of risk to donors that was higher than the current estimates of a 0.90% chance of ESRD.[10] The distribution of willingness to accept risk ranged from 0% - 60% (Figure 3).

Table 2 presents the univariate results. Individuals with potential LKDs (OR = 5.8, p=0.002) and African-Americans (OR= 2.48, p=0.08) were significantly more likely to be willing to accept a higher level of risk. Increased risk aversion was associated with greater age (OR = 0.94, p=0.009), and occasional attendance at religious services (OR = 0.37, p=0.07). Individuals who were on dialysis were slightly risk averse, but this was not statistically significant (OR=0.48, p = 0.14). Physical health composite score, mental health composite score, and DOSPERT subscales were not significantly associated with increased willingness to accept risk.

The multivariate model included age, race, religiosity, receiving dialysis, and having a living donor identified (Table 3). An interaction term with age and African American race was added to the multivariate model based on the marginal significance at the univariate level. In this model, having a LKD interested in donating to them remained very strongly associated with higher willingness to accept risk (OR 5.9, p=0.008). Age, race, religiosity, and receiving dialysis were not significant in the multivariate model.

Qualitative

Participants described a variety of reasons their preferences regarding donor risk. We identified four common reasons for limiting risks to donors (Table 4) and four common reasons for accepting risks to donors (Table 5). The DSRQ-R demonstrates how transplant candidates are considering the trade-offs of living donation differently. Some candidates were thinking of reasons why they would limit risk to a donor, why they would accept some risks to a donor, and some candidates engaged in both types of thinking. Eleven participants exclusively discussed reasons why they were limiting their risks to donors. Alternatively, 18 transplant candidates only discussed reasons why they were willing to accept risks to a donor. Ten participants said that their answer choices were arbitrary, or selected a number and were unable to articulate why. Eighteen participants balanced reasons why they would accept some risks to the donor and also limit the risk. As one such participant explained, “Would I like to live longer? Of course! But to put somebody else at risk? Do I want to do that or do I want to accept that responsibility at this point in my life? No, I don’t.” This quote demonstrates how some transplant candidates are considering both reasons for and against willingness to accept risk to donors.

Fishers’ exact test was conducted to examine the association between reasons for accepting levels of risk and maximum willingness to accept ESRD risk. There was no significant association between willingness to accept low levels of risk and mentioning low levels of risk in responses (p=0.57). Discussion of feeling concerned for a living donor was not significantly associated with willingness to accept low levels of risk

(p=0.63). Answer selections that were described by participants as arbitrary were nearly significantly associated with wiliness to accept higher levels of risk (p=0.06). There were some transplant candidates who felt that their willingness to accept risks may change as they learn more about the transplantation process. As one transplant candidate said, "As I said to [transplant surgeon], maybe as time goes on, the more I research, the more I give it some thought. This is all brand new to me…" A few transplant candidates said that the new patient clinic process was too busy and they were overwhelmed with the DSRQ-R information they received. Another participant explained, "Because so much is going through my mind because I've been told about so many different things, and I'm still trying to get a grasp on things."

A quarter of participants used the statistical information presented on risk literature to select their maximum level of risk acceptance. One participant used the instrument as a reference point for selecting a level of risk and said, "And I thought, "So it's 1% [risk of developing ESRD]," and I thought I'd just give you an extra percent. That's how I figured it out. I figured there's a margin of error of 1%, so I said 2% [risk of developing ESRD]". Another transplant candidate referenced the risk literature saying, "Even 0.9 might be too strong, but it is what is the lifetime risk for them so I agreed with it."

Other respondents discussed how they used the visual aid during the open-ended questions. Five participants said that the visual display of risks was helpful to better understand the risks of living transplantation. One such participant mentioned, "Well I'm glad that actually you're asking the questions because when you're receiving a kidney it's a wonderful thing. You should really think about what the other person is being subjected to." Another participant explained how the DSRQ-R was different by saying, "… [W]hen you see it on paper it just makes it more real to you."

Discussion

This is the first study focused on understanding transplant candidates' attitudes and willingness to accept risk of living donors by using a visual display of the most current risk to donors. Most potential recipients accept at least the current level of 0.90% ESRD risk for living kidney donors. A third of potential recipients are more averse to LKD risks, selecting a maximum level of risk that was below the 0.90% chance of ESRD.

Having a potential LKD interested in donating to the recipient had the strongest association with willingness to accept higher risk after controlling for dialysis status, race, age, and religiosity. It is possible that individuals who have had a LKD come forward have already accepted the risks associated with this surgery. An alternative hypothesis is that individuals who are more risk averse may be less willing to solicit LKDs, resulting in fewer offers of living donation.

Individuals of older age were found to be risk averse, which is consistent with previous research on risk regarding healthcare decision-making.[18-20] To better educate older transplant candidates, explanation of the risks of transplantation should be communicated in a multifaceted approach using detailed descriptions and figures, with

both quantitative and qualitative information.[21] Such aids have proven to be helpful for older patients. This would be especially valuable for older LKDs who face a lower lifetime risk of ESRD.

African American transplant candidates were willing to accept higher levels of risk for potential donors. This is unexpected given that historically African-Americans have significantly decreased rates of living kidney transplantation.[22] Other research suggests that African-Americans may be less willing to ask someone to consider living donation, and African-Americans may cope differently with ESRD.[23,24] One potential explanation for this difference is that the most risk averse individuals may not be pursuing transplantation due to the risks of the procedure and may not be captured in this study.

Other variables, such as being on dialysis and higher level of education, were hypothesized to be of importance in increased willingness to accept risk of ESRD, although these hypotheses were not supported in this study. Individuals who are on dialysis may have been more risk averse and less willing to pursue transplantation.

Education about risks to LKDs can help increase discussions about how to ask someone to consider donation and where to begin in the search for a living donor. Although participants were not asked questions about their thoughts on the DSRQ-R, five transplant candidates commented that this information was helpful to better understand the risks associated with living donation. Ten participants said that they need to think about the risks more, and that their answers about maximum willingness to accept risks may change. This shows that the DSRQ-R offers an opportunity to educate about risk literature and start a conversation about living donation. Yale-New Haven Hospital Transplant Center is considering adding this risk information to the educational material for both potential living donors and recipients. Specifically, the program is considering adding a visual icon array similar to the one used in this study to help communicate risk information to transplant candidates and potential donors. While we did not find any relationship between willingness to accept risk and members of the transplant team the participant had met with, further thought should be given to the to ideal timing for administration of the DSRQ-R. As some participants mentioned, the amount of info given during new patient clinic is overwhelming, and further work should be done to consider who the best person should be administer – social worker, surgeon, or someone outside the transplant.

Strengths of the study include using the most current risk estimates to LKD. Individuals participated in this study during their evaluation appointment, preventing any bias made by notification of transplantation status. Limitations of this study include a relatively small sample size. A third of eligible participants were not interested in this study; this population may have been uniquely different than the transplant candidates who participated, possibly being more risk averse. Individuals not interested in transplantation because of the risks associated with the procedure would not be captured in this study; this effect may be more pronounced in the African American population. Because the study questionnaires were not administered in Spanish, our results may not adequately represent the views of Hispanic transplant candidates. This

study did not assess knowledge or education on living kidney donation prior to study enrollment. This could have led to a misunderstanding of the risk literature presented in the DSRQ-R, however the pre-survey test question and interview portion after the survey helped to clarify any confusion. DSRQ-R follow up questions during the interview portion did not specifically ask about the use of the visual aid to answer willingness to accept risk questions.

Future research should assess why transplant candidates are willing to accept greater risks if they have a potential LKD and why older transplant candidates are more risk averse. Using the DSRQ-R in the new patient evaluation setting may help educate transplant candidates about risks of living donation. It also could be used start transplant candidates facilitate a conversation with potential donors. Transplant professionals' understanding of candidates' attitudes about risks to LKDs will enhance informed consent and facilitate dialogue between potential donors and recipients.

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Table 1: Participant Characteristics

Characteristic	Overall	No dialysis	Dialysis	p-value
Age in years (Mean, SD)	55.0 (11.6)	54.8 (14.0)	55.2 (8.3)	0.88
Male	56.1%	56.7%	55.6%	0.93
Race				
Non- African American	64.3%	70.0%	57.7%	0.34
African American	35.7%	30.0%	40.7%	
Hispanic (Percent)	8.8%	3.3%	14.8%	0.18*
Marital Status				
Married or unmarried couple	45.6%	56.7%	33.3%	0.21
Divorced or widowed or separated	24.6%	20.0%	29.6%	
Never married	29.8%	23.3%	37.0%	
Education Level				
High School or less	49.1%	36.7%	62.3%	0.096*
Some College	35.1%	40.0%	29.6%	
Graduate Degree	15.8%	23.3%	7.4%	
Employment				
Employed	35.1%	43.3%	25.9%	0.098*
Not employed for wages	43.9%	30.0%	59.3%	
Retired	21.1%	26.7%	14.8%	
Income per year				
Under $35,000	22.8%	6.7%	40.7%	0.013*
$35,000 to $100,000	50.9%	56.7%	44.4%	
Over $100,000	17.5%	23.3%	11.1%	
No answer / don't know	8.8%	13.3%	3.7%	
Receiving Supplemental Security Income or Social Security Disability Insurance	29.8%	13.3%	48.2%	0.008
Social Capital score, mean (sd)	3.8 (2.5)	4.0 (3.0)	3.5 (2.4)	0.51
Religiosity				
Frequently or Never	66.7%	73.3%	59.3%	0.26
Occasionally	33.3%	26.7%	40.7%	
Months on dialysis, mean (sd)	--	0	22.5 (36.1)	<0.001
Physical Composite Score, mean (sd)	40.9 (10.1)	41.7 (11.1)	39.9 (9.1)	0.50
Mental Health Composite Score, mean (sd)	51.6 (9.2)	50.6 (7.6)	52.8 (10.7)	0.38
Domain Specific Risk-Taking Scale, mean (sd)	11.7 (3.9)	12.1 (4.0)	11.4 (3.9)	0.51
Ethical	1.6 (0.7)	1.6 (0.6)	1.5 (0.7)	0.78
Financial	2.2 (1.0)	2.1 (0.9)	2.2 (1.2)	0.75
Health	1.9 (0.9)	1.9 (0.8)	1.8 (1.0)	0.73
Recreational	2.0 (1.3)	2.1 (1.4)	1.8 (1.1)	0.40
Social	4.2 (1.5)	4.4 (1.5)	4.1 (1.5)	0.47
Visits before survey administration				
Nephrologist	91.2%	10.0%	90.0%	1.0*
Surgeon	87.7%	13.3%	86.7%	1.0*

Social worker	79.0%	20.0%	80.0%	0.84
Has a living donor	59.7%	66.7%	51.9%	0.26

* Fisher's exact test used

Table 2: Univariate Analysis- Variables associated with willingness to accept ESRD risk

Variable	Odds Ratio	95% CI	p-value
Gender			
Female	--	--	--
Male	0.70	[0.27, 1.83]	0.46
Age	0.94	[0.90, 0.98]	0.009
Race			
Non – African American	--	--	--
African American	2.48	[0.88, 6.94]	0.08
Hispanic	0.72	[0.13, 3.94]	0.70
Education			
High school or less	--	--	--
Some college	0.88	[0.31, 2.54]	0.82
Masters or Doctorate	1.09	[0.27, 4.32]	0.91
Income			
Less than 35k	--	--	--
35K- 100K	1.81	[0.53, 6.17]	0.34
More than 100k	1.19	[0.26, 5.52]	0.83
DK, prefer not to say, other	3.82	[0.53, 27.30]	0.18
Employment Status			
Employed	--	--	--
Not employed for wages	0.61	[0.21, 1.81]	0.37
Retired	0.56	[0.15, 2.11]	0.39
Receiving SSI or SSDI	0.55	[0.19, 1.60]	0.27
Social Capital	0.95	[0.78, 1.16]	0.62
Religion			
Never or Frequently	--	--	--
Occasionally	0.37	[0.13, 1.07]	0.07
Living Donor Identified	5.74	[1.95, 16.88]	0.002
Currently on dialysis			
No	--	--	--
Yes	0.48	[0.18, 1.26]	0.14
Time on dialysis	1.00	[0.98, 1.02]	0.86
SF-12			
Physical score	1.00	[0.95, 1.05]	0.98
Mental score	1.00	[0.95, 1.05]	0.97
DOSPERT	1.01	[0.89. 1.15]	0.86
Ethical	0.94	[0.46, 1.92]	0.85
Financial	0.88	[0.55, 1.40]	0.59
Health	1.27	[0.73, 2.20]	0.40
Recreational	1.19	[0.80. 1.76]	0.39
Social	1.02	[0.73, 1.40]	0.93
Survey timing			
Nephrology	2.58	[0.43, 15.48]	0.30
Surgeon	2.24	[0.50, 10.19]	0.29
Social Worker	0.87	[0.27, 2.79]	0.81

Table 3: Multivariate Analysis - Characteristics associated with increased willingness to accept risk of ESRD

Variable	Odds Ratio	95% Confidence Interval	p-value
Age	0.97	[0.91, 1.03]	0.37
Race			
Non – African American	-	--	--
African American	3.99	[.01, 7.97]	0.65
Interaction African American*age	0.995	[0.88,1.12]	0.94
Religion			
Never or Frequently	-	--	--
Occasionally	0.48	[0.15, 1.60]	0.23
Living Donor Identified	5.88	[1.58, 21.92]	0.008
Currently on dialysis			
No	--	--	--
Yes	0.51	[0.17, 1.54]	0.23

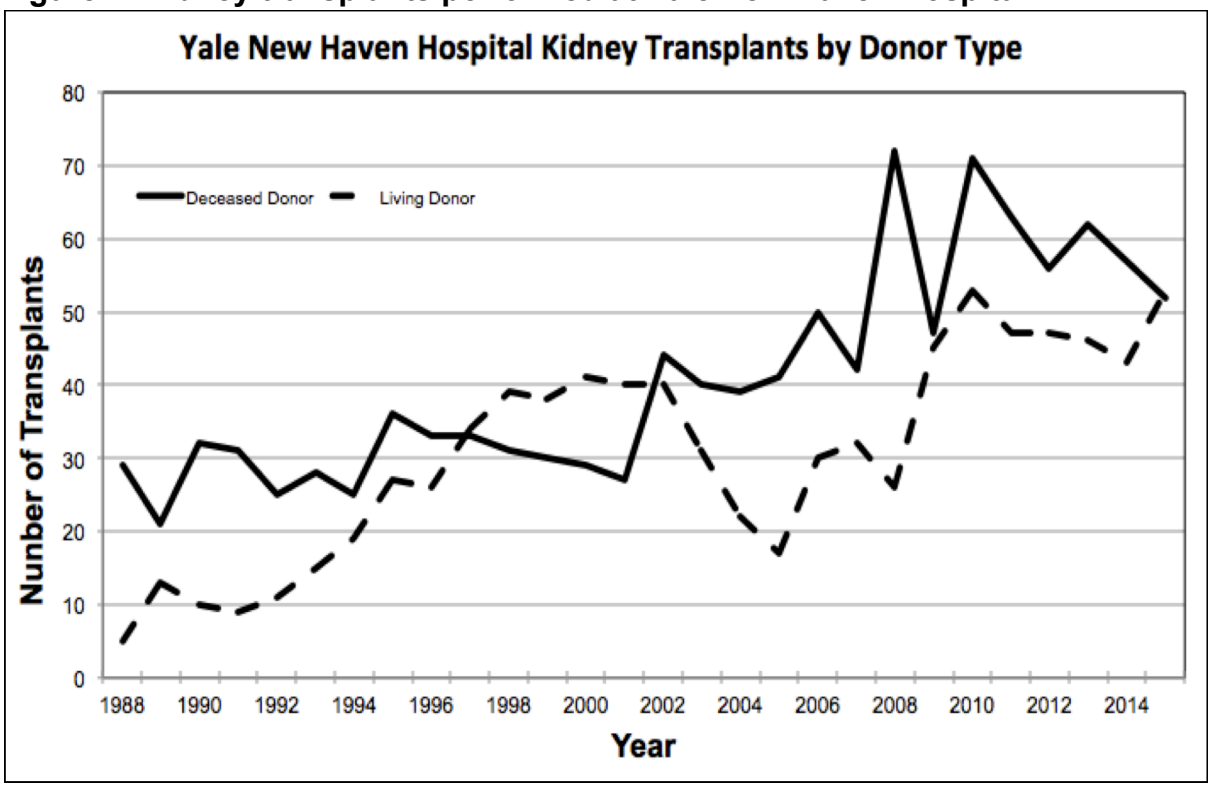
Table 4: Reasons for Limiting Risks to Living Kidney Donors

Code	How the code was used	Number of participants	Representative quotation
Concern for donor	concern for a living donor's welfare	25	"I just believe that they're giving up something that – out of their body and they wouldn't be the same as they was before they gave it up, so there's possibly they're going to have complications because of this."
Family or friend donating	more risk averse if their family or friend was a donor than if a stranger was the donor	6	"Although I have friends that would be willing to donate, but I never brought it up. I never asked them. I just feel uncomfortable getting help from my family or friends or – it's easier from somebody I don't know."
Deceased donor kidney option	deceased kidney transplant was an alternative	4	"I wouldn't want to do that to someone because there's other ways out there. Even if I had to stay on dialysis longer, I'm not going to want to put somebody who's helping me at risk and they can't do anything for themselves."
Responsibility for donor	Participants noted that they would feel responsible if an adverse event were to happen to a donor as a result of donation	3	"And when it comes to somebody else, it's hard enough making a decision on your own life, okay? … So for me to try to do that for somebody else, I just – it's not something I'm comfortable with…. That's somebody's life – that's just – I'm the one with the problem. To depend on somebody else to correct that problem for me based on their own life, the risk that they have to take – to me that one dot – that's too many, one dot too many right now….. to put somebody else at risk? Do I want to do that or do I want to accept that responsibility at this point in my life? No, I don't."

Table 5: Reasons for Accepting Risks to Living Kidney Donors

Reason	How the code was used	Number of participants	Representative quotation
Donors are healthy	living donors were healthy and thus, faced lower risks	7	**"**And the fact that if they were able to give the kidney in the first place they were probably very healthy. And so they wouldn't have a lot of other issues…"
All surgery has risk	all surgical procedures have some risks	5	"I've been through so many surgeries there but he's always explaining the complications and everything like that, so there is risk in any type of surgery."
UNOS priority	donors who developed ESRD post-donation would receive higher priority on the UNOS waitlist	4	"Well I was thinking they might get kidney failure in their remaining kidney, but they would already know what they need to do to be able to go through the process to get on the transplant list themselves. And then…people who had donated a kidney might get a priority on the list."
Recipient need	recipient need for a kidney transplant justified the donor risk	2	"So I have to be willing to accept those risks if I'm willing to take a kidney. I wish I didn't have to, but do or die for me."

Figure 1: Kidney transplants performed at Yale New Haven Hospital



Source: Organ Procurement and Transplantation Network, US Dept. of Health & Human Services

Figure 2: Sample frame

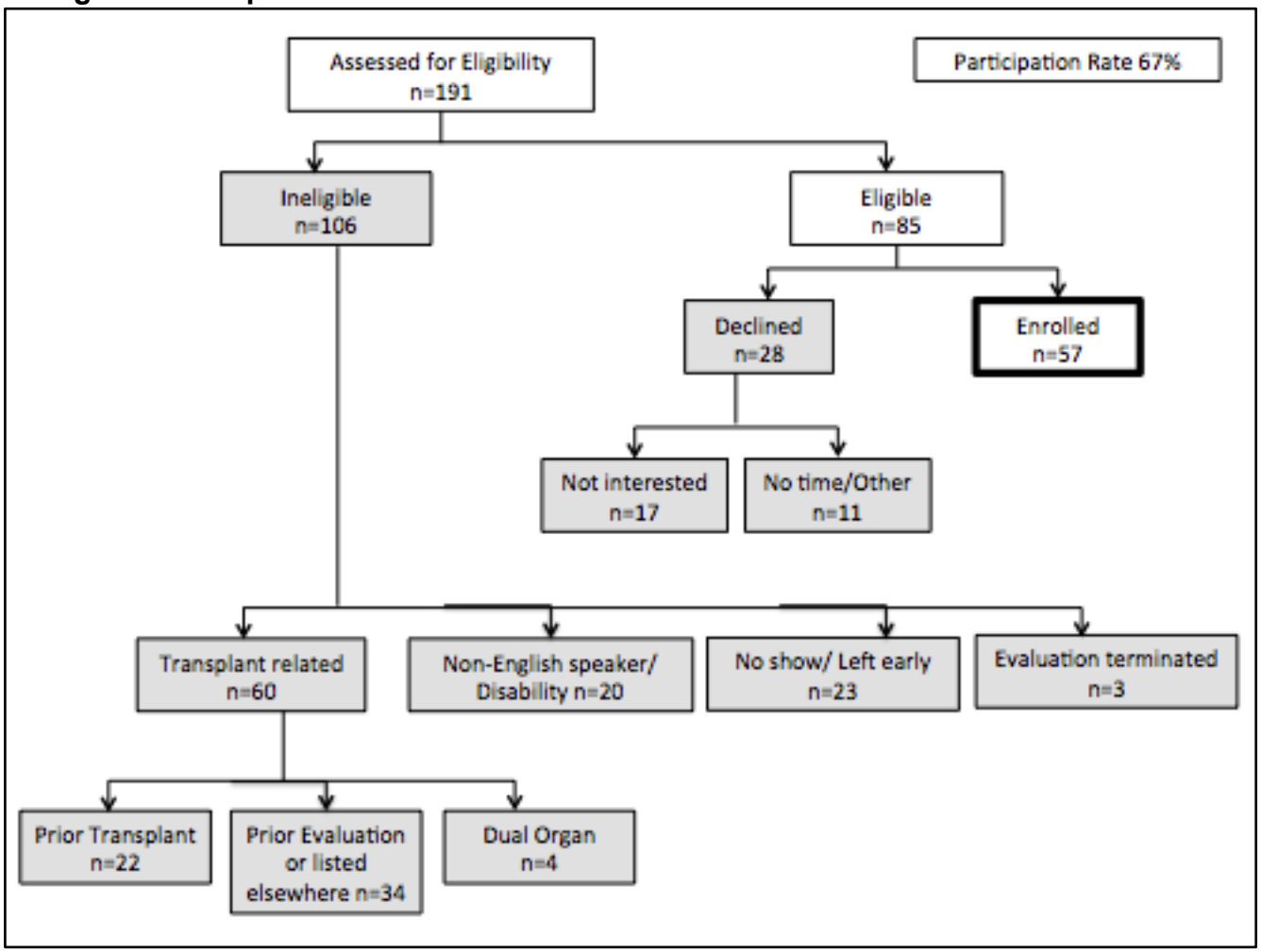


Figure 3: Distribution of Transplant Candidates' Maximum Risk Acceptance