

Web-based requests for living organ donors: who are the solicitors?

Rodrigue JR, Antonellis T, Mandelbrot DA, Hanto DW. Web-based requests for living organ donors: who are the solicitors? Clin Transplant 2008; 22: 749–753. © 2008 Wiley Periodicals, Inc.

Abstract: Websites have emerged to highlight the plight of patients awaiting kidney transplantation and to match them to potential good Samaritan living donors. Little is known about the patients who choose to solicit living donors online, so we examined the 224 profiles of potential kidney transplant recipients who registered on one donor matching website. The number of patients soliciting a living kidney donor is less than 0.5% of those who are awaiting kidney transplantation in the United States. Other than blood type, region, and gender surprisingly few sociodemographic and medical details were posted with most solicitation profiles. The considerable variability in what information is provided in patient profiles suggests that we know very little about who the solicitors are and further highlights one of the inherent ethical problems with public solicitation of living donors. Specifically, in some instances, a Good Samaritan's pursuit of living kidney donation may be based less on information potentially relevant to transplant outcome and more on the persuasiveness of the appeal.

James R. Rodrigue^a, Timothy Antonellis^a, Didier A. Mandelbrot^b and Douglas W. Hanto^c

Departments of ^aPsychiatry, ^bMedicine and ^cSurgery, The Transplant Center, Beth Israel Deaconess Medical Center, Boston, MA, USA

Key words: ethics – kidney transplantation – living donation – public solicitation

Corresponding author: James R. Rodrigue, PhD, The Transplant Center, Beth Israel Deaconess Medical Center, 110 Francis Street, LMOB-Suite 7, Boston, MA 02215, USA.

Tel.: 617-632-9821; fax: 617-632-9820; e-mail: jrrodrig@bidmc.harvard.edu

Accepted for publication 29 May 2008

There are more than 75 000 individuals awaiting kidney transplantation in the United States (1). While recent efforts to increase deceased organ donation rates and to expand deceased donation criteria are promising, many patients continue to experience long waiting times and high morbidity and mortality while waiting. Live donor transplantation offers patients the opportunity to avoid long waiting time and to enhance post-transplant outcomes (2). Indeed, this is the preferred option now at most transplant centers and 38% of all kidney transplants in the US are now performed using living donors (1).

However, not every patient has living donors available to them, because of social isolation, medical or psychiatric contraindications for potential donors to undergo surgery, or unwillingness of family members and friends to consider living donation. Moreover, patients often are very reluctant to ask relatives about kidney donation because of concerns about donor health, direct and indirect financial costs of donation, relationship issues, and guilt (3, 4). For these reasons, and the need for

more organs, websites have been developed that attempt to highlight the plight of those awaiting kidney transplantation and their need for living donors. Individuals can read patient profiles and if interested, establish contact with the patient and determine whether to pursue living donation on behalf of that potential recipient. Such Good Samaritan donors are rare (71 in 2005 and 68 in 2006 in the United States) (1) but they represent a source of hope for patients who do not have potential living donors in their family or social networks or who do not want to place the health of family members at risk. Ethical questions have been raised about the online solicitation of living donors (5, 6). Also, there are concerns about this practice impairing public trust in the organ allocation system and thus indirectly reducing the total number of living and deceased kidneys donated. However, donor-recipient matching services do not currently violate existing organ allocation policies.

Little is known about the patients who choose to solicit living donors online. What patients choose to reveal about themselves – either personally or

medically – may potentially influence prospective living donors. The purpose of this study was to examine the sociodemographic characteristics and profiles of patients who registered on one recipient-donor matching website in the US. This site was chosen because it is the largest recipient-donor matching website and it has been widely profiled and debated in the transplant community and mainstream media.

Methods

The patient profiles on the recipient-donor matching website were examined over a 48-h period by two independent reviewers. These profiles are posted by patients, their physician, or a designated patient representative and are readily available to the general public. Profiles contain basic sociodemographic information and a description of the patient's medical circumstances, which is written by the patient or his/her designate. In addition, patients can upload a picture of themselves. A fee is required for patients to register their profile, although it can be waived or reduced if patients are unable to afford the membership.

Sociodemographic and medical information was gathered and recorded by our two reviewers. In addition, each description of the patient's circumstances was reviewed and certain content was recorded as being present or absent. In particular, we were interested in capturing the length and reading level (Flesch Kincaid grade level) of the patient descriptions and what aspects of their medical or personal characteristics patients chose to highlight.

The Beth Israel Deaconess Medical Center's Institutional Review Board approved the study procedures. However, it was noted by our legal department that specific reference to the website by name may violate the website's terms and conditions.

Descriptive statistics were calculated for sociodemographic, medical, and profile characteristics. All data were entered and analyzed using the Statistical Package for the Social Sciences database (SPSS, Version 14, Chicago IL, USA).

Results

Reviewer agreement

All two hundred twenty-eight active patient profiles on the website were examined by both reviewers. Almost all patients ($n = 224$, 98%) were seeking a living kidney donor. The four patients (2%) who were soliciting a living liver

donor were excluded from subsequent analysis. For the 24 variables coded from the profiles, correspondence between the two reviewers ranged from 75% to 100%. The two reviewers resolved discrepancies in coding by reviewing the profile together and then discussing the variable(s) in question until complete agreement was reached.

Patient sociodemographics

Table 1 lists the sociodemographic characteristics of the 224 kidney patient profiles we reviewed. Both genders were equally represented (52% male) on the website. Mean age, available for 141/224 (63%), was 49.0 ± 12.7 yr, with a range of 21–78 yr. The majority (78%) were over 40 yr old. Of those who provided racial background information ($n = 91$, 41%), the majority (65%) were white. Marital status was obtained for 120 (54%) patients, with the majority ($n = 81$, 68%) being married. Most patients ($n = 128$, 57%) did not provide information regarding their employment status. All United Network for Organ Sharing (UNOS) regions were represented (Table 2), with fewer patients from Region 6 ($n = 5$, 2%) and the most patients from Region 5 ($n = 41$, 18%). Twelve patients (5%) resided outside the United States.

Table 1. Patient sociodemographic characteristics (N = 224)

	n (%)
Sex	
Male	116 (51.8)
Female	103 (46.0)
Unknown	5 (2.2)
Age, yr	
21–30	11 (4.9)
31–40	20 (8.9)
41–50	49 (21.9)
51–60	31 (13.8)
> 60	30 (13.4)
Unknown	83 (37.1)
Race	
White	59 (26.3)
Black	12 (5.4)
Hispanic	9 (4.0)
Asian	9 (4.0)
Other	2 (0.9)
Unknown	133 (59.4)
Married	
Yes	81 (36.2)
No	39 (17.4)
Unknown	104 (46.4)
Employed	
Yes	44 (19.6)
No	52 (23.2)
Unknown	128 (57.1)

Table 2. UNOS region of patients

UNOS region	n (%) on website	% of listed patients in region
1	13 (5.8)	0.53
2	24 (10.7)	0.23
3	28 (12.5)	0.28
4	9 (4.0)	0.14
5	41 (18.3)	0.23
6	5 (2.2)	0.27
7	19 (8.5)	0.30
8	21 (9.4)	0.66
9	30 (13.4)	0.48
10	10 (4.5)	0.18
11	9 (4.0)	0.14
Outside US	12 (5.4)	
Unknown	3 (1.3)	

Table 3. Patient medical characteristics (N = 224)

	n (%)
Blood type	
A	61 (27.2)
B	38 (17.0)
AB	8 (3.6)
O	107 (47.8)
Unknown	10 (4.5)
Previous transplant	
Yes	34 (15.2)
No	79 (35.3)
Unknown	110 (49.1)
Waiting time, months	
< 12	5 (2.2)
12–24	19 (8.5)
25–36	9 (4.0)
37–60	7 (3.1)
> 60	6 (2.7)
Unknown	178 (79.5)
Dialysis	
Yes	161 (71.9)
No	17 (7.6)
Unknown	46 (20.5)

Patient medical characteristics

Table 3 presents patient medical characteristics. Nearly half (n = 107, 48%) had blood type O. Thirty-four patients (15%) reported a prior transplant. Of those who reported how long they have been waiting for a transplant (n = 46, 21%), the mean waiting time was 35.0 ± 28.7 months, with a range of three months to 12 yr. The majority of patients (n = 161, 72%) were on dialysis.

Profile descriptions

On average, profiles had been available on the website for 169.3 ± 186.6 d (median 87 d, range

1–781 d). Most profiles (n = 189, 84%) were written in 1st person. When written in 3rd person, it was usually an adult child (n = 12, 33%) or spouse (n = 8, 22%) who prepared the donor solicitation. The length of patient descriptions varied considerably, with a mean of 202.0 ± 161.9 words and a range of 3–995 words. Mean reading level was 7.8 ± 4.0 grade. About one-third (n = 88, 39%) included a personal photo with their profile. Slightly more than half of the patients (n = 124, 55%) did not mention whether anyone known to the patient had already been evaluated as a potential living donor. However, 99 patients (44%) specifically stated that a family member or friend had been evaluated and ruled out as a potential donor. Sixty-one patients (27%) referenced God or another deity in their description and 16 (7%) identified themselves as the sole provider for minor children.

Discussion

Patients in need of kidney transplantation are encouraged to talk to others about possible living kidney donation to avoid long waiting times for a deceased donor organ and to enhance long-term outcomes. For a variety of reasons, some patients have chosen to solicit living donors from the general public using electronic media. The number of such patients is very small; > 0.5% of the 72 134 registered candidates awaiting kidney transplantation at the time of our review.

As transplant waiting times continue to increase, it is conceivable that more patients will consider this option. However, we suspect that most transplant candidates do not know that the public solicitation of living donors exists and is a potential option for them. We are unaware of any studies that have specifically examined patients' awareness of and attitudes toward websites designed to help them find suitable living donors. Even if more patients were informed of this type of online service, it is not entirely clear that transplant programs will accept publicly solicited donor-recipient pairs. In a recent survey of US kidney transplant programs (7), 70% of programs stated that they would not evaluate publicly solicited living donors. While the public solicitation of living donors does not violate existing national policies, some survey respondents expressed concern that such practices may lead to discrimination, favoring those who are more educated and wealthier, while exploiting potential donors and recipients.

Most patients on the website we reviewed are on dialysis and have O blood type. This is not

surprising considering the effects of dialysis on quality of life, as well as the relatively long waiting times for patients with O blood type. Currently, 52% of all wait-listed kidney patients have O blood type and the median waiting time is nearly twice that of those with A blood type (AB blood type yields the shortest waiting time) (1). Perhaps these patients feel more desperate in their search for a living donor, especially if they do not have any other living donor options.

One might anticipate that UNOS regions with longer waiting times for kidney transplantation would see more patients soliciting publicly for living donors. However, all regions are represented on the website we reviewed. While patients from Regions 5 (Arizona, California, Nevada, New Mexico, Utah) and 9 (New York, western Vermont) comprise nearly one-third of the website registrants, this may simply reflect high patient volume in these two regions. Region 8 (Colorado, Iowa, Kansas, Missouri, Nebraska) actually has the highest proportion of listed patients registered on the matching website, although it is still less than 1%.

Other than blood type, region, and gender, surprisingly few sociodemographic and medical details were posted with most solicitation profiles. Thus, we are unable to answer the question we posed in the title, "Who are the solicitors?" Considering that 37–59% of patients did not provide certain sociodemographic information, we have a limited picture of who the solicitors are. The information we did obtain suggests that, as might have been expected, the proportion of patients who are white or employed is higher than among the general waiting list population. Patients may omit certain personal or medical characteristics for a variety of different reasons. Some patients may question the relevancy of certain characteristics (e.g., marital status), whereas others may be concerned about how certain features (e.g., age, race, transplant waiting time, whether family members had been evaluated for donation) may contribute to bias or discrimination among potential donors.

We have very little information about what patient factors are important to potential living donors who pursue living donor evaluation in response to public solicitation messages. Good Samaritan donors appear to be motivated by altruism and spiritual beliefs (8, 9), the latter perhaps reflected in the spiritual and religious inferences we found throughout many of the patient profiles. However, considering the variability in what information is provided by or about patient, a Good Samaritan's pursuit of living kidney donation via this type of website may be

based less on information potentially relevant to transplant outcome and more on the persuasiveness of the appeal. Anecdotally, a patient from our transplant center recently asked for our guidance in the preparation of a profile for the website we reviewed. She stated her intention to hire a marketing consultant to develop a profile that would be most enticing to potential living donors. She elected not to provide information about her ethnicity or to post a photograph of herself on the website, believing that certain features (e.g., level of attractiveness, obesity, race) would lead to fewer donor inquiries. Such selective disclosure of sociodemographic and/or medical information – apparently at the suggestion of a consultant – to increase the likelihood of a favorable public response is concerning. It is not surprising that patients will present themselves in the most favorable light while omitting characteristics that they perceive as undesirable, as to do otherwise might reduce their success in attracting a suitable living donor. However, the transplant community has worked diligently for years to ensure that social worth and bias are removed or otherwise minimized from patient selection decisions, yet we passively accept such social worth judgments by Good Samaritan donors in the context of public solicitation.

If one accepts that, as the waiting list grows, more and more patients will consider the public solicitation of living donors via websites like the one we reviewed, it is imperative that we begin to ask – and answer – some key questions. What information is considered minimally and ethically necessary for patients to include in a public solicitation profile to assist potential Good Samaritan donors in making an informed choice about whether to initiate contact? What proportion of patients who register on a recipient-donor matching website receive donor inquiries, have prospective donors who undergo evaluation, and have live donor kidney transplants? How long must a profile be posted before donor inquiries are received and how many such inquiries must be received before an evaluation is initiated? Are there any psychological risks for the patient in posting a profile on a website? Perhaps most pertinent to the current study, are there patient characteristics that are highly predictive of receiving donor inquiries? The answers to such questions are essential for evaluating the efficacy, efficiency, and acceptability of recipient-donor matching websites.

Conflicts of interest

There are no conflicts of interest to report.

References

1. UNITED NETWORK FOR ORGAN SHARING. <http://www.unos.org> (accessed on August 15 2007).
2. MEIER-KRIESCHE HU, KAPLAN B. Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: a paired donor kidney analysis. *Transplantation* 2002; 74: 1377.
3. WATERMAN AD, STANLEY SL, COVELLI T et al. Living donation decision making: recipients' concerns and educational needs. *Prog Transplant* 2006; 16: 17.
4. ZIMMERMAN D, ALBERT S, LLEWELLYN-THOMAS H, HAWKER GA. The influence of socio-demographic factors, treatment perceptions and attitudes to living donation on willingness to consider living kidney donor among kidney transplant candidates. *Nephrol Dial Transplant* 2006; 21: 2569.
5. HANTO DW. Ethical challenges posed by solicitation of deceased and living organ donors. *N Engl J Med* 2007; 356: 1062.
6. TRUOG RD. The ethics of organ donation by living donors. *N Engl J Med* 2005; 353: 444.
7. RODRIGUE JR, PAVLAKIS M, DANOVITCH GM et al. Evaluating living kidney donors: relationship types, psychosocial criteria, and consent processes at US transplant programs. *Am J Transplant* 2007; 7: 2326.
8. MORRISSEY PE, DUBE C, GOHH R et al. Good samaritan kidney donation. *Transplantation* 2005; 80: 1369.
9. JACOBS CL, ROMAN D, GARVEY C et al. Twenty-two non-directed kidney donors: an update on a single center's experience. *Am J Transplant* 2004; 4: 1110.