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Solicited kidney donors: Are they coerced?

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Abstract

Most non-directed donors (NDDs) decide to donate on their own and contact the transplant centre directly. Some NDDs decide to donate in response to community solicitation such as newspaper ads or donor drives. We wished to explore whether subtle coercion might be occurring in such NDDs who are part of a larger community. One successful organization in a community in Brooklyn, NY, provides about 50 NDDs per year for recipients within that community. The donors answer ads in local papers and attend donor drives. Herein, we evaluated the physical and emotional outcomes of community-solicited NDDs in comparison to traditional NDDs who come from varied communities and are not responding to a specific call for donation. An assessment of coercion was used as well.

Keywords

living donor transplantation; quality of life; surgery

BACKGROUND

Studies of non-directed donors (NDDs) have shown comparable psychosocial functioning to traditional donors who donate directly to someone they know.[1] These NDDs came forward on their own unsolicited. Some NDDs decide to donate in response to billboard ads, Facebook postings, tweets on Twitter or through meetings at houses of worship. All of theses methods are completely legal although not everyone in the population has complete access to them such as people that cannot afford ads or do not have internet access. It may favor the well educated or those with financial resources.[2] Some have cautioned that online postings can be a sort of 'beauty contest' trying to attract donors and question its ethics.[3] Nevertheless, it remains unregulated but legal. We set out to explore whether solicited

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NDDs that are part of a close community might experience subtle coercion. One successful organization in Brooklyn, New York, serving an orthodox Jewish population provides about 50 NDDs per year for recipients within that community. Typically, a newspaper ad was used to invite people to attend a donor drive in order to help select a donor for a recipient that does not have any compatible donors. About 40 potential donors would attend the drive, learn about donation and then have a short medical interview. Blood for ABO and HLA typing was drawn on those potential donors that passed the initial medical screen, which consisted of questions about general health with a focus on diseases such as diabetes, hypertension, kidney stones or a strong family history of these entities. ABO-compatible donors against whom the recipient harboured no donor-specific antibodies were then invited to undergo a formal crossmatch and donor work up. Those not compatible with the recipient in question usually agreed to crossmatch against other potential recipients. The donor evaluation included the usual components of the medical evaluation, social work evaluation plus psychiatric assessment which we require of all NDDs at our centre, solicited or not. Psychiatric assessment of directed donors, as opposed to NDDs, is not usually a requirement at our centre. The NDDs do not know details about their recipients although we do disclose if the recipient has a high risk for a rejection episode or for recurrent disease so as to allow the NDD to make a more informed choice. Although we do not use an ethics committee, we do perform a psychiatric evaluation to test the donors' motivation and if any coercion is occurring. These activities by the Brooklyn community result in about 50 NDD transplants per year to the community with transplants occurring in several New York City area hospitals, some at our own centre. The NDDs meet the recipients after the surgery if both parties agree. Using survey tools, this study evaluated the physical and emotional outcomes of such community-solicited NDDs in comparison with traditional NDDs who come from varied communities on their own volition and are not responding to a call for donation. A survey assessing coercion was used as well. Our centre's Institutional Review Board approved the study.

METHODS

Community NDD donors who responded to ads or attended a donor drive (n = 9) and ended up donating at our centre were evaluated and compared with traditional NDD donors (n = 16) who donated around the same time. Our centre does not use an ethics committee for NDDs, but all NDDS have a psychiatric assessment. The community participants completed surveys 2 years post-donation on average (range 3 months to 6 years). The Short Form Health Survey (SF-36) was used for psychosocial and functional outcomes after donation. Then, the MacArthur Admission Experience Survey-Short Form 1 (MacArthur AES), a validated tool, was used to evaluate coercion. The MacArthur AES assesses coercion and consists of 16 questions with True or False answers and divided into three subscales: Coercion, Pressure and Voice which assess the patients' perception that they are being coerced or the feeling that there would be a negative consequence if they do not comply with donation (Pressure) and that they had a say in the matter of donation (Voice)[4] (Table 1). Sample questions included: 'It was my idea to donate a kidney', 'I felt free to do what I wanted about donating a kidney', and 'My opinion to donate a kidney didn't matter'. The surveys were mailed to patients who were asked to fill them out and returned to us in a self-

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addressed stamped envelope. A second mailing was sent to those that did not respond to the first mailing. Of the surveys sent out, 30% returned filled to us.

Statistical analysis

Descriptive statistics (including mean, standard deviation, median, frequency and percent) were calculated to characterize the traditional and community donors with respect to age, gender, SF-36 psychosocial and functional outcomes (i.e. physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain and general health), and MacArthur Admission Experience Survey outcomes (i.e. perceived coercion, negative pressures and voice). The two-sample *t*-test was used to compare age and SF-36 outcomes between traditional and community donors. The Wilcoxon rank-sum test (for comparing median values between the groups) was used to confirm the two-sample *t*-test findings. MacArthur Admission Experience Survey items could not be compared between the donor groups due to the lack of variability in responses on these measures. Fisher's exact test was used to compare gender between the traditional and community donors. All *P*-values are two-sided with statistical significance evaluated at the 0.05 alpha level. All analyses were performed in SPSS Version 22.0 (SPSS Inc., Chicago, IL, USA).

RESULTS

Community NDD donors and traditional NDD donors in this study were similar in terms of age, race and gender (Table 2). All the participants were Caucasian, and more than half were female. According to UNOS, 66% of live kidney donors are female and 70% are Caucasian (15). On the SF-36 survey, the two groups reported similar physical and emotional well-being after donation ($P = 0.3–0.8$). No statistical significance was found in any of the eight SF-36 sub-groupings (physical functioning, psychological health and social functioning) (Table 3). The MacArthur AES assessed for possible coercion but found none. The two groups did not differ at all, the responses being all identical (Table 4). Pressure to donate or coercion was not felt in either group. Typical responses were ‘No one tried to force me to donate a kidney’ and ‘It was my idea to donate a kidney’, and everyone felt ‘pleased’ after donating the kidney.

DISCUSSION

NDDs do as well after donation as directed donors. In a 2011 study by Rodrigue *et al*., NDDs had similar favourable outcomes to traditional donors donating to a loved one.[1] Similar results were seen in 2014 by Maple *et al*.[5] The aim of this study was to ask: Does community solicitation of NDDs confer a subtle coercion and is the outcome different for both kinds of donors? It seems not.

Although early reports in the literature described instances of pressure on family members to donate a kidney to the ailing relative,[6,7] more recent studies have shown that there was no coercion in kidney donors of all kinds: parents, donors in paired exchange or NDDs.[8–10] Psychosocial assessment of donors is now mandatory to help lower the risk of adverse donor outcomes,[11] and the advent of the independent living donor advocate (ILDA) now helps

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protect potential donors.[12] It is possible that the ILDAs help prevent cases of coercive donations thus lending to an improvement in donor outcomes and less coercion seen in the recent studies.

Public solicitation of kidneys has existed for years and is not illegal. Recipient families wish to attract kidney donors to their loved ones with the use of billboards, newspaper ads and social media. A study by Chang *et al*. described the success of Facebook solicitation: 32% of patients reported a donor coming forward to be tested, and 10% reported an actual donation occurring as a result of Facebook postings.[13] The pages that were most successful had more information about the recipient and about donation in general. It has been suggested that while internet solicitation is here to stay, it should have a higher standard of responsibility and accountability than it currently has.[14]

Our study has limitations, namely its small size, which makes generalization of its findings difficult to make. A larger study with a more heterogenous group of NDDs is needed. Despite a repeated mailing of surveys, only 30% of the patients responded. We were not surprised. In our experience, there is a low follow-up rate for donors, even the very enthusiastic NDDs. They donated, they are healthy and they wish to be left alone. This may partially account for the low donor follow-up rate in the USA in general. Our Community NDDs are a homogenous group of people within a specific community, usually orthodox Jews giving to other members of the faith, and their outcomes cannot be easily generalized to the US population. Another limitation is that this is a recall study, and the patient's perceptions of coercion may have been skewed with the passage of time. Also, there may be a selection bias as all the NDDs in this study were screened psychiatrically 2 months pre-donation, and perhaps those being coerced were denied donation. Nevertheless, we felt that a survey tool post-donation might be useful in assessing coercion.

CONCLUSION

In summary, our study is the first to evaluate community-solicited donors and shows that they fare comparably with traditional NDDs, deriving the same sense of well-being and functioning post-donation. There was no tendency towards experiencing greater coercion in the community-solicited donors.

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Table 1

Macarthur AES coercion tool (adapted to kidney donation)

	True	False	Don't know
1. I felt free to do what I wanted about donating a kidney.	[ ]	[ ]	[ ]
2. People tried to force me to donate a kidney.	[ ]	[ ]	[ ]
3. I had enough of a chance to say whether I wanted to donate a kidney.	[ ]	[ ]	[ ]
4. I chose to come donate a kidney.	[ ]	[ ]	[ ]
5. I got to say what I wanted about donating a kidney.	[ ]	[ ]	[ ]
6. Someone threatened me to get me to donate a kidney.	[ ]	[ ]	[ ]
7. It was my idea to donate a kidney.	[ ]	[ ]	[ ]
8. Someone physically tried to make me donate a kidney.	[ ]	[ ]	[ ]
9. No one seemed to want to know whether I wanted to donate a kidney.	[ ]	[ ]	[ ]
10. I was threatened with commitment.	[ ]	[ ]	[ ]
11. They said they would make me donate a kidney.	[ ]	[ ]	[ ]
12. No one tried to force me to donate a kidney.	[ ]	[ ]	[ ]
13. My opinion about donating a kidney did not matter.	[ ]	[ ]	[ ]
14. I had a lot of control over whether I donated a kidney.	[ ]	[ ]	[ ]
15. I had more influence than anyone else on whether I donated a kidney.	[ ]	[ ]	[ ]
16. How did donating a kidney make you feel? Did it make you feel:			
a. Angry	[ ]	[ ]	[ ]
b. Sad	[ ]	[ ]	[ ]
c. Pleased	[ ]	[ ]	[ ]
d. Relieved	[ ]	[ ]	[ ]
e. Confused	[ ]	[ ]	[ ]
f. Frightened	[ ]	[ ]	[ ]

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Table 2

Demographics

	Community NDD (*n* = 9)	Traditional NDD (*n* = 16)	*P*-value
Age (years)	43	50	0.16
Gender % (female)	66%	56%	0.69
Race % (Caucasian)	100%	100%	–

'–', not applicable.

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Table 3

SF-36 results

SF-36 scores	Community (n = 9)	Traditional (n = 16)	P-value
Physical functioning	99	99	0.58
Role limitations (physical)	94	100	0.35
Role limitations (emotional)	92	98	0.40
Energy/fatigue	80	81	0.78
Psych well-being	87	85	0.77
Social functioning	97	96	0.81
Bodily pain	94	96	0.62
Gen health	95	91	0.30

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Table 4

Macarthur AES (coercion)

MaCarthur subscales	Community (*n* = 9)	Traditional (*n* = 16)	*P*-value
Coercion	0	0	Identical*
Pressure	5	5	Identical*
Voice	1	1	Identical*

*Not enough variability in the coercion, pressures and voice scales to make comparisons between groups. Essentially, everyone responded the same on these scales.