

## Can a Social Work Intervention Reduce Kidney Donor Anxiety? A Pilot Test

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*The purpose of this study is to explore the effect of social work counseling on kidney donor anxiety in Nadiad, Gujarat, India. Thirty potential kidney donors were selected to receive counseling by a nephrology social worker during the kidney donation process, and 30 potential kidney donors were selected for a control group that did not receive counseling beyond the usual course of care. Anxiety was measured using the Comprehensive Anxiety Test. The group that received counseling from a social worker had a statistically significant decrease in their comprehensive anxiety, which was measured prior to kidney donation and at six months after kidney donation, when compared to the control group. These results suggest that counseling by a nephrology social worker during the kidney donation process may lower donor anxiety. This study and future research may help more kidney disease patients receive kidney transplants from living donors in India and beyond.*

When medically appropriate, a kidney transplant from a living donor is the optimal form of treatment for kidney failure (Abecassis et al., 2008; Tarantino, 2000). Compared to dialysis, kidney transplantation is less costly and results in lower morbidity, mortality, and hospitalization (Danovitch, 2008; Tonelli et al., 2011). A living donor kidney transplant (LDKT) also addresses the international phenomenon of a shortage of kidneys for transplant from deceased donors. LDKT is particularly important in countries such as India, where patients are responsible for much of their treatment costs and where there is no national kidney registry for deceased organs for transplant.

Kidney transplant donation from a living donor involves physical discomfort as well as significant surgery and recovery (Browne, 2012). Because of the potential physical and emotional consequences of donating a kidney, transplant centers around the world often require that the donor receive a thorough psychosocial evaluation prior to the donation. For example, in the United States, Medicare requires this to be done in every kidney transplant center (Medicare Program, 2007). In India, each living donor must also receive a thorough psychosocial assessment (Ministry of Law, Justice, and Company Affairs, 1994). These assessments can identify the psychosocial barriers to living donation, and transplant teams can work with potential kidney donors to ameliorate such barriers.

For example, Drotar, Ganofsky, Makker, and DeMaio (1981) found that counseling sessions helped donors and families cope with LDKT, and Kasiske et al. (1996) note that kidney donors found counseling helpful to cope with an unsuccessful LDKT. Nephrology social workers can provide individual counseling to kidney donors and prepare donors for the donation process by offering information, encouraging questions about the surgical procedure and recovery process, and discussing any of the donor's emotional concerns. The social worker stresses donor self-disclosure and openness within the individual donor's comfort level and views the donor with unconditional positive regard.

This paper presents the findings from a pilot study in India that examines the efficacy of counseling on kidney donor anxiety before and after kidney donation. This and future similar research may help ameliorate a portion of the barriers to LDKT and provide a way to encourage more living donor kidney transplantation around the world.

### METHODS

#### *Hypothesis*

Based on the clinical experience of the hospital social workers where this study was conducted, it was hypothesized that providing a tailored social work counseling intervention to prospective living kidney donors will reduce self-reported anxiety compared to donors who receive social work care as usual.

#### *Setting*

This research was conducted at the Muljibhai Patel Urological Hospital in Nadiad, Gujarat, India. This hospital was the first in the country devoted entirely to nephrology and urology, and provides dialysis and kidney transplant services by an interdisciplinary team including master's-level social workers.

#### *Participants*

The participants in the study were 60 individuals who were registered as possible kidney donors at the study site. That is, these individuals had been identified as potential LDKT donors for kidney patients, but they had not yet been formally listed as such.

**Editor's Note:** This work was featured on an award-winning poster at the NKF 2012 Spring Clinical Meetings.

**Table 1.** Frequencies for Demographic Variables

	Control Group (n = 30)		Intervention Group (n = 30)	
	n	%	n	%
<b>Gender</b>				
Male	14	47	15	50
Female	16	53	15	50
<b>Age</b>				
18-35	3	10	12	40
36+	27	90	18	60
<b>Marital status</b>				
Married	24	80	23	77
Single	5	17	7	23
Widowed	1	3	0	0
<b>Education</b>				
No formal education	8	27	5	17
≤ 8 <sup>th</sup> Grade	12	40	7	23
9 <sup>th</sup> – 12 <sup>th</sup> Grade	3	10	6	20
Some college	3	10	5	17
College graduate	4	13	6	20
Professional education	0	0	1	3
<b>Occupation</b>				
Agriculturist	2	7	3	10
Labourer	2	7	2	7
Business owner	0	0	3	10
Salaried Employee	4	13	6	20
Homemaker	15	50	13	43
Student	1	3	2	7
Unemployed	0	0	0	0
Retired	6	20	1	3
<b>Annual income</b>				
< 5,000 rupees <sup>1</sup>	12	40	10	33
5,000 – 10,000 rupees	13	43	9	30
>15,000 rupees	5	17	11	37

Note: There were no significant differences between the control and intervention groups.

<sup>1</sup> = As of March 11, 2013: 5,000 rupees = \$91.95 U.S. dollars

There were no significant differences between the demographic composition of the control and intervention groups (see Table 1). Both the control and intervention groups had about equal numbers of females and males. The predominant relationship of the donor to the transplant recipient in the intervention group (see Table 2) were mothers (33%), brothers (13%), and wives (13%). The predominant recipient relationships in the control group were mothers (27%), sisters (20%), and brothers (20%). The control group had a greater representation of fathers (17%) than the intervention group (7%). In addition, sisters and brothers were more highly represented in the control group than in the intervention group. However, there were no statistical differences in the relationship of the donor to the patient in either group. Both groups had a large percentage of homemakers and salaried employees. The control group had a greater percentage of retired employees (20%) than the intervention group (3%), while the intervention group had a larger percentage of business owners and overall higher incomes than the control group.

**Table 2.** Relationship of Donor to Patient

	Control Group (n = 30)		Intervention Group (n = 30)	
	n	%	n	%
<b>Relationship</b>				
Father	5	17	2	7
Mother	8	27	10	33
Sister	6	20	3	10
Brother	6	20	4	13
Wife	3	10	4	13
Husband	0	0	2	7
Son	0	0	2	7
Daughter	0	0	0	0
Emotionally related	2	7	3	10

Note: There were no significant differences between the control and intervention groups.

The Muljibhai Patel Society for Research in Nephro-Urology ethics committee (Nadiad, Gujarat, India) provided institutional review board (IRB) approval and oversight of this project; this project was deemed exempt from IRB approval from the University of South Carolina (Columbia, SC, USA); the SC authors did not participate in the planning or execution of this study and were involved only with de-identified post-hoc data analysis).

### *Procedure and Design*

Using a between-group design, the participants were randomly divided into two groups (intervention and control), with thirty individuals in each group. See Table 1 for the demographic composition of both groups of participants. Participants in both groups received the hospital's standard kidney donor psychosocial assessment and standard social work interventions that any LDKT donor would normally receive. In addition to the typical course of social work care, the individuals in the intervention group also received additional counseling conducted by a professionally trained social worker aimed at alleviating donor anxiety. Participants in both groups were assured that their participation in the study was voluntary, that it would have no impact on the usual care expected and received at the hospital, and that their responses were confidential.

### *Intervention*

The social workers involved in this study collaborated with their interdisciplinary team experts to create the content of the unique counseling sessions provided to the intervention group. The social work intervention consisted of counseling sessions designed to provide donors with reassurance, repetitive information, and clarification of communication (Drotar, Ganofsky, Makker, & DeMaio, 1981).

In the transplant clinic involved in this study, there are three phases of the kidney donation process. The first phase is at the time of registration; the second phase is prior to kidney donation; and the third phase is six months after donation.

Phase 1 of the kidney donation process occurred at the time of registration. As is typical in this transplant center, both the intervention and control groups received social work counseling from a master's-level social worker (MSW) in phase one. The counseling session consists of a psychosocial evaluation that explores the reasons for donation; the emotional attachment between the recipient and potential donor; the current social support systems; the understanding of kidney donation; mental health or substance abuse issues; the required medical tests and procedure; donor understanding of the LDKT surgical procedure; donor willingness to engage in necessary hospitalization and post-operative recovery; and the ability of the donor to cope in the event of organ rejection. Both the control and intervention groups completed the Comprehensive Anxiety Test (CA Test) during Phase 1, after the counseling session.

Phase 2 of the kidney donation process occurred prior to the actual kidney donation. Only the intervention group was involved in two special counseling sessions from an MSW during this phase. The first counseling session for the intervention group in this phase consisted of expressed appreciation for the participant's efforts and cooperation during the medical testing stage. The participant's feelings and concerns about the approaching kidney donation were explored and validated. The second counseling session for the intervention group in this phase consisted of a discussion of pre-hospitalization issues that may require attention,

such as child care, employment concerns, and financial concerns. Both the control and intervention groups completed the CA Test during Phase 2. The intervention group completed the CA Test after the counseling sessions in Phase 2.

Phase 3 of the kidney donation process occurred after the kidney donation. The first of three counseling sessions by an MSW in this phase took place soon after LDKT surgery for both the control and intervention groups. The focus of this session was to ascertain the donor's level of pain and discomfort, reassure the donor, and encourage the donor to resume daily activities when medically advised. The second counseling session in Phase 3 for the intervention group occurred one month after the LDKT. During this session, the donor and social worker discussed lifestyle changes, such as exercise resumption, sexual activity resumption, hobby pursuits, or the incorporation of meditation or prayer to improve total well-being. If the donor was female, issues concerning future child-bearing were also discussed.

The third counseling session for the intervention group in phase three occurred six months after the LDKT. The recovering donors were encouraged to discuss their perceived state of health as well as that of the kidney recipient. Potential emotional and medical impediments were discussed. In addition, the social worker advised the participants to obtain the medically advised follow-ups and seek counseling in the future if needed. The social worker offered her assistance in obtaining future counseling. Both the control and intervention groups completed the CA Test during Phase 3. The intervention group completed the CA Test after the third counseling sessions in Phase 3. The control group completed the CA Test after the standard (usual care) first counseling session in Phase 3.

### *Measures*

Potential donors in the intervention and control groups completed the Comprehensive Anxiety Test (CA Test) during the three phases of kidney donation. The 90-item CA Test was developed by Sharma, Bharadwaj, and Bhargava (1992) and explores the biological, psychological, and sociological correlates of anxiety. Each item of the CA Test requires a yes or no response. All yes responses are totaled to ascertain the anxiety score, which ranges from 1 (very low anxiety) to 90 (very high anxiety). A high score on the CA Test corresponds to a high level of anxiety experienced by the participant. The reliability of the CA Test was ascertained to be 0.94 using the split-half method (Sharma, Bharadwaj, & Bhargava, 1992). Some examples of the test items include: "Do you always want to keep yourself busy to forget your problems?," "Do you often remain worried?," and "Do you think that life is full of disappointment?" To our knowledge, the CA test has not been used in a nephrology setting (the investigators were unable to find an Indian-specific anxiety inventory that had been used in End Stage Renal Disease); however, this test was chosen because it has been widely used in India to explore anxiety in other chronic illnesses (Khan & Sehgal, 2010).

### Data Analysis

Chi-square testing was conducted to determine the differences between the demographic and relationship variables of the two groups of donors. Independent samples T-tests were performed to examine the differences in the mean anxiety scores of the two groups of donors at each phase of the project.

### RESULTS

The mean scores of the CA Test for the intervention group and control group were compared at the three phases of kidney donation (see Table 3). During Phase 1 (time of registration), both groups were counseled and completed the CA Test to measure participants' anxiety levels. In Phase 1 (pre-intervention), there was no significant difference ( $t = 1.39$ ,  $p = .08$ ) in the anxiety level between the control group ( $M = 37.2$ ,  $SD = 10.6$ ) and the intervention group ( $M = 33.4$ ,  $SD = 10.5$ ). In Phase 2 (pre-transplant), there was a significant difference ( $t = 2.72$ ,  $p = .004$ ) in the anxiety level between the control group ( $M = 37.2$ ,  $SD = 10.1$ ) and the intervention group ( $M = 30.1$ ,  $SD = 10.2$ ). In Phase 3 (post-transplant), there was a significant difference ( $t = 2.78$ ,  $p = .003$ ) in the anxiety level between the control group ( $M = 37.1$ ,  $SD = 9.2$ ) and the intervention group ( $M = 29.8$ ,  $SD = 11.1$ ). In both Phase 2 and Phase 3, the intervention group, which received the social work counseling, had significantly lower anxiety scores than the control group, which received usual care.

**Table 3.** Donor Anxiety Scores

	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>
Phase 1 Registration				
Control group	37.2	10.6		
Intervention group	33.4	10.5	1.39	.08
Phase 2 Pre-transplant				
Control group	37.2	10.1		
Intervention group	30.1	10.2	2.72	.004
Phase 3 Post-transplant				
Control group	37.1	9.2		
Intervention group	29.8	11.1	2.78	.003

### DISCUSSION

This preliminary study suggests that a social work intervention aimed at kidney donors may lessen the anxiety experienced by donors during the donation process (from registration to six months after LDKT). It appears that counseling may reduce kidney donors' fears and anxiety related to the LDKT. Kidney donors reported feelings of increased self-worth and positive regard throughout the counseling relationship. In addition, counseled donors also stated that they experienced empathetic understanding and acceptance from the counselor relationship.

Social work assessments done internationally on living donors for kidney transplants may want to incorporate attention to donor anxiety as a barrier to living donation, and address such anxiety with social work counseling. This work builds on the research done previously by Drotar, Ganofsky, Makker, and DeMaio (1981) and Kasiske et al. (1996) which suggests that counseling kidney donors can promote better outcomes for the donors. Helping donors cope with the significant choice to donate an organ may help promote more LDKT, which are necessary because of a world-wide shortage of organs for deceased donor transplants.

As this was a pilot test, there are limitations to the research findings. Primarily, the generalizability of the findings may be compromised because of the small sample sizes in the control and intervention groups. Also, these findings may not be applicable to a non-Indian population, as the anxiety scale has been primarily used with an Indian population. However, the promising results of this research can prompt further research in India and beyond that explores the impact of social work interventions on decreasing the anxiety of kidney donors and other barriers to LDKT. Future research may also explore the longer-term (more than six months after transplant) impact of such interventions. Future research could also examine the effect of social work interventions on the recovery process after a donation. For example, do such interventions help reduce surgical complications, length of hospitalization, or return to pre-donation level of activities? Finally, additional research can be conducted that explores the relationship between cultural and family belief and values and how they may promote or discourage LDKT.

Kidney donors who experienced counseling during the donation process reported a greater sense of fulfillment from helping someone in need of a kidney. This sense of fulfillment, coupled with an empathetic counseling relationship, appears to have resulted in lower comprehensive anxiety. Therefore, social work counseling may be efficacious in ameliorating the fear and anxiety normally associated with kidney donation.

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