

# **Research Article**

# The Impact of Religion and Spirituality on the Living Kidney **Donation** Process

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#### Abstract

Objective: Living kidney donors have altruistic personality traits, often including religiosity and/or spirituality. There have been no pre- and post-donation studies to determine the psychosocial impact of organ donation on the living donor, nor the impact of R/S on this experience.

Methods: This study provided pre- (1 month) and postdonation (6 months) questionnaires to living kidney donors, including the hospital anxiety and depression scale (HADS), the SF-36 functional assessment and novel questions regarding the donation process.

Results: Complete data were obtained from 157 donors. The donors were primarily female, older, educated, married and employed. R/S was self-reported by 81% of donors, and 64% reported that R/S contributed to the decision to donate. Overall, 80% of donors reported the use of prayer to alleviate concerns, and 56% consulted with clergy. R/S and non-R/S patients had statistically similar levels of anxiety and depression pre- and post-donation. These two groups did not differ in functional status or quality of life.

Conclusions: These results suggest that R/S plays an important role for a large percentage of living organ donors, but that the R/S and non-R/S patients had a similar donation experience with minimal anxiety and depression, with excellent return to their daily routine and with psychologic resiliency.

Keywords: Religion; Spirituality; Living donation; Kidney transplant

#### Introduction

Living donor kidney transplantation offers a viable treatment option for patients with end stage renal disease [1]. Without transplantation, these patients remain dependent on dialysis, have worse quality of life, and potentially have worse survival. Kidney transplantation is dependent upon organ donors for success. Living donors are an important source of high-quality organs. Living kidney donors come from one of three pools: Family members, non-related friends or altruistic living donors who are unknown to the recipient. All organ donors, whether family, friends or altruistic, are typically motivated to donate out of concern for their loved ones, or for other people in general, and are known to possess highly altruistic personality characteristics [2].

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A predominant trait in many organ donors is religiosity and spirituality (R/S). R/S patient characteristics can have positive clinical implications, and health care providers may gain an increased understanding of their patients by recognizing these traits. Collaborative religious coping styles, such as having hope or using prayer, have been associated with increased resilience. These coping mechanisms may facilitate coping in the setting of a major life event, such as preparation for and recovery from a major surgery [3].

This study analyzes a group of living kidney donors using before and after questionnaires to assess their quality of life, resilience, anxiety, and depression. Additionally, concerns specific to major surgery, organ donation and post-operative recovery are included [4]. This data is analyzed to investigate whether correlations exist between R/S characteristics and quality of life indicators, and how depression and anxiety are experienced with the R/S and the non-R/S donors. It is anticipated that these results will indicate if resilience is associated with R/S.

# **Methods**

This study is a prospective analysis of living kidney donors at a single, large U.S. transplant center. A 14-page survey was included in a pre-surgical packet which was mailed to all living kidney donors during the study period [5]. The packets were sent 2 to 4 weeks prior to surgery. A letter was included in this packet inviting the donors to participate in a pre- and post-donation survey. Participation was completely elective and no incentive was offered. Six months following the organ donation surgery, a similar survey was again mailed to each living kidney donor [6].

The surveys included in the packet included the [7] Short Form 36 Version 2 (SF-36), a standardized scale measuring quality of life, the [8] Hospital Anxiety and Depression Scale (HADS), and [9] additional non-validated questions of concerns and worries (Table 1 in Index). The survey began with a general inquiry of demographic information, followed by the SF-36 and the HADS. Additionally, a series of nonvalidated questions was presented in the pre-donation packet only, regarding pre-donation worries scored on a scale from 0 to 9 and potential coping mechanisms to deal with concerns or fears answered with a simple "yes" or "no". The post-donation packet excluded the previous non-validated questions, but instead added additional nonvalidated questions regarding the donation experience [10]. Each packet provided an area in which the participant was free to write in their own responses.

This study used the SF-36V2 (Medical Outcomes Trust and QualitNyMetrics Incorporated). There are unique modifications to the scoring standards for the SF-36, and this study employed the SF-36V2® Healthy Survey Acute, United States (English) scoring system for its ease of interpretation for the reader [11]. Quality of Life was assessed using the well validated SF-36V2 to evaluate resilience, general health and feelings of wellness. The HADS was used in its



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original format and can be found during the analysis of data, participants were categorized as R/S based upon their responses to 3 statements regarding their religious or spiritual faith. Specifically, participants were asked of the importance of their religion or spiritual faith in their decision to donate, their use of prayer to alleviate their concerns and fears, and talking with a spiritual leader to alleviate concerns and fears [12]. Participants who indicated that religion or spiritual faith was 'moderately' or 'very' important in the decision to donate were categorized as R/S. Those who indicated their use of prayer and/or a religious advisor in alleviating concerns or fears were also categorized as R/S.

Data were analyzed using the Statistical Package for the Social Sciences IBM SPSS Statistics 25, IBM Corporation, and Armonk, New York, USA. Statistical analysis of data included chi-square and analysis of variance testing for categorical and continuous variables, respectively. A p-value less than 0.05 were considered statistically significant [13,14]. This study was reviewed and approved by the University School of Medicine's Institutional Review Board and conforms to the ethical guidelines of the 1975 Declaration of Helsinki. Study subjects were informed that by returning the questionnaire, they were consenting to participation in the study [15]. Use of de-identified data was employed throughout the study.

# Results

During the study period (2011-2016), a total of 407 questionnaires were sent to prospective living kidney donors at a single transplant center. There were 157 of these donors which responded to both the pre- and post-donation questionnaires (39%). Due to a printing error, 37 surveys were missing data for 6 non-validated post donation questions on worries and what alleviated donors' worries. All 157 responding participants reported successful kidney donation, with 100% kidney graft function and recipient survival. Among this living donor population, there were 114 women (73%) and 43 men (27%). Mean donor age was 47 years range 22 to 68, SD 12, with 97% being Caucasian. Most donors had at least some college (81%), were married (75%), and employed (82%) at the time of donation. Overall, 87% of living donors were either a family member or friend of the kidney recipient, with 13% being completely unknown to the recipient [16].

Of these 157 living donors, 128 self-identified as either religious or spiritual (R/S) (81%). Of all respondents, 64% reported that their decision to donate was influenced by their faith [17,18]. There were 82% overall who used prayer to alleviate their concerns and/or fears regarding organ donation, and 56% who consulted with a spiritual advisor for that same purpose. A bivariate analysis was performed to compare demographic data among R/S and non-R/S donors. (Table 1) The median age of R/S donors was 48 years, compared to 36 years for non-R/S (p < 0.01). Among married donors, 87% were R/S compared to 65% R/S among non-married donors (p<0.01). Among R/S and non-R/S donor relation to recipient.

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	Number (% of total)	Religious/Spiritual (% within subgroup)	Not religious (%within subgroup)	p-value
Subjects	157	128 (81%)	29 (19%)	
Age in years (median, SD)	47, 12	48, 11	36, 12	<0.01
18 to 30	17 (11%)	65%	35%	0.19
31 to 45	52 (33%)	79%	21%	
46 to 60	74 (47%)	87%	14%	
Older than 60	14 (9%)	86%	14%	
Gender				
Male	43 (27%)	74%	26%	0.16
Female	114 (73%)	84%	16%	
Marital status				
Married	117 (75%)	87%	13%	<0.01
Not married	40 (25%)	65%	35%	
Employment				
Employed	128 (82%)	82%	18%	0.73
Not employed	29 (18%)	79%	21%	
Donor race				
White	152 (97%)	81%	19%	n/a
Black	1 (<1%)	100%	0%	
Other	4 (3)%	100%	0%	
Education status				
High school or less	29 (19%)	86%	14%	0.57

Some college	49 (31%)	82%	18%	
College graduate	44 (28%)	75%	25%	
Post graduate degree	35 (22%)	86%	14%	
Donor relationship to recipient				
Family	86 (55%)	80%	20%	0.53
Friend	50 (32%)	80%	20%	
Recipient unknown to donor	21 (13%)	91%	9%	
Family or friend	136 (87%)	80%	20%	0.26
Unknown to donor	21 (13%)	91%	9%	
Religious or spiritual involvement				
Decision to donate influenced by faith	101 (64%)	100%	0%	
Prayer used to alleviate concerns/fears	125 (80%)	100%	0%	
Consulted with clergy to alleviated concerns/fears	75 (56%)	100%	0%	

**Table 1:** Demographics of study population, stratified by religiosity/spirituality.

Results for the SF-36 functional assessment portion of the questionnaire are presented in (Table 2). All results showed healthy and similar patterns for quality of life indicators. The R/S and non-R/S

study groups really only differed in their reported "vitality," with R/S donor having higher reported mean vitality both pre- and post-donation (p=0.07 and p=0.13). All other comparisons were statistically equivalent [19].

	Pre-donation		Post-donation			
	Religious/Spiritual	Not Religious	p-value	Religious/Spiritual	Not Religious	p-value
(Mean/median)						
Physical functioning	98/100	98/100	0.89	97/100	98/100	0.75
Role physical	99/100	99/100	0.22	98/100	99/100	0.27
Role emotional	97/100	96/100	0.34	98/100	97/100	0.63
Bodily pain	92/100	90/100	0.36	94/100	92/100	0.3
Vitality	78/75	72/75	0.07	75/75	70/75	0.13
Mental health	87/88	85/85	0.19	87/90	86/90	0.46
Social functioning	98/100	99/100	0.53	98/100	96/100	0.4
General health	89/90	87/87	0.38	89/95	88/90	0.75
Physical component	57/58	57/57	0.61	57/58	57/57	0.54
Mental component	64/65	62/64	0.19	56/57	56/56	0.89

Table 2: Living kidney donors overall reported functional status before and after kidney donation.

Results for the HADS anxiety and depression assessment portion of the questionnaire are presented in Table 3. Comparing R/S and non-R/S donors, there were no statistically significant differences in levels of pre- or post-donation anxiety. However, further analysis suggests that R/S donors were more likely to have an anxiety score=0 13% vs

3% pre and 27% vs 15% post. The two groups were similar in their likelihood of experiencing clinical anxiety (score>7) both pre- and post-donation. In analyzing depression, the study groups similarly had essentially no differences in level of depression, likelihood of having a depression score=0, and in experiencing clinical depression. These findings regarding depression are expected, as significant depression

is an exclusionary criterion for living organ donation at our center [20].

	Pre-donation			Post-donation		
	Religious/Spiritual	Not Religious	p-value	Religious/Spiritual	Not Religious	p-value
Hospital Anxiety and Depression Scale						
Anxiety (mean/ median)(range 0 to 21)	3.9/4.0	4.3/4.0	0.46	2.8/2.0	3.3/3.5	0.54
Subjects with anxiety score=0	13%	3%	0.16	27%	15%	0.26
% with any clinical anxiety (score >7)	10%	14%	0.57	6%	5%	0.86
Depression (mean/ median)(range 0 to 21)	1.1/1.0	1.1/1.0	0.95	1.0/0.0	0.5/1.0	0.21
% with depression score=0	42%	38%	0.67	54%	55%	0.94
% with any clinical depression (score >7)	0%	0%	n/a	2%	0%	1

**Table 3:** Overall reported anxiety and depression in living kidney donors before and after kidney donation (religious n=128, non-religious n=29).

Table 4 lists a large number of potential concerns regarding living organ donation that were assessed only in the pre-transplant version of the questionnaire.

level of concern). These questions were generated by our research group and have not been independently validated [21,22]. The R/S and non-R/S groups differed for 3 concerns. The R/S group had a higher level of concern about missing church (p<0.01), whereas the non-R/S group had higher levels of concern about donation interfering with sex life (p=0.05) and concern for medical mistakes in their care (p=0.10).

The respondent is able to assess their level of concern by choosing a score from "0" (no concern) to "9" (highest

Concern	Religious/ Spiritual	p-value
(mean/median; each is scored from 0 to 9)		
General worry	1.9/2.0	0.45
Missing work	2.2/1.0	0.82
Missing chores	1.6/1.0	0.74
Pain after surgery	3.1/3.0	0.96
Missing exercise	2.6/2.0	0.33
Missing church	1.5/0.0	<0.01
Decreased attractiveness	0.6/0.0	0.29
Death during surgery	1.8/1.0	0.58
Future health problems related to this surgery	2.1/1.0	0.75
Future kidney failure for donor	2.1/1.0	0.57
Interference in sex life	0.8/0.0	0.05
Reduced energy	1.7/1.0	0.33
Failure of kidney transplant	3.7/3.0	0.24

Loss of control	1.0/0.0	0.16
Medical mistakes in your care	1.6/1.0	0.1
Loss of income	1.2/0.0	0.14
Inability to get health insurance in the future	1.5/1.0	0.43
Disruption of family relations	0.6/0.0	0.74
Damage to other organs	1.2/1.0	0.14

 Table 4: Pre-donation concerns about organ donation among living kidney donors with stratification by religiosity/spirituality.

Table 5 retrospectively assesses the donation process by presenting a list of subjective concerns and experiences that may have occurred during organ donation. Participants responded with either a "yes" or

"no," and the results are presented as a percentage of donors answering "yes." Among this list of concerns, R/S and non-R/S donors had a very similar experience. Non-R/S donors were more likely to report feeling less attractive after donation (17% versus 8%, p=0.12) and in having less energy after donation 38% versus 18%, p=0.02.

Post-donation self-assessment	Religious/ Spiritual	Not religious	p-value
Time until felt physically recovered (months; mean/median)	2.6/2.0	2.5/2.0	0.87
Given enough information to understand surgery	98%	97%	0.53
Transplant successful	100%	100%	n/a
More pain than expected	19%	24%	0.51
Surgical complications	6%	10%	0.43
Current health is good	98%	100%	0.5
Wish that you had not donated	0%	0%	n/a
Donating made me feel good about myself	97%	100%	1
Enough medical care / attention post donation	92%	89%	0.58
More disruptive of life than anticipated	10%	3%	0.25
Donation caused serious financial problems	3%	0%	1
Emotional let down after transplant	6%	3%	0.56
Feel less attractive	8%	17%	0.12
Mood problems since donation	6%	10%	0.44
Low energy since donation	18%	38%	0.02
Donation caused problems with family relationships	1%	0%	1
Missed more work than expected	4%	3%	0.9
Donation interfered with sex life	4%	3%	0.9
Experienced loss of control around time of donation	6%	3%	0.56
Donation significantly impacted ability to do physical things	6%	0%	0.27

Table 5: Post-donation concerns about organ donation among living kidney donors with stratification by religion/spirituality.

#### Discussion

There are varying definitions throughout the social science and medical literature regarding R/S. For purposes of this study, two common definitions representing both narrow and broad perspectives were considered. In 2012, Koenig defined religion as "beliefs, practices, and rituals related to the transcendent. Spirituality is to be separate from all other things - humanism, values, morals, and mental health, to connect with that which is sacred, the transcended." Spirituality, as defined by Puchalski and Romer, envelopes two main components, faith and religious beliefs, and meaning or spiritual wellbeing.

This understanding allows one to experience a transcendent meaning, but also acknowledges that origins of spirituality can be found in nature, art, music, family or community. Basically, spirituality can be whatever gives meaning or purpose to life.8 Because the broader perspective of R/S is more inclusive, the present study defined donors are being R/S based upon use of prayer or a spiritual/religious advisor, or if R/S faith was important in the decision to donate.

In this analysis of living kidney donors, certain populations are over-represented including women, the middle-aged, and those who are educated and employed. These findings have been reported by multiple international studies.

Through a rigorous screening process, potential donors who suffer from mental, emotional and/or physical challenges are generally rejected, skewing the donor pool not only to the physically healthiest of candidates, but also to those who have socioeconomic and psychological stability. The present study confirms this bias, as the study population was heavily skewed with 81%categorized as R/s which is higher than the 68% of the U.S. population which considers themselves to be highly or moderately religious in a Gallup tracking poll reported in 2016(at the time data collection from this study was completed.

This study, however, seeks not only to quantify the role of R/S in the decision to donate, but also attempts to determine the impact of R/S on the donor experience as they go through the donation process. Quality of life can be defined as finding meaning and purpose in life, which are also constructs of R/S. The transplant literature poses that quality of life is not generally affected by organ donation, and in many instances is improved after donation. Many donors express a willingness to donate again if it were possible, irrespective of complications. They endorse enhanced self-esteem. These quality of life indicators offer strong support for elective donation, and align with the constructs of R/S.

Reported quality of life from these studies show that most donors returned to their previous level of functioning within just 6 months, and in some circumstances exceeded their previous level of functioning. The present study found that the average timeframe for returning to the previous level of physical functioning was 2.6 months for R/S and 2.5 months for non-R/S (p=0.87). In fact, the only statistically significant finding from the SF-36 was with higher 'Vitality' for R/S donors (p=0.07).

Unfortunately, 'vitality' was not defined for the respondent, so the term could be interpreted as emotional, physical, mental or all the above. Perhaps having a religious or spiritual perspective does give someone more vitality, or even the increased perception of vitality, but this cannot be determined from this study. The process of organ donation, with its potential to dramatically improve the quality of life for the recipient, results in increased feelings of one's own sense of purpose and meaning in life for the donor. These feelings may positively impact the donor's ability to return to previous functional status, or to elevate their self-perception. The present study demonstrated strong resilience for all donors in returning to previous level of functioning, but no differences were seen for R/s and non-R/s donors. Thus, this study confidently recognizes a correlation observed with organ donors and healthy resilience levels, though there was no statistical significance between R/S and non-R/S. The demonstrated resilience among living organ donors is likely attributable to the careful screening process required of all organ donors.

In this study, low levels of anxiety were observed during the predonation period, and would be expected of anyone undergoing major surgery. These anxiety levels then decreased post-donation, as expected when the donor returned to their daily routine. Though not statistically significant, R/S patients overall experienced lower levels of both pre- and post-donation anxiety. They were also more likely to have an anxiety score of "0" and were less likely to experience clinically significant levels of anxiety. Possible explanations for these findings may include a sense of peace or confidence that R/S patients place in a higher power or in a source of spiritual 'goodness' to protect and offer them comfort.

Depression scores for all patients both pre- and post-donation were exceedingly low. In fact, 40%-50% of patients had a depression score equal to "0." These findings are not unexpected and likely result from the rigorous screening process. If a potential donor were struggling with clinical depression, they would be rejected from the donation process. However, post-donation clinical depression was detected in 2% of R/S patients compared to none in the non-R/S patients. The etiology of this depression is unknown.

These questionnaires provided a robust list of potential concerns regarding living organ donation. Overall, donors in general did not express significant concerns. Comparing R/S and non-R/S patients, the religious donors were significantly more concerned about missing church, while the non-R/S were significantly more concerned about donation interfering with their sex life and about the risk of medical mistakes. The post-donation questionnaire retrospectively addressed the donation process. Most donors again expressed overall satisfaction with the process, with little difference between the R/S and non-R/s patients. The non-R/S patients did report more concerns about feeling less attractive and about having lower energy after donation.

An important strength of this paper is the fact that data were collected both pre- and post-donation. This is unique in the living organ donor literature. The questionnaire was very thorough, using validated instruments to assess quality of life, anxiety, and depression. Additionally, an extensive list of concerns and experiences were presented to the donor, allowing them to fully report their pre- and post-donation experience. As with any questionnaire based research, however, this study has significant limitations that must be acknowledged. First, the response rate was only 39%. Those responding to any questionnaire are often those that have either a very good or a very bad experience, so that these results may not be reflective of the average organ donor. The population represented in this sample was overwhelmingly Caucasian, female, middle-age, educated, and married. This demographic does represent a large segment of living organ donors, and is consistent with the literature, but certainly does not represent all donors. This cohort of patients was

selected from donors at a single center in a Midwestern U.S. state. This state is demographically homogeneous with a strong religious and conservative presence.

## Conclusion

Living kidney transplantation offers a safe and definitive therapy for patients with end-stage renal disease, and may provide a meaningful way in which family and friends can participate in the care of their loved one. Transplantation allows organ recipients to achieve a higher quality of life, and has the potential to also improve the quality of life for the donor through this life-changing experience. For a large percentage of donors in this study, their spiritual or religious constitution played a role in their decision to donate (64%). Additionally, 82% of donors reported using prayer as a means of alleviating fears or concerns related to the donation process, and 56% actually consulted with a spiritual advisor. This study, therefore, highlights the importance of religion and spirituality in the organ donor population. Awareness of a patient's R/S perspectives may offer valuable insight into how health care providers may support and encourage these patients. In this study, R/S patients did not necessarily differ from non-R/S patients regarding anxiety, depression or quality of life experienced around the time of donation. Likely, most of those people who choose to become organ donors have already self-selected as a group of persons who are high functioning and resilient, with low levels of anxiety and depression. Future studies regarding the organ donation process should generally focus on the immediate pre- and post-donation experience. Quality of life and psychological studies of organ donors after 6-months post-donation are unlikely to be productive because unique life experiences will occur after that time period that cannot necessarily be attributed to being an organ donor.

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