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What's Mine is Yours: Long-Term Experiences of Good Samaritan Organ Donors

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Abstract

This study is a long-term follow-up on the health and quality of life of Good Samaritan living organ donors who donated an average of 10 years ago. Thirteen donors (kidney, liver, and lung) completed 2 surveys. Data from the RAND 36-Item Health Survey showed that for all domains, as well as the physical and mental component summary scales, the Good Samaritan donor outcomes were superior to the general population ($P < .0001$). Data from the European Living Donor Satisfaction Survey (EULID) showed that in all 8 theme areas, the donors reported statistically significant positive reactions as compared to negative reactions. With regard to self-reported health status, there was a strong, positive correlation between the RAND 36-Item Health Survey and the EULID ($n = 13$, Pearson correlation coefficient: 0.874). All but 1 donor reported good, very good, or excellent health status. Although donors overwhelmingly reported positivity about the donation experience, narrative comments about adverse events and recipient death must keep transplant teams alert to these critical areas. Good Samaritan organ donors come to the hospital healthy, give a gift to a stranger, and sometimes leave and linger disabled. Donor teams should be observing, questioning, and responding in an effort to maximize their welfare. This research is unique because investigation of the long-term health and psychosocial outcomes of Good Samaritan organ donors is rare. Existing studies that report long-term outcomes of kidney donors do not separately analyze Good Samaritan donor data from related living donors.

Keywords

living donors, kidney, liver, lung, quality of life

Introduction

Good Samaritan organ donation, the act of giving a living organ to a stranger, is a relatively rare but valuable contribution to the organ pool for kidneys as well as liver, lung, and other tissues (1). The UK's 2014-2015 Annual Activity Report (2) indicates 107 such kidney donations but none for liver or other organs. In 2014, there were 184 kidney and 4 liver Good Samaritan donations in the United States but none for lung or other organs (3). Good Samaritan donation has many other names including nonrelated donation, non-directed donation, anonymous donation, altruistic donation, and benevolent donation (4,5), but the main concept is that the donor and recipient are strangers. This study is a long-term follow-up on the health and quality of life of Good Samaritans who donated an average of 10 years ago (1). This research is unique because investigation of the long-term health and psychosocial outcomes of Good Samaritan organ donors is rare. Existing studies that report long-term outcomes of kidney donors do not separately analyze Good

Samaritan donor data from related living donors (6–8), and thus the resultant pooled data does not allow for exploration of the experiences of these unique donors.

Methods

Participants

The 22 Good Samaritan living organ donors who participated in a prior study on altruism and organ donation (1) were eligible to participate in this follow-up study. These 22 adults resided in United States ($n = 20$), Canada ($n = 1$), and

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Belgium (n = 1) and had been living kidney (n = 16), liver (n = 5), or lung donors (n = 1).

Survey Distribution

In October 2015, the 22 Good Samaritan living organ donors indicated above were e-mailed an invitation to participate in this follow-up study. Those who did not respond were sent a follow-up e-mail, followed by an invitation via postal mail (to rule out the original invitation having been blocked by spam filters). Those who indicated their desire to participate were sent 2 questionnaires: (1) RAND 36-Item Health Survey 1.0 (9) and (2) European Living Donor Satisfaction Survey (EULID) (10). Two participants completed their surveys telephonically due to computer accessibility issues.

Survey Content

The RAND 36-Item Health Survey (version 1.0) is a validated tool that explores 8 health domains: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue (vitality), and general health perceptions. Additionally, one question is focused on perceived change in health. The 36 questions are identical to the SF-36 tool (11), with a slightly altered scoring method. All domains are scored on a scale from 0 to 100, with 100 representing the best possible health status. Physical component summary scores (physical functioning, physically based role limits, bodily pain, and general health) and mental component summary (MCS) scores (vitality, social functioning, mental health, and emotional-based role limits) were also calculated (12,13). Results were compared with the US normative SF-36 data (men and women combined, aged 55-64 years) (14) as this was the most suitable reference range.

The European Living Donor Satisfaction Survey (EULID) is a validated tool consisting of 54 questions that explore 3 spheres of the living donation experience: perception and acceptance of the donation process, quality of life, and psychological well-being. Four EULID questions (#45-48) are identical to 4 questions in the RAND 36-Item Health Survey (version 1.0; #1,32-34). Fifty-two questions are multiple choice with many using a Likert scale response. Two questions are open-ended for narrative responses (How did you experience the recipient's recovery after the transplantation and how is he now? If there are any comments you would like to add or feelings to express that you couldn't explain through the questionnaire, you can write them down here.) The survey also contains 6 demographic questions: age, sex, donation date, relation to recipient, organ donated, and employment status at the time of donation. There is no scoring formula for the EULID, rather 47 questions are grouped into themes and responses categorized according to positivity, negativity, and neutrality (10).

Statistical Analysis

Statistical significance was analyzed using the following methods: 2-tailed unpaired *t* test (GraphPad Software Inc, La Jolla, California); χ^2 , 2-tailed, 2 degrees of freedom (Turner online calculator; Southwestern Adventist University, Keene, Texas); Fisher exact test, 2-tailed (BGI Cognitive Genomics, Shenzhen, China); and Pearson correlation coefficient (Vassarstats, New York). Narrative responses were coded as follows: positive, negative, and neutral/mixed.

Study Approval

The study protocol conforms to the ethical guidelines of the 1975 Helsinki Declaration. The study was approved by the Bond University Human Research Ethics Committee, approval# 0000015353. All donors gave written consent to participate.

Results

Thirteen donors (10 kidney, 2 liver, and 1 lung) agreed to participate in this follow-up study, resulting in a response rate of 59.1% (13 of 22). Their demographics are reported in Table 1. The average age of the participants was 58.8 years (range: 47-70 years; standard deviation [SD]: 7.3) and they averaged 9.9 years since their donation (range: 5-16 years; SD: 3.8). Most (69.2%, 9 of 13) had a 4-year university degree or higher at the time of donation and most (69.2%, 9 of 13) professed a religious affiliation. All are white, non-Hispanic, 61.5% male. All participants are residents of North America (12 United States and 1 Canada).

The RAND 36-Item Health Survey results are shown in Table 2. The US normative SF-36 data associated with age range 55 to 64 years (males and females combined) were selected as the closest match with the study population age range (47-70 years). For all domains, as well as the physical and mental component summary scales, the Good Samaritan donor outcomes were superior to the general population ($P < .0001$).

European Living Donor Satisfaction Survey data are shown in Tables 3 and 4. In all 8 theme areas, the donors reported statistically significant positive reactions as compared to negative reactions. With regard to the open-ended narrative responses (Table 4), negative responses were generally focused on physical complications from donation and hospital follow-up care. "Labor situation at time of donation" data could not be analyzed from the EULID surveys because some participants interpreted the question as asking for a job title or role, whereas other participants interpreted the question as asking for time commitment (full time vs part time). It was not possible to compare these EULID results with other studies because the EULID tool is relatively new and currently there is only 1 study that reports its use (presented data set was incomplete)(7).

Table 1. Donor Demographics.

Donor	Organ	Gender (M/F)	Education at Time of Donation (Degree, Other) ^a	Religion ^a	Donation Year	Current Age (years)	Time Since Donation (years)
1	Kidney	F	Associate arts	None ^b	1999	70	16
2	Kidney	F	Master's	Catholic	2003	57	12
3	Kidney	F	High school	Protestant	2005	65	10
4	Kidney	F	Doctorate	Protestant	2006	65	9
5	Kidney	M	Bachelor's	Catholic	2007	62	8
6	Kidney	F	Bachelor's	Protestant	2007	61	8
7	Kidney	M	Bachelor's	Protestant	2007	50	8
8	Kidney	M	Bachelor's	None	2009	49	6
9	Kidney	M	Master's	Agnostic	2009	47	6
10	Kidney	M	Master's	Protestant	2010	66	5
11	Liver	M	High school	None	1999	63	16
12	Liver	M	Associate arts	Protestant	2005	55	10
13	Lung	M	Bachelor's	Protestant	2000	55	15

Abbreviations: F, female; M, male.

^aData collected during prior project. (1)

^bBelieves in God but reports no religious affiliation.

Table 2. RAND 36-Item Health Survey (Version 1.0) Domain Results.

Domain	Mean (SD), n = 13	US Normative SF-36 Data, Mean (SD) ^a	P Value (Unpaired, 2-Tailed t Test)
Physical functioning	92.7 (18.3)	47.6 (10.6)	< .0001
Role limits due to physical health	80.8 (38.4)	48.3 (10.9)	< .0001
Role limits due to emotional health	100	49.8 (10.7)	< .0001
Energy/fatigue/vitality	73.5 (1.1)	51.2 (10.7)	< .0001
Emotional well-being	88.9 (8.5)	51.3 (10.2)	< .0001
Social functioning	91.5 (22.2)	49.9 (10.7)	< .0001
Body pain	82.9 (27.2)	48.4 (10.9)	< .0001
General health	80.6 (23.0)	49.1 (10.7)	< .0001
Component summary scale			
Physical component summary	84.2 (27.4)	47.4 (10.8)	< .0001
Mental component summary	88.3 (17.4)	51.7 (10.3)	< .0001

Abbreviations: MCS, mental component summary; PCS, physical component summary; SD, standard deviation.

^aMales and females aged 55 to 64, n = 1046; <http://www.sf-36.org/research/sf98norms.pdf>.

Table 3. European Living Donor Satisfaction Survey Data, All Donors.^a

Themes	Positive Responses, %	Neutral Responses, %	Negative Responses, %	Statistical Significance ^{b,c}
Feelings about organ donation (Q1, 2)	84.6	15.4	0	< .0001 ^c
Decision-making (Q3, 4, 8, 21, 22)	95.4	4.6	0	< .0001 ^c
Information received (Q5, 7, 9, 10, 11, 26)	82.1	7.7	10.3	< .0001 ^b
Stress from donation (Q6, 16, 18, 19, 20, 27, 35)	57.1 (less than expected stress)	20.9 (no impact or stress level as expected)	22.0 (stressed)	< .0001 ^b
Protection (Q23, 25, 30, 31, 33)	38.5	41.5	20.0	.0189 ^b
Psychological well-being (Q28, 37, 38, 42, 44)	92.3	1.5	6.2	< .0001 ^c
Social impact (Q24, 29, 32, 39, 49, 50, 51, 52)	43.3	47.1	9.6	< .0001 ^b
Quality of life (Q34, 36, 43, 45, 46, 47, 48)	45.1	44.0	11.0	< .0001 ^b

^an = 13.

^b χ^2 , 2-tailed, 2 degrees of freedom.

^cFisher exact test, 2-tailed.

Table 4. European Living Donor Satisfaction Survey Narratives.

Positive donation experience

"[The recipient is the] mother of 2 post-donation children and went to med school and is a practicing doctor. It [donation] was an honor." (Kidney donor, 8 years postdonation)

"[Donation] is the best thing I have ever done. I would do it again in a heartbeat!" (Liver donor, 16 years postdonation)

"No complications [for donor or recipient]. I consider that a miracle!" (Kidney donor, 8 years postdonation)

"I recovered very quickly with only 2 weeks of real pain (even then, was able to get out although moved very slowly) and no residual effects." (Kidney donor, 8 years postdonation)

Negative donation experience

"My spleen was nicked [during nephrectomy] and I had a splenectomy as well as the kidney donation." (Kidney donor, 9 years postdonation)

"I've been turned into an invalid." (Kidney donor, 5 years postdonation)

"They [hospital] were great before and during the surgery but NO follow-up or concern later." (Kidney donor, 12 years postdonation)

"I miss her [recipient] greatly." (Kidney donor, 6 years postdonation; recipient died 5 years posttransplant)

Neutral or mixed reactions about donation experience

"I am aware that they [recipient] appreciated it a lot but that is all I know." (Liver donor, 10 years postdonation)

"Unfortunately, he passed away [8 years post-transplant], but [I] still enjoy a close relationship to his father and brother." (Lung donor, 15 years postdonation)

With regard to self-reported health status, there was a strong, positive correlation between the RAND 36-Item Health Survey and the EULID ($n = 13$, Pearson correlation coefficient: .874). All but 1 donor reported good, very good, or excellent health status. Five (38.5%) of 13 donors were aware their graft recipient had died. Three (23.1%) donors were unaware of the vital status of their graft or the recipient. The reason for this is these donors never came to know their recipient after donation. Analysis of the mean MCS scores comparing donors with deceased recipients (90.8, SD: 10.7) and alive recipients (82.6, SD: 23.0) finds that both groups have scores well above US norms. The mean MCS for donors with alive recipients was lower than the mean MCS for donors with deceased recipients but not statistically significant ($P = .4904$). Furthermore, this was likely due to 1 donor in the former group enduring severe, chronic disability as a result of donation.

Discussion

Good Samaritan organ donors are a rare and valuable part of the donation community, thus understanding their experience and outcomes is important. Research on the long-term health and psychosocial outcomes of Good Samaritan organ donors is rare. Existing studies that report long-term outcomes of kidney donors do not separately analyze Good Samaritan donor data from related living donors (6–8). The resultant pooled data does not allow for exploration of the experiences of these unique donors. Also, because the pooled data contain data from Good Samaritan donors, it cannot be used as control or comparison data.

Overall, this small study of Good Samaritan donor long-term experiences finds generally positive outcomes for both physical health and quality of life. Donors overwhelmingly reported positivity about the donation experience but narrative comments about adverse events and recipient death must keep transplant teams alert to these critical areas. Specifically, donor teams should use patient experience data to

inform pre- and postdonor care. Health-care workers should take an active stance in soliciting patient narratives (pre-op and post-op) by directly asking donors questions like, *What can I do to improve your stay?* (15) *What can I do to improve your care today?* (16) Although it can be easy to think of Good Samaritans as "superhuman" (1) and living donation as "relatively safe," long-term outcome data shown in this study indicate that negative experiences are indeed occurring in this philanthropic population.

There are many clinical implications. As the experience set grows, educational information for donor candidates should be updated so that the informed consent process has greater accuracy with regard to donation risks (physical, psychological, and financial). Because some Good Samaritan donors eventually discover the identity of their recipients and even develop relationships with them, recipient loss and donor grieving should not be left unattended. Donor team social workers should have psychological and spiritual support services at the ready for these donors, and access should not be limited by financial means. Donor surgery techniques should continue to evolve so as to reduce morbidity and mortality. Postdonation medical care should be accessible for all donors, especially in light of their known future risk of hypertension (17).

Organ donations are a community good, as is giving pre- and postdonation care to organ donors. Although it may not be practical to administer "experience surveys" to all donors pre- and postdonation, all health-care workers have the daily opportunity to learn their patient's experience and potentially improve it, by asking questions (15,16), listening, showing empathy, and taking action. Great outcomes and giving great care should not be assumptions, but rather they require active observation, questioning, and responding. Good Samaritan organ donors come to the hospital healthy, give a gift to a stranger, and sometimes leave and linger disabled. Donor teams should be observing, questioning, and responding in an effort to maximize their welfare.

The current study has several limitations. The sample size is small and as such, this study could be considered a pilot for a future, prospective larger study using the RAND and EULID tools at short-, medium-, and long-term follow-up. Also, there is no baseline or medium-term data for the RAND 36-Item Health Survey or the EULID for this study population. These surveys were not used in the original study of this population (1); however, results are consistent. Additionally, it might not be possible to generalize Good Samaritan donation data to the general population of living organ donors. This is because the motivations of these donors can be very different and this could potentially impact their perceptions of quality of life, satisfaction with life, donation decision-making, stress and well-being, and expectations about donation (1). Also, situational context can impact questionnaire responses; namely, at the time of study participation, one of the donors was recovering from a recent unrelated surgery which could impact responses pertaining to health, fatigue, and quality of life, for example. There is also the possibility that for the donors who did not participate in this follow-up study ($n = 9$), some of them might have declined because of adverse events, thus skewing this sample set toward positive outcomes. It is suggested that the EULID survey be further developed to include a formal scoring formula as well as the demographic question about employment status be clarified.

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Declaration of Conflicting Interests

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