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Satisfaction With Life Among Living Kidney Donors: A RELIVE Study of Long-Term Donor Outcomes

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Abstract

Background—Little is known about living kidney donors' satisfaction with life (SWL) after donation. We compared donors' SWL to previously reported general population samples and investigated predictors of donors' SWL.

Methods—Three transplant centers mailed questionnaires to assess SWL, physical health, optimism, retrospective evaluation of the donation experience, and demographic characteristics to living kidney donors' homes between 2010 and 2012. 2,455 donors who were between 5 and 48 years from the time of their donor surgery completed the questionnaire.

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Charlotte A. Beil - Participated in data analysis

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Results—84% of donors were satisfied with their lives (scores ≥ 20 on the Satisfaction With Life Scale). Donors were at least as satisfied with their lives as previously reported general population samples. After adjusting for physical health, optimism, and demographics, donors' satisfaction with life was significantly associated with donors' recalled experience of donation. Social support and positive effects of the donation on relationships predicted greater SWL. Financial difficulties associated with donation and longer recovery times predicted lower satisfaction with life. Recipient outcomes were not significantly related to donor satisfaction with life.

Discussion—Limitations include the lack of pre-donation SWL data, potential bias in post-donation SWL due to the situational context of the questionnaire, and a sample that is not representative of all US living kidney donors. Nonetheless, strategies focused on improving the donation experience, particularly related to recovery time, financial issues, and social support, may result in greater satisfaction with life after donation.

Keywords

quality of life; kidney donation; satisfaction with life; financial and social support

Introduction

Recently, there has been interest in examining the post-donation quality of life (QOL) of living organ donors (1, 2, 3, 4). Much of this research has focused on health-related QOL (HRQOL) using measures such as the Short Form Health Survey (SF-36). The SF-36 and similar HRQOL measures are appropriate instruments to assess perceived health status in community samples and patients, including living organ donors. Measures assessing other domains of QOL have been developed, but are less frequently studied.

Our study focused on satisfaction with life (SWL), an aspect of QOL that is theoretically and empirically distinct from that measured by HRQOL assessments such as the SF-36. SWL is a psychological, subjective measure of QOL — the cognitive element of subjective well-being (5) — and relates to judgment of one's life relative to one's personal expectations. Two people with the same life circumstances may be more or less satisfied due to differences in their expectations or their perceived gap between their life circumstances and their expectations.

SWL is often measured by the Satisfaction With Life Scale (SWLS; 6). The SWLS ranges from 5 to 35; scores of 20 are considered neutral. Scores on the SWLS tend to be stable over time (5), and are strongly associated with other personality characteristics. For instance, individuals who are optimistic tend to have higher SWLS scores (7).

Although SWL tends to be generally stable, positive and negative life events are related to increases and decreases in SWLS scores (5) and SWL can change after an intervention (8). Therefore, an event as important as kidney donation may be expected to have a lasting impact, positive or negative, on SWL. This study examines SWL in the decades after kidney donation to assess how satisfied donors are and identify factors associated with donor SWL.

Results

Participants donated between 5 and 48 years before study participation and were 24 to 94 years old when they completed the questionnaire. The majority of participants were female (61%), white or European American (93%), and not Hispanic or Latino (98%; Table 1). Most donors were related to their recipients; 41% were siblings, 18% were parents, 13% were children, 9% were spouses, and 5% were other relatives.

SWL Compared to Norms

Donors' SWLS scores covered the entire range of the scale (Figure 1). Eighty-four percent of donors had scores of 20 or above, suggesting they were at least neutral or satisfied with life (9); 16% were dissatisfied with life, as indicated by scores lower than 20.

Donors' SWLS scores averaged 26.2 (SD = 6.7), indicating that the typical donor was in the range of "very satisfied with life" (9). Donors' mean SWLS scores were no different than similarly aged people in a community sample (all age groups $p > 0.01$, [10]). The average SWLS score of donors was significantly higher than two samples of college students (M = 23.5 and 23.7, both $p < 0.0001$, reported by Diener et al [6] and Pavot et al [11]), and outpatients (M = 23.6, $p < 0.0001$, [12]).

Associations with SWL

SWLS scores were related to concurrent well-being (all correlations, $p < 0.0001$, Table 2). Due to high correlations between optimism and mental HRQOL, we narrowed our focus to two of the three measures in multivariable analyses: optimism and physical HRQOL.

The top section of Table 3 shows results from Model 1 using demographics, concurrent optimism, and health to predict donor SWLS scores. SWLS scores were positively associated with optimism and physical health (both $p < 0.0001$). Donors who were married or living with a partner ($p < 0.0001$) or had higher educational attainment ($p = 0.0040$) had higher SWLS scores. Black donors had lower SWLS scores than non-black donors ($p = 0.0041$). Age at questionnaire completion, time since donation, and sex were not significantly related to SWLS scores in the multivariable regression and were not included in subsequent models.

The lower sections of Table 3 show effects of donation experience variables that were significantly related to SWLS scores after controlling for donor characteristics (Model 1), along with approximate wording of the items from the QOL questionnaire. Donors who were more comfortable with their decision to donate had higher SWLS scores ($p = 0.0015$). SWLS scores were higher for donors who recalled that family, friends, or health care providers were supportive (both $p < 0.0001$), and who would donate again ($p = 0.0008$). SWLS scores were also higher for donors who gave more positive ratings about the overall donation experience ($p < 0.0001$), the effect of donation on their lives ($p < 0.0001$), their health ($p = 0.0001$), and their relationship with their spouse or significant other ($p = 0.0011$). If a donor's recipient was still alive, the donor's report of the effect of donation on their relationship was positively related to SWLS scores ($p < 0.0001$).

Donors who reported having problems paying medical or household/routine bills, or financial burden because of donation, had lower SWLS scores at the time of the QOL questionnaire (all $p < 0.0001$). SWLS scores were lower for donors with longer time to return to daily activities ($p = 0.0059$) and stronger agreement with the statement, 'no one paid attention to me' after the surgery ($p < 0.0001$). Those who took unpaid medical leave from work ($p < 0.0001$) or had at least one medical or psychological complication ($p = 0.0026$) had lower SWLS scores. Donors who wished they had not donated ($p < 0.0001$), felt depressed after surgery ($p < 0.0001$), felt pressured not to donate ($p = 0.0002$), or felt pressured to donate ($p < 0.0001$) had lower SWLS scores.

Recipient outcomes were not significantly related to donors' SWLS scores. Donors' reports of recipient vital status, graft status, medical complications, and the effect of donation on the recipient's health were not significantly related to donor SWLS scores.

Qualitative Results

1,153 donors (47%) provided text in response to the question, "Do you have any further comments about organ donation?" Some donors suggested donation had no long-lasting effect on their SWL. For instance, one donor wrote, "Donating my kidney has not changed my life at all." Another donor wrote, "It really did not affect me too much." However, of the 1,153 donors who provided written responses, 141 (12%) wrote text suggesting donation had an impact on their SWL. Of these 141 donors, 119 (84%) said the impact was positive, while 14 (10%) said the impact was negative, and 8 had ambivalent comments (e.g., both positive and negative, or neither positive nor negative connotations).

Many positive comments identified donation as one of the most fulfilling experiences in the donor's life. For example, donors wrote, "Organ donation was the most meaningful event of my life after becoming a father" and "Being able to help my sister was the high point of my life." Other comments indicating a positive association between donation and SWL often focused on benefits to the donor, such as "Donation gave me a sense of direction and purpose for my life" and, "I have more self-esteem after donation than I ever had my whole life" or comments about an enhanced relationship with the recipient. The mean SWLS rating for donors with positive comments was 27.3 (SD = 5.9).

Negative comments focused on questioning whether the decision was actually a good choice and on poor relationships with others. For example, one donor, whose donation to an in-law was not supported by her husband, wrote, "It is very difficult to feel resented for something like this." Another, whose recipient became ill during recovery and died within a year of transplant, wrote "I feel the whole affair was a waste of life, much pain and of course expense." Donors who wrote about negative impacts of donation averaged SWLS scores just above neutral ($M = 21.5$, $SD = 8.8$); their SWLS scores were significantly lower than donors who wrote positive comments ($p = 0.0077$), but did not significantly differ from the overall sample.

Finally, eight donors provided ambivalent text related to their SWL. For instance, one donor wrote, "I think I'm ambivalent about the donation experience. While I am very happy I was able to give my brother more time to live his life, sometimes I question the wisdom of that

decision. His life is a sad one-he continues to have major health problems ... and it's painful to witness.”

Discussion

We examined SWLS scores among living kidney donors up to 48 years after donation. The majority of donors were satisfied (SWLS 20) with their lives, and the respondents were at least as satisfied as previously reported population samples.

Several donor characteristics related to SWLS scores were consistent with prior research in non-donors. Physical health is related to SWLS scores (13); we found that donors' HRQOL was positively associated with SWLS scores. Age was not related to SWLS scores in other studies (12, 14), and was unrelated in RELIVE donors as well. Black donors had lower SWLS scores than white donors, and married or partnered donors had higher SWLS scores than non-married donors, similar to non-donor samples (14, 15).

A novel finding of this study was that several donation experiences were positively related to SWLS scores. These included positive effects of donation on the donor: on their life overall, their health, their relationships with their spouse or significant other and with their recipient. The association between SWLS scores and a positive effect of donation on the relationship with one's recipient confirms previous findings (4). Social support – an indication of strong social networks – was also related to SWLS scores (8). Our measures of social support focused on the donation experience – whether family and friends and the health care providers were supportive. Having support during the time of donation is likely more common among donors who have support throughout life. Transplant centers may wish to pay special attention to evaluating prospective donors' social support networks.

Stressors have been reported to be negatively related to SWLS scores (7); in our sample of donors, we found evidence of this association specific to donors' recollected experience of donation. Financial stressors because of donation were associated with lower SWLS scores. Kidney donors with lower income or low savings may be more likely to face financial hardship in many circumstances, including after their donation. Ideally, donation should not result in an additional financial burden for donors; donors with financial instability are at higher risk for poor psychosocial outcomes (16). A sense of pressure, either to donate or not to donate, was also related to lower SWLS scores. Feeling uncertainty or external demands about a decision that could alter not only one's own life but also the life of another could be a source of stress and may indicate life circumstances that extend beyond the donation experience, such as a lack of social support.

The finding that recipient outcomes were not related to SWLS scores was surprising and important. Other studies have shown that recipient complications were related to lower QOL in liver donors (17), recipient graft loss was related to donor doubt about the donation (18), and recipient death was related to poor donor psychosocial outcomes (19). However, Verbesey et al (4) found that liver donors appeared to be satisfied with the donation regardless of the outcome for the recipient. It may be that when a graft functions for the

recipient, even if only for a brief time, donors view the donation as having a positive impact on the recipient and maintain their own SWL.

The association between donation and SWL was confirmed by qualitative analysis of optional text responses to a general question about donation. Without prompting, 12% of donors who provided additional text described their donation in a way that suggested an impact on their SWL. Whether the other 88% had similar impressions is unclear.

Limitations

This study was cross-sectional, and we have no baseline SWLS data. Although the RELIVE sample is a rich source of information about post-donation QOL, we do not know whether donors' QOL increased, decreased, stayed stable, or fluctuated during and after their donation experience. These results demonstrate the need for inclusion of baseline assessments in future investigations of living donors.

Situational context may influence SWLS scores (5). Individuals were invited to participate in this study because they previously donated a kidney. The knowledge that they were completing the questionnaire because they were living donors may have made the donation surgery and related events more salient at the time that they completed the SWLS. To mitigate this possibility, the SWLS appeared earlier on the questionnaire than additional questions about the donation experience. Nonetheless, any apparent impact of donation on SWL may have been temporarily stronger while donors were completing the questionnaire.

Finally, our sample is not representative of all US living kidney donors. RELIVE donors were less racially and ethnically diverse and more likely to be related to their recipient than the overall US living kidney donor population in recent years (22). However, RELIVE donors did mirror the majority (i.e., female sex) distribution of the US living kidney donor pool. Future studies with a more diverse sample may find additional racial or ethnic effects, and might find that the association between race and SWLS scores is confounded by socioeconomic status.

Conclusions

This study suggests that living kidney donors report satisfaction with their lives on par with or greater than the general population. Donors' reports of experiences related to donation correlated with their current SWLS scores. The association between living kidney donation and SWLS scores appeared to be independent of the outcome for the recipient, perhaps reflecting cognitive dissonance of donation-related experiences. Our study identified features of the donation experience associated with lower SWLS scores, including lack of social support, financial strain, or complications occurring at the time of donation. Additional research is needed regarding the impact of financial difficulties, perceived pressure (both to donate and not to donate), and social support. Additional follow-up care and support for donors at risk for poor outcomes may foster more positive long-term donor SWL.

Methods

All living kidney donors who donated between January 1963 and June 2005 at the three kidney transplant centers in the Renal and Lung Living Donors Evaluation Study (RELIVE) consortium (Mayo Clinic, Rochester, MN; University of Alabama at Birmingham; and University of Minnesota), and who were believed to be alive were eligible as participants in this cross-sectional study (N = 6,909). This study was approved by the IRB at each transplant center and at the University of Michigan.

Between 2010 and 2012, transplant centers contacted donors by mail requesting participation and called donors who did not respond. Donors who consented were sent a packet, including a QOL questionnaire. 3,465 donors were successfully contacted and 2,455 (71%) consented and returned the QOL questionnaire. Baseline information, such as sex, age at donation, and date of donation, was abstracted from medical records. Race and ethnicity were obtained from medical records when donors did not provide this information on the QOL questionnaire. Additional information about study design and data collection is reported by Gross et al (20).

The primary outcome in this study was the SWLS (6). The SWLS sums five items, each rated on a 7-point scale. High reliability of the SWLS has been demonstrated in a variety of sample populations (5); Cronbach's alpha in this sample was 0.90.

The questionnaire also measured concurrent psychosocial characteristics, such as optimism, with the Life Orientation Test-Revised (LOT). The LOT ranges from 0 (least optimism) to 24 (most optimism). Mental and physical health were assessed using the mental component summary (MCS) and physical component summary (PCS) scores of the SF-36 (version 2; higher scores indicate better health), adjusted for sex and age group norms.

In the questionnaire, the QOL and psychosocial scales preceded items assessing donation-related experiences. Most response options were 5-point scales, except three items about recovery time (4 category responses), and yes/no items about medical complications, emotional, psychological, or substance abuse difficulties, recipient outcomes, and specific financial outcomes. Donors were not asked to report surgical complications, though it is possible that some surgical complications may have been reported under the category of medical complications. Donors also reported their marital status and educational attainment at the time of questionnaire completion.

Statistical analyses

We report descriptive characteristics of donors who participated in the QOL survey. Missing values were multiply imputed (10 imputations) using IVEWare software (21). We used t-tests to compare the mean SWLS score of donors with previously reported general population sample means. We calculated Pearson correlation coefficients between the SWLS and other measures.

To examine relations between SWLS scores and donor characteristics, we used a modification of multiple linear regression robust to outliers. We began by examining donor

characteristics at the time of the QOL questionnaire (age, sex, race, educational attainment, marital status, time since donation) and concurrent measures (optimism, physical HRQOL). We used a best subsets approach to identify the best fitting ordinary least squares model (with the highest R^2), and tested these covariates using robust regression, retaining variables significant at $p < 0.01$ to provide some protection against Type 1 errors. All model results are reported as pooled estimates and standard errors from 10 imputations. Ordinary least squares and robust regressions results gave comparable coefficients.

After identifying Model 1 with general predictors of SWLS scores, we examined the relation between donation experiences and SWLS scores in regressions with covariates in Model 1, one donation experience variable at a time to ensure interpretability.

Analyses were conducted using SAS version 9.2 (SAS Institute; Cary, North Carolina, USA).

Qualitative analyses

To supplement quantitative analyses and develop a clearer understanding of ways that donation may contribute to SWL, two authors coded text written by donors at the end of the questionnaire. Comments were coded as related to SWL if donors focused on themselves (rather than solely on the recipient) and involved a cognitive judgment or evaluation. Comments were also coded as positive, negative, or ambivalent. Interrater reliability was 0.96.

Wilcoxon rank-sum tests were used to compare SWLS scores between donors with positive and negative comments.

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Abbreviations

| | |
|--------------|--|
| HRQOL | health-related quality of life |
| LOT | Life Orientation Test-Revised |
| MCS | mental component summary |
| OPTN | Organ Procurement and Transplant Network |
| PCS | physical component summary |
| QOL | quality of life |
| SWL | satisfaction with life |
| SWLS | Satisfaction With Life Scale |
| SRTR | Scientific Registry of Transplant Recipients |

SF-36 Short Form Health Survey

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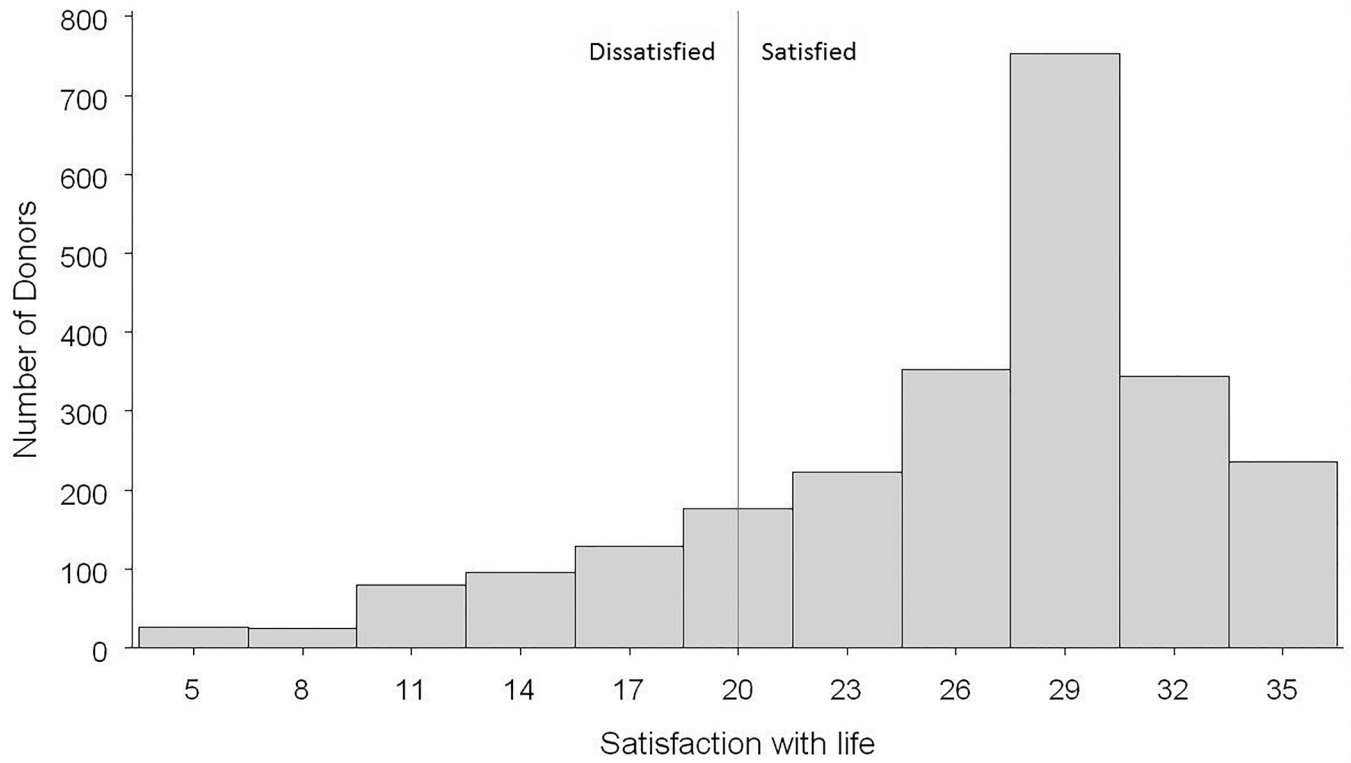


Figure 1.
Histogram of living kidney donors' scores on the Satisfaction With Life Scale

Table 1

Demographic characteristics of RELIVE living kidney donors

| | N | Percent | | |
|--|-------|---------|------|-----------|
| Total | 2455 | 100.0 | | |
| Female | 1505 | 61.3 | | |
| Race | | | | |
| White or European American | 2282 | 93.0 | | |
| Black or African American | 113 | 4.6 | | |
| American Indian | 16 | 0.7 | | |
| Asian or Pacific Islander | 11 | 0.4 | | |
| Multi-racial | 20 | 0.8 | | |
| Latino | 31 | 1.3 | | |
| Relationship of donor to recipient | | | | |
| Parent | 450 | 18.3 | | |
| Child | 316 | 12.9 | | |
| Sibling | 1011 | 41.2 | | |
| Other relative | 130 | 5.3 | | |
| Spouse | 219 | 8.9 | | |
| Friend | 173 | 7.0 | | |
| Other unrelated | 149 | 6.1 | | |
| Educational attainment at questionnaire completion | | | | |
| Less than high school | 66 | 2.7 | | |
| High school graduate/GED | 497 | 20.2 | | |
| Some college/Associate's degree | 920 | 37.5 | | |
| College graduate | 510 | 20.8 | | |
| Post-college | 449 | 18.3 | | |
| Marital status at questionnaire completion | | | | |
| Married/living with partner | 1,852 | 75.4 | | |
| Single | 141 | 5.7 | | |
| Divorced, separated, or widowed | 449 | 18.3 | | |
| | | | Mean | SD |
| | | | | N missing |
| Age at donation | | | 40.5 | 11.4 |
| Age at questionnaire completion | | | 57.8 | 11.3 |
| Years since donation | | | 17.3 | 9.8 |
| Optimism (LOT-R; 0 to 24) | | | 17.8 | 4.1 |
| Physical HRQOL (PCS score, age and sex adjusted (normed M = 0, SD = 10)) | | | 3.6 | 8.8 |
| Mental HRQOL (MCS score, age and sex adjusted (normed M = 0, SD = 10)) | | | 2.0 | 8.9 |
| Satisfaction with life (SWLS; 5 to 35) | | | 26.2 | 6.7 |

Note: SD = standard deviation. GED (Tests of General Educational Development Data) were missing for 13 donors regarding race, educational attainment, and marital status, 8 donors regarding ethnicity, and 7 donors regarding relationship to recipient.

Table 2

Correlations with Satisfaction With Life Scale scores

| Variable | Correlation (r) | p-value |
|--|------------------------|----------------|
| Optimism (LOT-R) | 0.57 | < 0.0001 |
| Mental HRQOL (MCS, age and sex adjusted) | 0.55 | < 0.0001 |
| Physical HRQOL (PCS, age and sex adjusted) | 0.34 | < 0.0001 |

Note: LOT-R (Life Orientation Test-Revised), HRQOL (health-related quality of life), MCS (mental component summary), PCS (physical component summary)

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Table 3

Results of multivariable robust linear regressions predicting Satisfaction With Life Scale scores (range 5 to 35, N = 2,455). Regression coefficients above 0 indicate positive associations with SWLS scores and coefficients below 0 indicate negative associations with SWLS scores.

| | Regression coefficient | 95% CI | p-value |
|--|------------------------|----------------|---------|
| Model 1: Characteristics of donors (multivariable; R ² = 0.37) | | | |
| Optimism (LOT-R, per 5 units)* | 4.08 | (3.85, 4.31) | <0.0001 |
| Married or living with partner (ref: separated, divorced, widowed, never married)* | 2.52 | (2.10, 2.93) | <0.0001 |
| Physical HRQOL (PCS, per 0.5 SD)* | 0.60 | (0.51, 0.70) | <0.0001 |
| Educational attainment at survey (per level, 5 levels)* | 0.25 | (0.08, 0.42) | 0.0040 |
| Black (ref: white, other race)* | -1.50 | (-2.51, -0.48) | 0.0041 |
| Theorized protective effects (i.e., associated with higher SWLS scores; all on a 1–5 scale, entered one at a time with donor characteristics in Model 1) | | | |
| How comfortable are you now with your decision to donate? (very uncomfortable ... very comfortable) | 0.64 | (0.24, 1.03) | 0.0015 |
| How would you rate your overall organ donation experience? (poor ... excellent) | 0.60 | (0.40, 0.80) | <0.0001 |
| My family or friends supported me throughout the donor surgery (SD ... SA)* | 0.57 | (0.35, 0.79) | <0.0001 |
| If you could do it over again, would you donate again? (Definitely not ... Definitely yes) | 0.55 | (0.23, 0.87) | 0.0008 |
| How did your donation affect your life overall? (VN ... VP)* | 0.49 | (0.28, 0.70) | <0.0001 |
| How did your donation affect your general health? (VN ... VP) | 0.47 | (0.23, 0.71) | 0.0001 |
| If applicable, how did your donation affect your relationship with the recipient? (VN ... VP) | 0.45 | (0.25, 0.65) | <0.0001 |
| There was support available to me from the health care providers (SD ... SA) | 0.43 | (0.29, 0.58) | <0.0001 |
| How did your donation affect your relationship with your spouse or significant other? (VN ... VP) | 0.35 | (0.14, 0.55) | 0.0011 |
| Theorized risk factors (i.e., associated with lower SWLS scores; entered one at a time with donor characteristics in Model 1) | | | |
| I had problems paying medical bills (yes vs. no, don't know) | -3.31 | (-4.72, -1.89) | <0.0001 |
| I had problems paying household/routine monthly bills (yes vs. no, don't know) | -2.09 | (-2.96, -1.22) | <0.0001 |
| Do you feel that donating your kidney caused a financial burden? (no burden ... extreme)* | -1.32 | (-1.59, -1.05) | <0.0001 |
| I took unpaid medical leave from work (yes vs. no, don't know) | -1.02 | (-1.48, -0.56) | <0.0001 |
| Recovery time for daily activities (<3 months ... never, 4 levels) | -0.78 | (-1.34, -0.23) | 0.0059 |
| Donor had at least one medical, emotional, psychological, or substance abuse complication after donation (yes vs. no) | -0.67 | (-1.10, -0.23) | 0.0026 |
| Once surgery was over, no one paid attention (SD ... SA)* | -0.62 | (-0.80, -0.43) | <0.0001 |
| I sometimes wish I would not have donated (SD ... SA) | -0.51 | (-0.76, -0.25) | <0.0001 |
| I felt depressed for a while after the surgery (SD ... SA) | -0.46 | (-0.63, -0.28) | <0.0001 |
| I sometimes felt pressured to donate (SD ... SA) | -0.42 | (-0.63, -0.22) | <0.0001 |
| I sometimes felt pressured to NOT donate (SD ... SA) | -0.31 | (-0.48, -0.15) | 0.0002 |

SD = Strongly disagree, SA = Strongly agree, VN = Very negatively, VP = Very positively. Response options included 5 levels unless otherwise specified. Response options for recovery time included: a) less than 3 months, b) 3 to 6 months, c) more than 6 months and d) I never returned to my usual daily activities.

* Variable remained significant ($p < 0.01$) when all theorized protective effects and risk factors were simultaneously entered in the model. R^2 of model with all significant effects = 0.41.

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