Quality of Life and Life Events of Living Unrelated Kidney Donors in Iran: A Multicenter Study

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Background. A controlled living unrelated kidney donors (LURDs) transplant program has been started from 1988 in Iran. We surveyed LURDs to investigate the extent to which they experienced stressful life events before donation and their quality of life after donation.

Methods. Five hundred donors were approached. Donors were included in the study provided that donation had taken place at least 3 months before the study. Paykel Life Events Scale and The World Health Organization Quality of Life-Brief version (WHOQOL-Bref) were used in this study.

Results. Complete data were available for 424 (84.8%) donors. The mean age was 27.6 ± 4.6 years and 84.4% of the participants were men. Ninety-five percent of the respondents reported having experienced at least one stressful life event during the 6 months before kidney donation. The three most frequently experienced life events were the increase in life expenses, low income, and household duties. The most stressful life events were job loss, financial problems, and death of a family member. The participants reported more stressful life events with a mean total stress score (112.6 ± 75.0) double than the findings of a previous study in normal population. In all the four domains of WHOQOL-BREF, the participating donors scored lower than previously determined community norms.

Conclusion. We observed that the quality of life of Iranian LURDs may be low and they may be at risk of experiencing more stressful life events. To be most efficient, the health services should continue after donation and compensate for mental health and psychosocial problems as well.

Keywords: Quality of life, Life stressors, Living unrelated kidney donors, Psychosocial, Iran, Transplantation.

(Renal transplantation is accepted as the treatment of choice for most patients with end-stage renal disease (1). The first renal transplantation in Iran was performed in 1967 and the organized renal transplant program was started in 1985 (2). Until 1988, all renal transplants were obtained from living related donors (LRDs). Later, to help the increasing number of end-stage renal disease patients on waiting lists and to expand the kidney donor pool, a government funded and controlled living unrelated donor (LURD) program was initiated. At the end of 2002, most of the kidneys were donated by LURDs (2). This program has been effective in reducing the number of patients with end-stage renal disease, awaiting transplantation (3). The volunteers for kidney donation should register in the Dialysis and Transplant Patients Association (DTPA); and after the donation, they are rewarded with a financial incentive (the equivalent of $1200 U.S. Dollars and 1 year of medical insurance) provided by the government.

Debate over the Iranian paid donation model continues (4). According to a law passed by the parliament in April 2002, cadaveric organ donation was permitted from the patients with brain death; the number of renal transplants from cadaveric sources has increased slowly since that time. Nevertheless, the number of organs received from cadavers has not been sufficient enough to meet the current demand (3, 5). Overall, quality of life (QOL) significantly improves after kidney transplantation in recipients (6, 7). Furthermore, the graft and patient survival from LURD transplants are shown to be equivalent to those from LRD and higher than cadaveric transplants (8, 9).

Psychosocial assessment and monitoring of LURDs is not a standard practice in Iran. There are many arguments about renal transplantation from living donors and general concerns exist about the risks and psychosocial effects of donating an organ. Some studies have been focused on the factors that motivate people to donate an organ. Although organ donation is voluntary, poverty is suggested to be the main factor in some cases (8, 10, 11). The donors’ low socioeconomic and educational level may put them at risk for poor outcomes of postdonation. It is of more concern if they are not psychologically well prepared for the surgery, because it seems that altruism is not the main motive for organ donation.

The risk of developing long-term renal failure in living donors is similar to the normal population (11, 12). However, studies about the psychosocial status of LURDs are rare. Life events and stressors with significant severity may adversely affect mental health of the people (13–16). There is also a mutual relationship between QOL and mental health. The QOL changes after donation are not consistent. Some investigators have reported small changes in QOL and even high self-esteem and improved sense of well being in the groups of
donors who were mostly LRDs (17–19); others have observed some sources of distress, mainly depression, anxiety and adjustment disorders, possibly because of the loss of an organ (20). Impairment in psychosocial function is also mentioned among living donors (19, 21, 22).

Giving attention to psychosocial status of the donors has turned into a major issue considering the large number of kidney transplants from LURDs in Iran.

To study these concerns, we surveyed kidney donors to investigate the extent to which they experienced stressful life events before donation and their QOL after donation.

MATERIALS AND METHODS

Participants

Participants were selected from postoperative living unrelated kidney donors. The assessments were performed at the time of referral to Tehran headquarter of Charity Foundation for Special Diseases (CFSD) to receive the incentive allocated to donors by the government. Donors were included in the study if they had donated the kidney at least 3 months before the study in 30 transplant centers across the Iran. All of the centers contributed donors to the study. Five hundred donors were approached between April and October 2007. After obtaining informed consent, participants were interviewed by two trained physicians and questionnaires completed during interviews.

Instruments

Paykel Life Events Scale and The World Health Organization Quality of Life-Brief version (WHOQOL-Bref) were used in this study. The questionnaires were self-administered. If the donor was illiterate, the questions were read for them by the practicing physician of CFSD. The Farsi version of the questionnaires, validated for the Iranian population, was used in this study (23, 24). The demographic data of the participants were recorded.

Paykel Life Events Scale was used to measure subjective stress. The mentioned scale is a 65-item instrument and covers a comprehensive range of recent life events, their timing and severity for the subject with scores from 1 to 20. It has two time frames for evaluation: (1) life events that occurred during the 6 months before the assessment; (2) those that occurred before the last 6 months (25).

World Health Organization Quality of Life-Brief version is a 26-item abbreviated version of the WHOQOL-100 (25). It is based on a four-domain structure: (1) physical (7 items); (2) psychologic (6 items); (3) social (3 items); and (4) environmental (8 items). It is concerned with what the different aspects of life mean to the respondents and how satisfactory or problematic these experiences are for them. A time frame of 15 days is indicated in the assessment; it uses a five-point scale to grade the patient’s response to the QOL items. Twenty-four of the 26 questions are used to compute the QOL scores. Other two scores show the individual’s overall perception of QOL and general health. A higher score signifies better QOL. Domain scores were calculated according to the WHO guidelines (26).

Data Analysis

Statistical analyses were performed using SPSS version 13. The mean total scores and each domain or subscale scores were calculated for the two questionnaires. The overall frequencies of life events were estimated. Pearson correlation coefficients were calculated to evaluate the relationship between total scores and age. Total scores were compared among people with different level of education and marital status using independent samples t test and one-way analysis of variance; a P value less than 0.01 was considered statistically significant.

RESULTS

The donors’ characteristics are shown in Table 1. The mean age was 27.6±4.6 years and 84.4% of the participants were men.

Paykel Life Events Scale

During the 6 months before Kidney Donation

Complete data was available for 424 donors. Ninety-five percent of the respondents reported having experienced at least one stressful life event during the 6 months before kidney donation. The average total stress score was 112.6±75.0 and on average each person had experienced seven stressful life events. Total stress scores in men (117.4±77.8) and women (86.2±49.5) were significantly different (P=0.003). We did not find any statistically significant correlation between the total stress score and age of the participants during this time, neither between stress and marital status. Furthermore, the total stress score was not significantly different among people with various levels of education. Table 2 demonstrates the most prevalent events during the 6 months before kidney donation. The three most frequently experienced life events were the increase in life expenses, low income, and household duties. The mean severity of each life event was calculated and shown in Table 3. The most stressful life events during this period were job loss, financial problems, and death of a family member. For the purpose of comparison, the results of a previous study in the normal population of Tehran, the capital of Iran (27), was also provided in Tables 2 and 3.
During the Period Before the Last 6 Months Before Kidney Donation

In this period, 97.3% of the participants had at least one stressful life event. The average total stress score was 161.0±91.5. Total stress score in men was higher than women; however, the difference was not significant (163.9±94.5 vs. 144.2±70.1, P>0.01). The correlation between total stress score and age of the participants during this time was not significant (r=0.1, P=0.035). The four most frequently experienced life events were engagement (77.1%), marriage (70.6%), low income (68.9%), and household chores (68.9%). The mean severity of each life event was calculated. The most stressful life events were offspring death, physical or mental disability of a family member, and financial problems (19.1±1.8, 18.8±3.3, and 18.3±3.4, respectively).

World Health Organization Quality of Life-Brief Version

Complete data were available for 420 subjects. The mean score of overall QoL and general health perception was 2.93±0.95 and 3.67±0.91, respectively. The mean score for each domain was demonstrated in Table 4. For the purpose of comparison, the score of the four domains in a previous study on the general population of Tehran (23) was also showed in Table 4.

There was not any statistical correlation between age and the values of the four domains. No difference was found in the values between men and women. Social relationship was higher among the married than the other donors (mean difference: 1.76, P<0.0001). Overall QOL and general health perception were negatively associated with total stress score (r=0.16 and 0.32, respectively, P<0.0001). All the four domains were negatively correlated with the total stress score (P<0.0001).
living related kidney donors showed that social relationships and community involvement were found to be unchanged or improved after donation (28).

The lower scores in the dimensions of QOL in our study may be owing to a large proportion of living donors in other countries are LRDs, which potentially makes the donation an altruistic behavior with improved self-perception. In contrast, the majority of kidney donors in Iran are LURDs whose main motivation is “a financial gain” because of poverty (10). The low score in QOL may improve over months after donation. Walton-moss et al. (29) reported that the health-related QOL measured with the Short Form 36 Health Survey (SF-36) decreased at 3 months after transplantation but demonstrated complete recovery at 12 months. On the other hand, some studies have reported no difference in QOL considering the time since donation (19, 30).

The participants reported more stressful life events with a mean total stress score double than the previous findings, which showed a mean total stress score of 57.6 in a sample of Tehran residents (27). The most challenging events were mainly because of occupation, family, and financial problems. These findings are in line with the results of a study which evaluated the socioeconomic status of the Iranian LURDs and observed that most of them were living under the poverty line (10).

The findings of this study may reveal the need for mental and psychosocial assessment and follow-up in people who will to donate their kidneys. Recently, donor’s day clinics are being established in transplant centers to monitor physical health of donors. In addition, potential donors are referred for psychiatric evaluation by some of physicians evaluating the donors; this evaluation, however, is not mandatory.

One of the main limitations of this study was the lack of the specific control group. Another limitation was that while we described the postdonation QOL of the donors, we did not compare it with the predonation QOL. In addition, recall bias may have also played a role as respondents were asked to recall details about stressful events they had experienced before donation.

CONCLUSION

We observed that the QOL of Iranian LURDs may be low and they may be at risk of experiencing more stressful life events. To be most efficient, the health services should start before donation and continue after donation and compensate for mental health and psychosocial problems as well.

The different aspects of Iranian controlled LURDs program should be appraised and necessary changes should be made before presenting it as a successful model to the rest of the word.

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REFERENCES