Depression and self-report disclosure after live related donor and cadaver renal transplants

L. SCHLEBUSCH, B. J. PILLAY, J. LOUW

Summary

Important psychological reactions are associated with renal transplantation in general. Differences in psychological adjustment between recipients of kidneys from live related donors (LRRs) and recipients of kidneys from cadavers (CRs) and recipients of kidneys from live related donors (LRRs), however, have been poorly researched. In this study 10 LRRs (mean age 35.7 years; mean number of years after transplant 4.5) were compared with 30 CRs (mean age 38.6 years; mean number of years after transplant 5.3). The prevalence of depression and self-disclosed stress-inducing factors which might have affected long-term psychological adjustment after the transplant were investigated. The psychological status of each patient was assessed by means of a clinical interview, a mental status examination, the Beck Depression Inventory and a self-report questionnaire. There were found to be no long-term statistically / significant differences between the LRR and CR groups in terms of the prevalence of depression, although 20% of the patients overall were depressed to varying degrees. The CR group was more concerned about the psychological and personal characteristics of the donors and their families than the LRR group, who expressed concern about the future well-being of the donors. Many members of both groups expressed having experienced both fear of graft rejection, before and immediately after the transplant, and anxiety, which decreased with time. The therapeutic value of a positive psychological climate in the renal unit and of supportive family relationships was confirmed for both groups. In comparison with their existence while on dialysis, most of the patients, irrespective of donor type, ultimately enjoyed an enhanced quality of life.

For patients with end-stage renal disease (ESRD), the ideal treatment is a successful renal transplant. Psychologically this removes the status of being sick and, compared with the other substitute therapies, produces less psychological stress. Despite ongoing research about the psychological problems involved in renal dialysis, knowledge in this field is still lacking. The same is true of psychological adjustment to renal transplantation. Reasons for this include the almost exclusive interest in technical and medical advances in transplantation and in immunological therapy, histocompatibility and organ preservation, as well as the need for renal unit staff at the various transplant centres to define the attendant psychological problems in the absence of the services of a psychonephrologist. However, in some instances this situation has improved in recent years. Renal transplantation has important psychological effects on live related donors, recipients and their respective families.

Sub-Department of Medically Applied Psychology, Department of Psychiatry, University of Natal, Durban
L. SCHLEBUSCH, PH.D.
B. L. PILLAY, M.A. (CLIN. PSYCH.)
Department of Psychology, University of Cape Town
J. LOUW, PH.D.

Recent South African studies acknowledge the importance of such variables but do not systematically investigate them. Family relationships, in particular, appear to be affected by transplants, and the possibility that the generosity of the kidney donation is based on unconscious guilt on the part of the relative has been reported. A related psychological dimension is the way in which renal transplant recipients perceive the transplanted organ itself. Recipients of cadaver kidneys seem to be affected by fantasies about the cadaver and by changes in their attitude to death and dying. The way in which a transplant patient copes with an altered body image plays a significant role in the occurrence of postoperative emotional disturbances. The degree to which the patient integrates the new organ into the 'body schema' may affect the success of the transplant, since it is sometimes perceived by the recipient as not merely a psychological object but as representing another whole person. Renal transplant recipients may feel that the donor resides 'inside' them, and believe that they have acquired certain crucial characteristics or traits from the donor. Thoughts about the donor depend to a large degree upon their perceived psychological integrity. Psychological compatibility with the donor is therefore important, and the quality of the donor-recipient relationship can influence the outcome of the transplant. When fantasies of the donor and recipient match, physiological acceptance appears more likely.

Although long-term psychological reactions of related donors and both recipients of kidneys from a live related donor (LRR) and from a cadaver (CR) remain fairly positive, some renal transplant patients prefer a cadaver kidney, thus avoiding the difficult problem of indebtedness to a family member, whereas for cultural reasons, others do not. This gives rise to an interesting discrepancy between medical and psychological factors, since LRRs tend to do better than CRs and are spared the psychological anguish associated with long waiting lists. Although each group may have its own peculiar problems of adjusting to the transplant, such differential psychological variables have resulted in limited research. This study does not address cultural influences on renal transplantations, discussed elsewhere, but instead compares the psychological adjustment of LRRs with CRs as regards depression and self-reported stress-inducing factors.

Patients and methods

Of 62 transplant patients (4 blacks (6.5%), 20 whites (32.2%), 6 coloureds (9.7%) and 32 Indians (51.6%) attending the Renal Unit at Addington Hospital, Durban, at the time of the study, 40 were studied after having given informed written consent. To keep the study group as homogeneous as possible, criteria for exclusion were age below 20 years (thus avoiding reported difficulties peculiar to adolescent adjustment to renal transplantation) and recent transplantation (< 1 year), since the first year after transplantation is critical for rehabilitation. Some patients refused to participate, and others had transport and communication problems, moved to another city, or died during the study period. The final sample of 40 (mean age 38.0 years) included 10 females, ranging in age from 24 to 66 years (mean 39.3 years), and 30 males, ranging in age from 22 to 51 years (mean 37.4 years); 32.5% of the patients were
white, and the mean number of years since the transplant was 5.1. The sample was divided into two groups, 10 LRRs and 30 CRs. The mean age of the LRRs was 35.7 years, 90.0% were males, 70.0% were white, and 60.0% had received a kidney from a sister and 40.0% from a brother; and the mean number of years since the transplant was 4.5. The mean age of the CRs was 38.6 years, 70.0% were males, and 66.7% were non-white; the mean number of years since the transplant was 5.3.

The research design included a mixture of quantitative and qualitative measures. All patients were individually psychologically assessed during a routine follow-up visit to the renal unit. This included a clinical interview and a mental status examination, administration of the Beck Depression Inventory (BDI) to obtain quantitative data, and an open-ended self-report questionnaire used to obtain pre- and postoperative qualitative data. The BDI is widely used for measuring the relative severity of depression and has been used extensively in medical research. The self-report questionnaire (Table I) was constructed in order to tap some of the relevant stress-inducing observations experienced by renal patients.

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**Results**

An analysis of variance was done on the total scores obtained by each of the respondents on the BDI (Table II). It showed no significant statistical differences between the two groups in terms of depression. However, individual BDI scores of the 40 patients showed that 8 (20.0%) were depressed to varying degrees; 3 (37.5%) were mildly depressed (2 male CRs who had undergone transplantation 7 years and 1 year previously, and 1 male LRR (1 year)), 2 (25.0%) were moderately depressed (1 female LRR (just over 1 year) and 1 male CR (2 years)), and 5 (37.5%) were severely depressed (1 LRR female (4 years), 1 CR female (3 years), and 1 male CR (6 years). Of the patients who were depressed, most were males (62.5%) and/or CRs (62.5%), and on average they had undergone transplantation 3.4 and 3.8 years previously.

Responses to the self-report questionnaire revealed notable differences between the two groups in respect of questions 5 and 6. The balance of the questions evidenced certain trends throughout the entire sample. Fear was commonly reported (question 1); most patients (40.0%) reported pre-transplant fear of rejection or general fear of the operation itself, 5.0% were afraid of the operation, and 7.5% were afraid of 'something going wrong with the donor', 'not finding a donor', 'the scar after the operation'; others expressed anxiety over being 'fully recovered', and 'postoperative treatment'; others expressed anxiety about receiving a new kidney or about whether they would ever be normal again, while an LRR was concerned about whether the donor, a sister, would be able to cope with one kidney.

Responses to question 2 confirmed that after the transplant most anxiety was caused by fear of rejection (50.0%); other patients expressed anxiety about being 'fully recovered', and being 'normal' (22.5%), and returning home (12.5%). Anxiety at this stage in the remainder (15.0%) was related to the danger of the operation, whether urine output would be normal, participation in sport, whether creatinine levels would remain normal, the safety of the donor (expressed by an LRR), self-injury, infection, and getting married.

Questions 3 and 4 were included to provide some feedback on patients' attitudes regarding their hospital treatment. Most (55.0%) stressed the psychological value of what they felt to be good nursing care and a positive attitude on the part of the staff (question 3). The balance (45.0%) reported occupational therapy, physiotherapy and related paramedical services as helpful in their adjustment, along with less severe dietary restrictions, the ability to pass urine easily again, more freedom, religious support, and communication with other renal transplant recipients. All the patients considered that the psychonephrology service had been of benefit to them, some more so than others. Most patients (72.5%) were generally satisfied with their treatment (question 4). The remainder (27.5%) felt that there should have been more explanation and information about the transplant, more family involvement in the procedure, and a more holistic approach to their management. One patient (2.5%), who was first treated elsewhere, reported feeling more comfortable at the previous hospital.

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<th>TABLE II. ANALYSIS OF VARIANCE OF THE TOTAL SCORES ON THE BECK DEPRESSION INVENTORY</th>
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Responses to question 5 revealed that while 90.0% of the LRRs were not concerned about the psychological and personal characteristics of the donor, 73.3% of the CRs were. The latter’s main concerns included the donor’s age (20.0%), sex (20.0%), race (10.0%) and health before death (10.0%). Other concerns (40.0%) related to the donor’s height, name, religion, hair type, figure (fat or thin), marital status, number of children, interests and sporting abilities. Responses to question 6 showed that the LRRs were more concerned with the psychological climate of the renal unit, the patients’ need for support, the psychological climate of the renal unit, and the optimism of the staff, which assists patients and貝工作 становиться основным. Важность психологического климата для пациентов, их семей, и при участии в случае кадавер-доноров, на что бы они делали, когда они живы.

Family relationships, tapped by response to questions 7 and 8, were positive, patients feeling that their families were generally supportive. Most (81.2%) reported positive feelings towards their families, and some (10.0%) appreciated their families treating them as ‘normal’ and leaving them to do things independently. Only 2.5% felt that they were treated as still being ill, and 1 respondent (2.5%), a female CR, found it stressful having her family living with her for a short while.

Although 42.5% of the patients had not undertaken any new activities since their transplant (question 9), most (52.5%) were more active; 20.0% participated in sporting activities, 17.5% indicated an increase in social activities, and 15.0% were working full-time. One patient (2.5%) had married. Most patients reported that they either felt more normal (40.0%) or had become more appreciative of life (31.0%) since their transplant (question 10). The data indicate that most patients had resumed previous activities and were functioning adequately. Some patients felt that the transplant had heightened their own appreciation of their families, while others were glad to be independent of dialysis. One patient (2.5%) reported having become more aware of body and organ function. With regard to future expectations (question 11), most patients (60.0%) saw themselves as ‘normal’ 5 years hence and 30.0% felt ‘optimistic’. A few (10.0%) ‘wanted to be a mother’, felt ‘pessimistic’, ‘were not sure’, and ‘felt grateful to the donor’.

Most patients (77.5%) initially experienced troublesome post-transplant side-effects (question 12a) but for the majority (65.0%) these became fewer as they recovered, particularly after the first year (question 12b). As they reported good kidney functioning their stress levels decreased, a factor which greatly aided post-transplant psychological adjustment. The above results were confirmed by data gained from the clinical interviews and mental status examinations.

Discussion

Depression is a common response to disease, especially when there is an actual or a threatened loss to the patient, as in ESRD. In this study neither sex nor donor type affected the prevalence of depression in the recipients, although 20%, predominantly males, were depressed. However, while depression is common in renal transplant patients, particularly in the first year, the low prevalence of depression in the majority of patients in the present study suggests satisfactory post-transplant psychological adjustment after 4 - 5 years on average. This was confirmed by the positive responses about future expectations in the self-report questionnaire. This study did not compare levels of depression before and after transplantation, but depression is also common in pre-transplant patients. Our evidence indicates that although patients are depressed before and initially after transplantation, they are less likely to be depressed some years after the transplant as they come to terms with their ‘new’ health status.

After this important ‘life-extending’ procedure, fears, particularly of rejection of the donated kidney, understandably appear to be a major concern of transplant patients. Patients on dialysis who are awaiting transplantation face many constant stresses, including the threat of death and an uncertain prognosis. Association with other patients on the chronic renal failure programme and the need to educate themselves about ESRD make these patients aware of possible complications after transplantation. Renal transplant recipients are acutely aware of the potential for graft rejection in the immediate postoperative phase, and many report feelings of ‘sitting on a powder keg’, which result in anxiety, emotional lability, depression and pessimism, should there be any indication of possible graft rejection. The transplant, however, is also viewed as a chance for a ‘new life’, and ambivalence about whether they will be afforded this chance is indicated by the fears of these patients. Those who reported no fear could have been employing denial (a common defence mechanism in ESRD and transplant patients to avoid anxiety invoked by the possibility of graft rejection) or, alternatively, wish-fulfilment fantasies of a complete cure - an attitude prevalent among both donors and recipients. Also, some authors do not report a persistent, significant and pervasive fear of loss of the renal graft in the long term. The fact that many patients considered themselves fully recovered and felt ‘normal again’ confirmed their desire to change from a dependent to a more independent lifestyle, thereby assuming more responsibilities and participating in normal activities.

The findings that the majority of patients were satisfied with their treatment, and could not necessarily be attributed to the nature of the questionnaire, or due to denial conflicts described by others. The psychological climate of the transplant unit, and the optimism of the staff, which assists patients and donors to feel more positive, are important factors in patient adjustment, as is the availability of a good psychonephrology service. Conversely, patients’ response can also affect the staff and the psychological climate in the renal unit; if patients do well, the impact on the unit can be psychologically positive, and if they do poorly it can be psychologically negative.

Being familiar with their donors, the LRRs did not hanker to know as much about the characteristics of the donors as did the CRs, but were more concerned about the feelings and health of the donors. In contrast, subsequent enquiry showed that the thoughts of the CRs about their donors were strongly influenced by their not ‘knowing’ their donors, their need to know the donor’s family, and a belief that they had obtained certain traits from the donor. These factors often operate reciprocally in cadaver donor families who feel that their loved one’s characteristics of the donor, 73.3% of the CRs were. The transplant, however, is also viewed as a chance for a ‘new life’, and ambivalence about whether they will be afforded this chance is indicated by the fears of these patients. Those who reported no fear could have been employing denial (a common defence mechanism in ESRD and transplant patients to avoid anxiety invoked by the possibility of graft rejection) or, alternatively, wish-fulfilment fantasies of a complete cure - an attitude prevalent among both donors and recipients. Also, some authors do not report a persistent, significant and pervasive fear of loss of the renal graft in the long term. The fact that many patients considered themselves fully recovered and felt ‘normal again’ confirmed their desire to change from a dependent to a more independent lifestyle, thereby assuming more responsibilities and participating in normal activities.

The findings that the majority of patients were satisfied with their treatment confirm other observations that good relations with and confidence in hospital staff are therapeutically beneficial to individuals coping with a disease. Staff-patient relationships, the psychological climate of a transplant unit, and the optimism of the staff, which assists patients and donors to feel more positive, are important factors in patient adjustment, as is the availability of a good psychonephrology service. Conversely, patients’ response can also affect the staff and the psychological climate in the renal unit; if patients do well, the impact on the unit can be psychologically positive, and if they do poorly it can be psychologically negative.

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Neither the LRRs nor the CRs reported the type of family conflicts described by others. This may have been an artifact of the self-report nature of the questionnaire, or due to denial because of the patients’ need for supportive family relationships. Also, family conflict may be more common within the first year after the transplant, which is critical for patient and graft survival, and when patients are psychologically more stressed, rather than later, as was found in the present study. Viederman quotes studies that indicate that post-transplant enhancement of quality of life is related to the degree of internalisation by the recipient of the renal graft into the ‘body schema’. Thus renal transplant recipients with well-functioning grafts may enjoy an improved quality of life when comparing...
their present status to their pre-transplant days, although their health may not be equal to that of normal physically healthy individuals. The post-transplant increase in vocational rehabilitation and sporting and social activities reported in this study therefore reflected both an enhanced quality of life, as reported by others, and probably adequate internalisation of the transplanted organ into the body image of the recipients. Although only 15.0% of the patients resumed full-time employment, many more could have done so. In fact, several of the patients who reported no new activities were planning to return to work, something that they did not construe as a new activity. One patient reported marriage as a new activity — something she had not considered while on dialysis.

In conclusion, despite some differences between LRRs and CRs, the positive outlook to life and appreciative attitude of most of these patients was in keeping with the findings of previous researchers. For many of them, irrespective of donor recipient type, their increased physical well-being was both an exhilarating and a ‘rebirth’ phenomenon, with typical feelings that the transplant had extended their lifespan, confirming the view previously expressed that successful renal graft survival is the best psychotherapy for patients with ESRD, even though initial adjustment may be psychologically highly stressful for all concerned.

This research was supported by a grant from the South African Medical Research Council.

REFERENCES