

Factors That Influence Nonadherence in Immunosuppressant Treatment in Pediatric Transplant Recipients: A Proposal for an Educational Strategy

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ABSTRACT

Kidney transplant is the best treatment for patients with chronic renal failure. Scientific advances have optimized immunosuppressive treatment; however, adherence to medical treatment is not always achieved. Our aims were to identify the key factors that influenced nonadherence behavior to define effective educational strategies. A qualitative study was performed through an analysis of patient/tutor questions in interviews. A quantitative analysis was applied to epidemiologic variables, time posttransplant, and percentages/frequencies of responses from the interviews. A transplant nurse, psychologist, and social worker elaborated an instrument based on seven questions related to the transplant, the risk and/or loss of the graft, events that happened as consequence of this fact, allowing interviewees to freely express their opinions. The interviews were recorded on a microcassette recorder for later transcription. The analysis was determined by categories containing the answers to each question according to frequency. Informed consent was obtained from the parent/tutor. Among 150 transplants performed from 1989 to 2006 there were 15 nonadherences among 80% interviewed subjects. The mean age was 9.7 years. Loss of the graft occurred in 50%, at 37.7 months, post-transplant from 67% deceased and 33% living donors with 25% of cases preemptive transplants. The main factors for nonadherence were lack of supervision in taking medications, numbers and fastidious schedules, family conflicts, and poor communication between parents and the medical team. In conclusion, it is necessary to modify the pattern for transplant patient care that allows the patient and family to actively participate in the medical process including a multidisciplinary group.

KIDNEY TRANSPLANTATION represents the therapy of choice for patients with end-stage renal disease (ESRD). Scientific advances have optimized immunosuppressive treatment; however, we do not always achieve adherence to medical treatment. Nonadherence to immunosuppressive medications is one important factor for graft rejection and loss.^{1,2} For some authors, this represents the third most common cause of acute rejection and permanent graft loss, including between 4% and 30% of cases. It is higher in adolescents.³ Nonadherence in adolescents is 53%, compared with 17% among prepubertal children, with 15% graft loss and 26% graft dysfunction rates. Adolescent graft survival is best at 3 months posttransplant but worse at 5 years.¹ The identification of these individuals by means of a careful psychosocial evaluation, as well as the implementation of measures to improve adherence to the treatment are the main goals of any program for organ transplanta-

tion.⁴ Recently, we noted that a significant portion of late acute rejection episodes was caused by noncompliance to immunosuppressive therapy.⁵ This observation prompted us to undertake this study to identify the factors that influenced nonadherence behavior to design more effective educational strategies.

PATIENTS AND METHODS

A prospective study included pediatric transplanted recipients who showed nonadherence to immunosuppressant treatment in the follow-up period. Among 150 kidney recipients between 1989 and 2006, 15 (10%) were nonadherent and 10 (80%) were interviewed including 9 adolescents. The data were obtained

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using a validated questionnaire specifically designed for these patients. A qualitative study was performed by an analysis of patient/tutor questions through interviews. A quantitative analysis was applied to epidemiologic variables, time posttransplant, and percentages/frequencies of responses. A transplant nurse, psychologist, and social worker participated to develop an instrument based on seven questions related to the transplant, risk and/or loss of the graft, and the events that happened as consequence. Interviewees expressed their opinions freely. The interviews were recorded on a microcassette for later transcription. The analysis was determined by categories containing the answers to each question according to the frequency. Informed consent was obtained from the parent/tutor.

RESULTS

We interviewed 10 patients and 5 parents. Their mean age was 17 ± 7 years (range, 10 to 22). The mean age at transplant was 11.2 ± 3.5 years (range, 2.5 to 11). The mean age to detect nonadherence for the first time was 9.7 years (range, 3 to 12). The mean posttransplant time to detect nonadherence was 14.6 months (range, 8 to 22). Also, nonadherent behavior was detected in three (5%) cases on dialysis; 25% were preemptive transplant patients. Nonadherence was suspected in six patients (40%) due to increased serum creatinine levels; insufficient immunosuppressive medication levels occurred in six cases (40%). Acute rejection was confirmed in 30% with 50% of them losing their graft. A significant difference was observed among nonadherent subjects who received grafts from deceased donors (67%) versus living donors (33%). The categories containing the answers were: (1) Risk of loss of graft owing to nonadherence to immunosuppressant treatment; (2) irregular/insufficient intake of medication as a fundamental factor in nonadherence; and (3) adolescents identifying with their chronic illness. The lack of supervision in taking medications, quantities, and schedules of medications, family conflicts, and poor communication between parents and the medical team seemed to be the main factors for nonadherence. The chronicity of immunosuppressive treatment was incompatible with adolescence. The educational strategies were performed to modify the model for transplant patient care and make the immunosuppressive schedule administration easy. Emphasis on these factors in adolescent care was important, even though the patient looked well and the tests were good. Immaturity in adolescence is a key factor to long-term adherence. Adopting an "Interactional Model" based on a pattern of chronic suffering that allows both patients and their parents to be part of a team to help "coach," but not to control adolescents is helpful. All health care professionals form part of a team to create a multidisciplinary group. In the long term, continuing with frequent follow-up visits must continue education, support, and monitoring.

DISCUSSION

Although in the last few years the scientific literature has begun to show the importance of nonadherence as cause of

graft loss, it has not been sufficient. Dobbels et al.³ reported that nonadherence constitutes 14% of graft loss in renal, 15% in liver, and 35% in heart transplantation. These findings show that nonadherence is a problem for all patients with chronic disease. Therefore, the multidisciplinary group approach must be directed at creating strategies by which the patient and their family are part of the process and the medical team becomes an instrument of this process. The qualitative aspect is considered to be an active process of research, in which decisions are taken about the investigation itself. This is the first prospective study in our country about adherence to treatment among renal transplant recipients' experiences, attitudes, beliefs, thoughts, and reflections.

One of the aspects to emphasize is the behavior of the parents. As children become adolescents, they are given more independence, which is reflected in the way that medication is taken. However, adolescents are not mature enough to be responsible to take their medications alone.

Psychosocial factors associated with nonadherence included insufficient family support, low self-awareness caused by poor cognitive abilities, and denial. Consequently, if these factors take a negative form, there are feelings of sadness and abandonment. This phenomenon begins with the news of a chronic disease, which produces protective feelings in parents toward their child.⁴ The factors that support acceptance are the presence of both parents, strong emotional support, and a greater knowledge of the disease from the medical team. If these factors are interpreted in a positive and optimistic way, the patient will show greater adherence to the treatment. Another factor is related to the social support given to the patient; this is a fundamental influence in adherence. Changes in the environment can favor or make adherence to treatment difficult. Thus, hostile environments, characterized by absent or overprotective parents, ignorance, and fear of death, can generate hostile atmosphere. In contrast, good advice, a cohesive family, and a greater commitment by the medical team facilitates adherence to the immunosuppressant treatment.

The prevalence of noncompliance has been observed to be highest among adolescents who were responsible for their own medications and who underwent deceased donor kidney transplantation (67%) and lower after living-related transplantation (33%), consistent with the report by Feinstein et al.⁶ The absence of cases of nonadherence among adolescents who underwent commercial living unrelated kidney transplantation suggested that although noncompliance is prevalent, it is not inevitable.⁴ Strategies to decrease nonadherence in young patients with chronic illnesses can be learned from experiences with transplant recipients.⁷ The general pediatrician has a central role to identify and address this problem in adolescents with chronic disease.

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