

Evaluation of Non-adherence in Patients Undergoing Dialysis and Kidney Transplantation: United States Transplantation Practice Patterns Survey

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ABSTRACT

Introduction. We performed a survey of United States transplantation centers to evaluate practice patterns in the assessment of nonadherence before and after kidney transplantation.

Methods. An electronically administered, anonymous survey was sent to 181 United Network for Organ Sharing (UNOS) approved transplantation centers in 2012.

Results. Seventy-nine centers completed our survey. Of them, 51.3% had a protocol to evaluate medication/dialysis adherence before the listing; most common (36.4%) was the Simplified Medication Adherence Questionnaire. As an alternative to a questionnaire, the most common measure of nonadherence was the number of missed hemodialysis sessions (77.0%). The most common reason for poor adherence to dialysis regimens was difficulty with transportation (81.3%). Also, 94.4% noted the lack of a questionnaire to evaluate adherence to medications but relied on drug levels (73.4%) and self report. Only 12.9% used a questionnaire for the measurement of quality of life (Karnofsky performance scale). Of the participating centers, 27.1% used a formal cognitive testing for potential living donors. A social worker was used by most centers for nonadherent patients. Respondents indicated that patients (in the pretransplantation state) were more compliant with dialysis than with medication regimens. Finally, 37.7% of respondents noted graft failure due to medication nonadherence in 15% to 29% of their patients.

Conclusions. There was a significant variability in the methods of screening for non-adherence while the patient was on dialysis, during pretransplantation work up, and during post-transplantation follow-up examinations. We recommend that there should be a standardized technique to evaluate nonadherence to facilitate focused clinical trials to improve adherence.

POOOR ADHERENCE to medication regimens is common, contributing to substantial worsening of disease, death, and increased health care costs [1–4]. Nonadherence is defined as “deviation from the prescribed medication regimen sufficient to adversely influence the regimen’s intended effect” by the consensus conference on non-adherence to immunosuppressants [5,6]. In a meta-analysis, which included 147 studies of kidney, heart, liver, pancreas/kidney, or lung/heart recipients published between 1981 and 2005, the rate for nonadherence to immunosuppressants, diet, exercise, and other healthcare requirements was 19 to

25 cases per 100 patients per year [7]. Immunosuppressant nonadherence was observed to be highest in kidney recipients (36 cases per 100 patients per year versus 7 to 15 cases in other recipients). A meta-analysis of adult renal transplant recipients reported prevalence of nonadherence to be 22% [8]. Nonadherence in renal transplantation has a negative impact on clinical outcomes and results in allograft rejection and graft loss [9–13]. A variety of measures such as

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drug levels, biological markers, electronic monitoring, pill count, refill/prescription records, and self reporting have been proposed to assess adherence; all of these methods have limitations [14–17].

The aim of this study was to obtain information about how transplantation centers assess adherence in patients before and after successful kidney transplantation and use the results to improve adherence. We also surveyed screening methods for depression or psychological illnesses and quality of life before and after transplantation.

METHODS

We designed a 23-question electronic survey to gather information about methods to assess and improve adherence before and after kidney transplantation. The survey included factors related to adherence, psychological assessment, cognitive testing, and quality of life measures before and after transplantation (Table 1).

A list of all UNOS-approved transplantation programs was obtained from the website. Transplantation professionals, including nephrologists, surgeons, nurses, and social workers, were further identified through transplantation program websites or a phone call to the institution. The electronic anonymous survey via a secured hyperlink (www.surveymonkey.com) was sent to these individuals, and their responses were collected over a 1-year timeframe (from May 2012 to April 2013). If a provider did not respond to the original survey request, a subsequent one was sent every 3 months during the collection period. The provider was given the option to opt out of the survey as well, in which case he/she received no

further reminders. We received 79 completed surveys, making a response rate of approximately 43.6%.

The survey consisted of 23 questions, most of which were in multiple-choice format; the provider was allowed to select more than one option and give free-text responses. The survey questions were designed to assess the nature of the transplantation program and how adherence to medications/follow-up was monitored and encouraged. Responses to each question were computed via the survey monkey tools. Results are presented and discussed below using descriptive statistics.

RESULTS

Half of the respondents (54.4%) were from university hospitals; 20 were private, university-affiliated hospitals; 11 were non-university affiliated private hospitals; and 6 were from other affiliations. Thirty-six of the responding centers (45.6%) performed less than 74 renal transplantations in a year and 25 centers (31.6%) performed 75 to 149 renal transplantations annually. Of the larger transplantation centers, we received responses from 8 (10.1%) centers performing 150 to 224 renal transplantations annually and 10 (12.7%) with an annual rate of 225 and greater. Only half (51.3%) of the respondents claimed any knowledge of a protocol to evaluate medication/dialysis adherence before listing. Of those respondents, 89.6% claimed no usage of a questionnaire for such an evaluation (Fig 1). Of those who use a questionnaire, the most common (36.4%) was the Simplified Medication Adherence Questionnaire [18]. As an

Table 1. Study Survey Questionnaire

Study of Practices to Measure Adherence and Quality of Life Before and After Kidney Transplantation in UNOS Centers	
1.	How many kidney transplants are completed at the program each year?
2.	How would you describe your hospital?
3.	Does your program have a protocol or standard operating procedure (SOP) for evaluation of medication or dialysis adherence before listing for kidney transplant?
4.	Do you use a questionnaire for this purpose?
5.	If yes, what is the questionnaire?
6.	If you do not use a questionnaire, do you use any other measure of adherence to dialysis or medication?
7.	Reasons listed by patients for dialysis non adherence
8.	Reasons listed by patients for medication non adherence
9.	What is your program's screening method for depression or psychological illnesses before listing for kidney transplant?
10.	Does your program use a formal questionnaire to evaluate adherence to medications or follow up after kidney transplant?
11.	If yes, what is the questionnaire?
12.	If you do not use a standardized questionnaire which of the following qualitative methods do you use to detect non-adherence after transplant?
13.	Does your program have a questionnaire to measure quality of life before transplant or after transplant?
14.	If yes, what is the instrument?
15.	Does your program use formal cognitive testing of potential living donors? If yes, which one?
16.	Does your social worker see patients who are suspected to be non-adherent?
17.	Does your Psychologist see patients who are suspected to be non-adherent?
18.	What is the percentage of patients in your program presumed to have documented non-adherence to medications before transplant?
19.	What is the percentage of patients in your program presumed to have documented non adherence to dialysis treatments?
20.	What is the percentage of patients in your program whose graft failure is presumed to be due to non-adherence?
21.	What reasons do patients give for their non-adherence when confronted (check any that apply)
22.	What percentage of your post-transplant patients know the names and correct dosage of their medications?
23.	What methods or tools do you use to assist your patients with adherence

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