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Accuracy of Dialysis Medical Records in Determining Patient Interest in and Suitability for Transplantation

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Abstract

Background—We sought to determine the accuracy of dialysis medical records in identifying patient interest in and suitability for transplantation.

Study Design—Cluster randomized controlled trial

Setting and Participants—167 patients recruited from 23 hemodialysis facilities.

Intervention—Navigators met with intervention patients to provide transplant information and assistance. Control patients continued to receive usual care.

Outcomes—Agreement at study initiation between medical records and (a) patient self-reported interest in transplantation and (b) study assessments of medical suitability for transplant referral.

Measurements—Medical record assessments, self-reports, and study assessments of patient interest in and suitability for transplantation.

Results—There was disagreement between medical records and patient self-reported interest in transplantation for 66 (40%) of the 167 study patients. In most of these cases, patients reported being more interested in transplantation than their medical records indicated. The study team determined that all 92 intervention patients were medically suitable for transplant referral. However, for 38 (41%) intervention patients, medical records indicated that they were not suitable. About two-thirds of these patients successfully moved forward in the transplant process.

Conclusion—Dialysis medical records are frequently inaccurate in determining patient interest in and suitability for transplantation.

Keywords

Dialysis; Transplantation; Medical Records; Accuracy

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Author Contributions

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Introduction

Compared with long-term dialysis treatment, kidney transplantation generally offers a longer life span and better quality of life.¹ Eight sequential steps are required to obtain a kidney transplant including medical suitability, interest in transplant, referral to a transplant center, first visit to center, transplant workup, successful candidate, waiting list or identify living donor, and receive transplant. Many patients, especially minorities, women and the poor, have difficulty navigating this complex process.^{2–7} We conducted a cluster, randomized controlled trial at 23 Northeastern Ohio dialysis facilities to determine the effect of a patient navigator on forward progress through these steps. In this paper, we present a secondary analysis specific to the first of these sequential steps.

Dialysis providers are required to discuss treatment options with patients at least annually and to record this information in their medical records. The accuracy of dialysis medical records with respect to transplant planning is unknown. Inaccurate records may lead to a delay or absence of transplant education and referral. This may result in patients not getting transplants or getting them after a longer period of time on dialysis (which portends poorer graft outcomes).⁸ We used our clinical trial as an opportunity to check the accuracy of dialysis medical records in determining patient interest in and suitability for transplantation.

Methods

Participants and Facilities

All 23 hemodialysis facilities that belong to the three largest hemodialysis chains in Cuyahoga County, Ohio participated. Study staff abstracted medical records to identify community-dwelling patients age 18–70 years old with no absolute contraindications to transplantation. Absolute contraindications to transplantation at our two local transplant centers include systemic infection, extreme obesity, and active or recent malignancy. We excluded nursing home residents, patients >70 years old, and patients who had a communication barrier (e.g., those who were mentally incompetent or did not speak English). We also excluded patients who had already made a first visit to a transplant center or received a kidney transplant in the past as they demonstrated the ability to complete key steps in the transplant process without the help of a navigator. Study coordinators described the study to eligible patients during a dialysis treatment and obtained written informed consent. Each participant was given \$15 every 6 months to thank him or her for participation. This study was approved by the institutional review board of MetroHealth Medical Center, Cleveland, Ohio.

Baseline Assessment

Study staff reviewed all notations in available medical records including electronic and written documentation about each patient's interest in and suitability for transplantation. If there were any discrepancies among the notations, the most recent entry was used as an indicator of "medical record assessment of patient interest and suitability."

Study staff asked patients two separate questions about their interest in 1) deceased and 2) living donor kidney transplantation. The answer choices were interested, not sure, or not interested. These two answers were combined as an indicator of "patient self-reported interest" as follows: patients interested in either form of transplantation were categorized as interested, patients unsure about either form were categorized as unsure, and patients uninterested in both were categorized as not interested.

Patients with absolute contraindications to kidney transplantation listed in their medical records were not eligible to participate in the study. However, some patients were listed as unsuitable for transplantation in their medical records but had no absolute contraindications listed in their records. For intervention patients, study staff contacted the participant's nephrologist for clarification of medical suitability. Such clarification was not done for control patients to prevent contamination of the study design.

Intervention and Control Group

Participants were recruited between January 2009 and August 2009 and were followed up for 24 months or until they died, moved, withdrew, or reached the study end in February 2011. Navigators who were trained kidney transplant recipients met with intervention patients on a monthly basis. The navigator determined the patient's current step in the transplant process and provided specific information tailored to each patient's needs. Patients in the control group continued to receive usual care from their nephrologists and dialysis facility personnel.

Outcomes

The primary outcomes of this secondary analysis are agreement at study initiation between medical records and (a) patient self-reported interest in transplantation and (b) study assessments of medical suitability for transplant referral. Secondary outcomes are completion of three key steps in the transplant process, including referral call to transplant center, completion of pre-transplant workup, and successful transplant candidate. These secondary outcomes were determined by review of transplant center charts.

Statistical Analysis

We used descriptive statistics (proportions, means, standard deviations) to examine the demographic and medical characteristics of participants. We used a 4×3 table to examine agreement between medical record assessment of interest and patient self-reported interest. As an objective indicator of interest and suitability, we determined the number of patients who completed three key steps in the transplant process.

Results

Patient Characteristics

One hundred and sixty-seven patients enrolled in the trial: 92 intervention patients and 75 control patients. A full description of the flow of the trial has been published previously.⁹ As indicated in Table 1, most patients were 55–64 years old, more than half were male, and majority were black. The most common cause of renal failure was hypertension and most of the patients were receiving dialysis less than 18 months. There was no statistical difference in baseline characteristics between control and intervention patients.

Interest in Transplantation

Among all 167 patients, 141 (84%) reported being interested in transplantation, 13 (8%) were unsure, and 13 (8%) were uninterested in transplantation. Medical records indicated that 58 (35%) were interested in transplantation, 22 (13%) were unsure, and 55 (33%) were uninterested in transplantation. For 32 (19%) of the study patients, there was no information in the medical record about interest in transplantation. There was disagreement between medical records and patient self-reported interest in transplantation for 66 (40%) patients. In most of these cases (64 of 66), patients reported being more interested in transplantation than their medical records indicated (Table 2). Patients who were interested in transplantation at the baseline assessment were on dialysis for a shorter duration of time as

compared to patients who were uninterested in transplantation at the baseline assessment (2.7 ± 3.2 yrs vs. 5.0 ± 4.6 yrs, $p=0.06$).

Among 58 patients for whom both the medical record and patient indicated interest in transplantation, 43 (74%) moved forward in the transplant process. Among 83 patients (16+41+26) whose medical records did not reflect their interest, 36 (43%) moved forward in the transplant process (Table 3). By contrast, only 4 of 26 (15%) patients who were unsure or uninterested in transplantation moved forward in the transplant process (not shown in Table 3).

Medical Suitability for Transplantation

The study team determined that all 92 intervention patients were medically suitable for transplant referral. However, for 38 (41%) intervention patients, medical records indicated that they were not suitable. A majority of these patients (26 of 38) successfully moved forward in the transplant process. Note that there was no information in the medical record about suitability for 11 (12%) patients (Table 4).

Discussion

We found that medical records underreported patients' interest in transplantation. Many patients who were categorized as uninterested in dialysis facility records moved forward in the transplant process suggesting that the records were inaccurate about interest. Over 40% of intervention patients were categorized as not suitable for transplantation by their records but were categorized as suitable for transplant referral by the study team. A majority of these patients moved forward in the transplant process suggesting that dialysis facility records were inaccurate about suitability. In addition, a sizeable number of patients had no information about interest in or suitability for transplantation in their medical records.

The strengths of our study include a longitudinal design that allowed us to determine patients' progress through the sequential steps in the kidney transplant process. We were able to reconcile the documentation in the medical record with direct patient input, assessment of contraindications to transplantation, and clarifications from patients' nephrologists. We enrolled patients from the 3 largest hemodialysis chains in the county and therefore, a variety of electronic and written medical record formats were included in the study. With the exception of race, the patient characteristics were similar to those of hemodialysis patients nationally.

Previous studies have shown that medical records may underestimate the actual care provided to patients.¹⁰ Moreover, the sensitivity of medical records to measure different types of services rendered, including health habit counseling, is low.¹¹ Similar to our findings with differences in recorded information from treatment discussions between nephrologists and patients, Manley and his colleagues found that dialysis facility records commonly contained discrepancies regarding medications.¹²

Our findings have important implications for patients, providers and health policy makers. Patients should engage their dialysis providers in conversations regarding transplantation. If told that they are unsuitable for transplant, patients should ask for an explanation. Patients should also take advantage of their ability to self-refer to transplant centers for evaluations. Clinician inertia to discuss transplantation more frequently or understand patients' reservations about transplantation and address them in those that are candidates may result in lack of progress in the complex process of obtaining a kidney transplant. Nephrologists rounding at dialysis facilities should make it a priority to record details about treatment discussions that are held with patients and not defer the responsibility to educate patients

about transplantation to ancillary staff. Clinical reminders integrated into the dialysis medical record may serve an important role to help improve the accuracy about suitability for and interest in transplantation. Policy makers may consider asking for documentation about the treatment options for dialysis patients to be more detailed and occur more frequently to ensure that patients are obtaining consistent information about transplantation.

Several limitations must be considered when interpreting our results. We did not assess suitability for transplantation for the 75 control patients because this was not necessary for our clinical trial. Interest and suitability may change over time, but we present data at a single time point for each patient. We did not collect information about when the medical record was last updated. Limiting our study to a single geographic region may hinder its generalizability. We were unable to determine if inaccuracy of dialysis medical records acted as a barrier to transplantation. While our navigator intervention did not affect the baseline agreement between medical records and patients' interest and suitability for transplant, it did enhance movement in the transplant process. As a result, the use of navigators may have influenced our findings about movement in the transplant process (Tables 3 and 4) for intervention patients.

In conclusion, dialysis facility medical records are frequently inaccurate in determining patient interest in and suitability for transplantation. Since these are key steps in obtaining a transplant, we urge providers to document this information with the same rigor that they document dialysis dose, anemia management, and serum albumin.

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Table 1

Characteristics of 167 Intervention and Control Patients at Study Initiation

Characteristic	n (%)
Age	
18–44 yr	23 (14)
45–54 yr	49 (29)
55–64 yr	69 (41)
65–70 yr	26 (16)
Male	94 (56)
Race	
black	114 (68)
white	38 (23)
other	15 (9)
Cause of renal failure	
hypertension	73 (44)
diabetes	58 (35)
glomerulonephritis	17 (10)
Other	19 (11)
Time receiving dialysis	
<18 mo	69 (41)
18–36 mo	44 (26)
>36 mo	54 (32)
Comorbid conditions	1.7 (\pm 1.2)

Note: Count data are expressed as total number and percentage, and, continuous variables as mean \pm standard deviation.

Table 2

Agreement Between Medical Record and Patient Self-Reported Interest in Transplantation Among 167 Intervention and Control Patients at Study Initiation

Medical Record Assessment of Interest	Patient Self-Reported Interest		
	Yes	Unsure	No
Yes	58	0	0
Unsure	16	4	2
No	41	7	7
No Information	26	2	4

Table 3

Movement in Transplant Process Among 141 Intervention and Control Patients Reporting Interest in Transplantation at Study Initiation

Patient Self-Reported Interest	Medical Record Assessment of Interest	n	Movement in Transplant Process				Successful Transplant Candidate
			No Contact with Transplant Center	Referral Call to Transplant Center	Completed Pre-Transplant Work-Up		
Yes	Yes	58	15	21	5	17	
Yes	Unsure	16	8	2	3	3	
Yes	No	41	28	8	2	3	
Yes	No Information	26	11	8	3	4	

Table 4
 Movement in Transplant Process Among 92 Intervention Patients by Medical Record Assessment of Suitability at Study Initiation

Medical Record Assessment of Suitability	n	Movement in Transplant Process			
		No Contact with Transplant Center	Referral Call to Transplant Center	Completed Pre-Transplant Work-up	Successful Transplant Candidate
Yes	43	12	14	4	13
No	38	12	18	3	5
No Information	11	3	5	1	2