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The Quality of Health Insurance Service Delivery for Kidney Transplant Recipients: A Patient Perspective

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Abstract

Increased attention has been devoted to improving quality care in kidney transplantation. The discourse on quality care has focused on transplant center metrics and other clinical parameters. However, there has been little discussion of the quality of health insurance service delivery, which may be critical to kidney recipients' access to transplantation and immunosuppression. This paper describes and provides a framework for characterizing kidney transplant recipients' positive and negative interactions with their insurers. A consecutive cohort of kidney recipients (n=87) participated in semi-structured interviews on their interactions with insurance agencies. Patients reported negative (37%) and/or neutral or positive (79%), interactions with their insurer (a subset (16%) reported both). Perceived negative experiences included: poor service, logistical difficulties with confusing and time-consuming paperwork, poor communication, rude behavior, and concerns about adequate coverage. Positive experiences related to: having good coverage, a simple application process, straightforward transactions, and helpful communication. Findings suggest that even when patients have insurance coverage, difficult interactions with insurers and limited skills in navigating insurance options may limit their access to needed medications and health services. Future research is needed to test this hypothesis in a larger population.

Keywords

Quality care; health insurance; health services; delivery; kidney transplantation;
immunosuppressant medications; ethics; access to care; qualitative research

Since the publication of the Institute of Medicine report, *Crossing the Quality Chasm*, [1] greater attention has been devoted to analyzing the quality of health care and health services. In transplantation, quality efforts have focused on the impact of transplant center metrics on patient outcomes. [2] However, few studies have considered the quality of non-clinical health insurance service delivery despite insurers' endeavors to foster quality care. [3] Most commercial health plans measure patient satisfaction as a quality indicator [3] but focus on limited dimensions of patients' interactions with insurers. [4–5]

The limited available research on the quality of health insurance service delivery has concentrated on either: 1) describing beneficiaries' experiences of difficult interactions with

insurers, including obtaining referrals to out-of-network specialists[6] and long queues and delays when calling insurer representatives,[7] or 2) the impact of beneficiaries' interactions with health insurers on health[6] or trust in providers.[8–9] For example, administrative delays in insurance coverage were associated with increased odds of developing chronic disability in a sample of employees with back injuries (n=35,304).[10] Although anecdotal reports abound,[11] there has been little systematic examination of beneficiaries' reported interactions with insurers in the US[12–13] or of unique issues raised by kidney transplant recipients. A survey of Medicare beneficiaries (n=2,997) found that poorer familiarity with the Medicare program is associated with delayed care, lack of prescription medication use, and poorer overall health.[14] In other health contexts, patients' perceptions of disrespect from clinicians adversely affect healthcare utilization.[15]

Beneficiaries' perspectives of their interactions with insurers are a needed component of quality care measurement.[16] Health insurance is an essential element of the health care system. As approximately 255.1 million (84.6%) people had health insurance in 2008,[17] beneficiaries will likely have concerns regarding service delivery. The American Medical Association's 2010 National Health Insurer Report Card finding that one in five health insurance claims are wrongly handled supports this point.[18] Additionally, effectively navigating the health insurance system requires knowledge and skills to understand insurers' policies, ask the right questions, and pursue inquiries into unresolved claims.[19]

The quality of insurance delivery is especially important for kidney transplant recipients. First, most kidney recipients rely on health insurance coverage *long-term* for costly immunosuppressive drugs.[20] Second, having greater insurance coverage is associated with higher graft survival.[21] Third, kidney recipients have frequent interactions with insurers given their frequent clinic visits, testing, medication regimen adjustments, and the *coordination of benefits period* (when their primary and secondary insurance carriers eventually switch).[22]

This paper examines how kidney transplant recipients evaluated their interactions with insurance companies and describes the types of difficulties patients encountered when interacting with insurance agencies. This paper provides a patient perspective on insurers' strengths and weaknesses in serving this patient population.

METHODS

Study Population

All adult (age 18+) English-speaking kidney transplant recipients were recruited in an incidence cohort from Loyola University Medical Center (LUMC) in Maywood, IL (July 2004 – May 2006) and Albany Medical Center (AMC) in Albany, NY (September 2006 – March 2008). Kidney recipients were eligible for participation if they received a kidney transplant within the previous six weeks.

Qualitative Research

We conducted qualitative research because it is well suited to develop hypotheses, test theory, or describe phenomena when little is known about them.[23] Semi-structured interviews were conducted with kidney recipients on average two months post-transplant either in person or by telephone. The data reported herein are part of a larger study examining the impact of self-care on kidney graft outcomes. Topics covered included: patients' evaluation of interactions with insurers as positive/neutral or negative, patients' descriptions of interactions with insurers, and demographics (age, gender, education, marital status, income, financial strain). Since the purpose of ethnographic qualitative research is to understand experiences from the respondent's point of view, using open-ended interviews

allowed respondents to discuss issues of significance without imposing the researcher's ideas.[23] While a minimum of 12 interviews is sufficient for the development of themes for qualitative research,[24] the larger sample enabled us to undertake mixed qualitative and quantitative analyses to assess demographic correlates of evaluations. Interviews lasted on average 2 hours and were audio-recorded. Respondents were compensated \$20 for participation. Institutional Review Board approval was obtained from LUMC and AMC. Study participants provided written informed consent.

Evaluation of interaction with insurers was assessed by initially asking patients a 'grand tour' open-ended question: "What has been your experience with obtaining the funds to pay for your transplant medications, for example, through public aid or insurance?" This was followed by tailored questions: "How did you navigate the system? What did you do to get through it or get what you needed? What is the system like?" Patients' interactions with insurers were designated as negative if they identified problems. Patients reporting positive and negative experiences were coded as both. We separately analyzed negative and positive/neutral evaluations as they were not mutually exclusive.

Financial strain was assessed using the Economic Strain Scale, a 9-item measure assessing whether an individual has enough money to afford food, medical care, clothing, and leisure activities and how the patient's finances balance at month's end.[25] Cronbach's *alpha* is 0.86;[26] and test-retest reliability correlation is 0.59.[25] Scores range between 0 and 11; a lower score reflects greater strain. For analysis purposes, we used a conservative cut-off of 7 (and lower) to indicate financial strain, as the mean score was 8.

Qualitative Data Analysis

The open-ended responses were transcribed verbatim and analyzed by ethnographic content analysis,[23,27] facilitated by the qualitative data analysis software, The Ethnograph 5.0. [28] Content analysis is an iterative process in which a researcher reviews each transcript to systematically search for themes, patterns, and repetitions emergent from the data.[27] Codes were applied to a first group of patient responses, the coding scheme was revised to adjust for a second set of responses, and these modified codes were applied to the previous set of responses. This process was repeated until no new codes emerged and saturation was achieved.[27] We inductively generated themes by using the constant comparative method to compare and differentiate data bits into categories, then search for text segments with common codes to identify repetitions signaling themes.[23,27] Evaluations were coded independently (by EJG and a research staff member) with discrepancies resolved through consensus to ensure validity.[27]

Simple analyses of demographic predictors of evaluation of interactions with insurers were based on Pearson's Chi-square test, two-sample t tests and one-way analysis of variance. All tests were two-tailed and $p < 0.05$ was considered statistically significant. All statistical analyses were performed using SPSS 15.0 (Chicago, IL).

RESULTS

Demographics

A total of 90 out of 158 (57%) eligible patients participated. Twenty-two percent ($n=35$) refused participation due to post-surgical complications, feeling overwhelmed with the transplant, time commitments, burden of paperwork involved, or disinterest; 4% were undecided ($n=7$); and 16% ($n=26$) gave oral consent but were unable to be reached for an interview. Three participants with incomplete data were excluded from analysis. Our final analysis is based on a sample of 87 (41 from LUMC, 46 from AMC). Study participant characteristics by type of interaction are summarized in Table 1. Most patients were male

(59%), European American (69%), with a mean age of 48 years. Among the total sample, patients identified their primary insurance as private (52%), Medicare or Medicaid (41%), or unknown (1%). Approximately 12 different private primary insurers were identified. Participants did not demographically differ from nonparticipants.

Evaluation of Interactions

Given the option to report either or both types of experiences, over a third (37%) of kidney recipients reported negative interactions, most (79%) reported neutral or positive interactions, and a subset (16%) reported both negative and positive interactions with their insurer. Demographic correlates of negative interactions included financial strain and donor source, while positive interactions were correlated with marital status (Table 1). Specifically, patients reporting negative interactions were more likely to experience financial strain ($t(48) = -1.78, p < 0.04$) and have received organs from living donors ($X^2 = 4.33; p < 0.05$), while those reporting positive interactions were more likely to be married ($X^2 = 12.56; p < 0.03$).

I. Negative Interactions—The major themes regarding negative interactions with insurers are presented in Table 2. A major problem patients experienced is that poor insurance service results in poor health care. Patients also reported encountering poor service relating to communication, paperwork processing, and the time-consuming application process. Although these themes overlap, they are discussed individually below.

A. Poor insurance service results in poor care: Eleven patients reported that problems with the service provided by their insurer resulted in worse medical care, including delayed treatment, no access to medications, and constraints on where medications can be purchased. Patients defined poor service as delays or denials in coverage and pre-approvals ($n=5$) and errors in processing their paperwork ($n=4$). These errors pertained to incorrect documentation that failed to get fixed due to inadequate internal review, fact checking, and communication problems. For example, one patient recounted how the delay in insurance coverage, due partly to the insurer's lack of knowledge and disbelief about the silent onset of ESRD, resulted in her delay in receiving the transplant.

[Supplementary Material Quote 1]

Another patient's narrative illustrates how insurer's errors in processing claims delayed his access to health care.

[Supplementary Material Quote 2]

B. Processing paperwork is difficult and time consuming: Many patients ($n=19$) reported that processing insurance paperwork and applications was difficult and time-consuming. Application forms for Medicare or public aid were considered difficult to understand and required patients to prove their ESRD condition. After enrollment, insurers sent patients much paperwork to complete daily and patients perceived that insurers themselves were confused with the forms. When the paperwork did not coincide with the facts, resolving issues was difficult because it entailed working with a large bureaucracy. For example:

I had to go through a big hassle with them [insurance company] before they [agreed to cover the transplant]... Well, we had [insurance company 1] and then starting the first of the year, they changed—my husband's company— to [insurance company 2]. Well, Loyola was not covered by [insurance company 2], so it took me a good two months to six weeks and we were getting down to a week before the surgery for them to say that they were going to give me the transition of care. We were having

surgery on the 30th, and then on the first, they're changing over the insurance. That got to be kind of a hassle, but finally it worked out. (55-year-old white female, total family income: \$45,000–\$60,000; #10014)

Other patients reported frustration with insurers who did not believe patients had ESRD or needed a transplant, and required proof of their condition.

[Supplementary Material Quote 4]

C. Communication: Several patients (n=11) reported experiencing communication problems with insurers which entailed: being on hold for a long time; having to place frequent phone calls to reach representatives; representatives who were rude, unhelpful, and unable to provide assistance; representatives who provided contradictory information; and representatives who would not contact colleagues in other Medicare offices in order to correct mistakes in the system. For example:

Really a big pain in the butt. I mean, you know all the papers and the bureaucracies, really, I mean, it takes a long time to get anything done. Sometimes months before you even know if you're covered or not. ... 'Cause I mean sometimes you have to call every day for 3 weeks just to find out if you've been covered or not. I mean, it's not like you just pick up the phone and call and say hi. You're there on hold for 45, 50 minutes. I mean, one day I was on hold for 2 and a half hours. (36-year-old Native American male, income unknown; #12321)

A patient's rights activist related her interactions with her insurer.

[Supplementary Material Quote 6]

D. Concerns about coverage: Nine patients reported that they did not receive adequate coverage from insurers in terms of bills not being paid by insurers, being 'nickel and dimed,' and slow payments by their insurers. Two patients reported that because insurers were unwilling or slow to pay bills, patients were caught in the middle to mediate between insurers and care providers, particularly when private insurance companies switched with Medicare to become the primary insurer.

[Supplementary Material Quote 7]

As the patient's quote above also shows, health literacy skills appear to be necessary to effectively navigate the health insurance services. Two other patients commented that they had learned the system and pitied those who did not, as stated:

Well, with HMO's you have to have a referral for every breath you take. I mean you really have to keep on top of the HMO's. People who don't know the system, I don't know how they get by, I really don't. (55-year-old white female, total family income: \$45,000–\$60,000; #10014)

II. Positive or Neutral Interactions—Patients' positive or neutral experiences can be classified into four themes: having good coverage (64%), simple application process (25%), straightforward transactions (12%), and helpful, proactive communication (7%) (Table 2).

A. Having adequate insurance coverage: Many patients (n=44) reported positive or neutral experiences because their insurer provided ample or adequate coverage of their medical bills. Patients commended their insurers' service for covering expected costs as planned (n=24), paying the bills without problems (n=7), being flexible in service delivery (n=4), and being transparent about billing and costs (n=2). For example, they praised

insurers for paying bills even when physicians failed to call in advance, allowing patients to purchase medications from many locations, allowing patients to purchase a three-month supply of medicines at one month's cost, and allowing medication purchases over the Internet. Minimal interactions with insurance companies were considered a positive experience (n=6).

[Supplementary Material Quote 9]

B. Simple application process: Many patients (n=17) reported that their application process was simple, and for a subset (n=10), having the dialysis social worker or transplant coordinator complete the application paperwork contributed to their positive evaluation of their experience.

[Supplementary Material Quote 10]

C. Straightforward transactions with insurers: Eight patients stated that billing transactions were straightforward in terms of pharmacies taking care of the billing (n=4), billing from insurers (n=2), transitioning from secondary to primary insurer (n=1), and consistency in insurance companies (n=1).

[Supplementary Material Quote 11]

D. Helpful, proactive communication: Five patients reported that insurance companies were polite, helpful, and even initiated contact with patients to ensure they were well taken care of.

[Supplementary Material Quote 12]

DISCUSSION

In this qualitative study of kidney transplant recipients' perceptions of interactions with insurers, we found that a third (37%) had negative experiences, and two-thirds (79%) had positive or neutral experiences. The rate of negative interactions found herein may be higher than for other patient groups as ESRD patients are legally barred from enrolling in Medicare-managed care plans which are designed to enhance quality care.[29]

Our findings suggest that even when patients have insurance coverage, difficult interactions with insurers may affect their ability to obtain necessary care and medications. Analyses revealed that the slow delivery of service, errors, poor coordination of care, and poor communication with insurers were perceived to delay care and cause much frustration. Negative interactions were partly driven by factors unique to the kidney transplant population: the silent, acute onset of ESRD and the transition in coverage period. Narratives of positive or neutral interactions indicated that providing ample coverage and straightforward and helpful communication characterized quality service, as corroborated by patient satisfaction surveys.[4,13] Consistent with our findings, research in Sweden found that 73% of long-term sick leave survey respondents reported positive interactions with social insurance representatives.[13] Our findings also suggest that patients require knowledge and skills to effectively navigate the health insurance system to obtain information, respond to claims, or correct claims on a timely basis.[19]

Given the strengths of this manuscript, some limitations should be noted. The low participation rate may have resulted in a biased sample. Recruitment attrition may have been related to poor health. If our hypothesis that poor interactions with insurers are related to worse outcomes were accurate, then the sample may under-represent patients experiencing

negative interactions. The relatively highly educated sample may be a vestige of characteristics of patients willing to participate in the study. We relied on patients' self-report and did not independently validate actual interactions with insurers. External validity was enhanced by the multi-site study design. As a qualitative study, our findings are not meant to be generalizable to all populations, but used to generate hypothesis that can be tested in the future.

Patients' narratives of interactions with insurers are valuable because they provide a much-needed patient perspective on the quality of insurance service delivery, which may affect their access to medications, health care, and services. Future research is needed to systematically test the hypothesis that poor health insurance delivery results in poor transplant outcomes among a larger, more racially and ethnically diverse sample. Such a study should develop questions that directly assess patients' perceptions of service delivery quality in terms of the frequency of coverage delays, denied immunosuppressant medications and other medications, errors in obtaining coverage, and patients serving as the middleman between insurers and health providers. Future research should also develop measures that assess both the newly identified dimensions of quality interactions with insurers, and patients' navigational knowledge and skills with insurers. Using a longitudinal approach, future research should analyze the impact of insurance quality on short-term outcomes like stress, intermediate outcomes like medication adherence, use of services, number of hospitalizations, and long-term outcomes like kidney function, kidney biopsies, infections, proteinuria, and hypertension. Should such relationships bear out, findings would guide further research into the development of educational interventions that increase patients' knowledge and skills to effectively navigate the health insurance options.[12] For example, further research may entail evaluating the effectiveness of patient navigators in guiding transplant recipients through the complex health insurance system, as used successfully in the oncology setting to reduce racial/ethnic disparities in access to care.[30] Educational interventions could be tailored to patients at greatest risk for experiencing negative interactions, including those facing financial strain. Adequate insurance coverage is essential for kidney transplant recipients to obtain necessary immunosuppressive medications to attain optimal outcomes. Thus, transplant centers should play an active role in assisting recipients in obtaining, retaining, and understanding health insurance coverage.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table 1
Characteristics of Study Participants with Positive and Negative Experiences Interacting with Insurers (N=87)*

Variable	POSITIVE EXPERIENCE			NEGATIVE EXPERIENCE		
	Yes	No	P	Yes	No	P
Total	N (%)	N (%)		N (%)	N (%)	
Sex	69 (79)	18 (21)		32 (37)	55 (63)	
Male	39 (45)	12 (14)	0.59	21 (24)	30 (35)	0.37
Female	30 (35)	6 (7)		11 (13)	25 (29)	
Participants' age, Mean	69	47	0.77	32	46	0.67
Marital Status			0.03			0.30
Married	58 (67)	10 (12)		23 (26)	45 (52)	
Not Married	11 (13)	8 (9)		9 (10)	10 (12)	
Years of education completed, Mean ^a	68	14	0.84	32	14	0.92
Race			0.25			0.64
White	50 (58)	10 (12)		21 (24)	39 (45)	
Non-White	19 (22)	8 (9)		11 (13)	16 (18)	
Employment status ^a			0.79			0.65
Employed (part or full time)	38 (45)	9 (11)		19 (22)	28 (33)	
Not Employed	29 (34)	9 (11)		13 (15)	25 (29)	
Economic Strain, Mean ^a	69	9	0.10	31	8	0.04
Gross Income ^a			0.45			0.30
< \$29,999	16 (20)	6 (8)		11 (14)	11 (14)	
\$30,000 – \$74,999	27 (34)	7 (9)		10 (13)	24 (30)	
\$75,000 +	21 (26)	3 (4)		9 (11)	15 (19)	
Primary Insurer ^a			0.11			0.18
Private/Group Insurance	39 (46)	6 (7)		13 (15)	32 (38)	
Medicare/Medicaid	29 (34)	11 (13)		18 (21)	22 (26)	
Cause of End-Stage Renal Disease			0.79			0.62
Diabetes	6 (7)	1 (1)		2 (2)	5 (6)	
Hypertension	18 (21)	3 (3)		6 (7)	15 (17)	

Variable	POSITIVE EXPERIENCE				NEGATIVE EXPERIENCE				P
	Yes	N	(%)	No	Yes	N	(%)	No	
Glomerulonephritis		14	(16)	4	(5)	6	(7)	12	(14)
Other		31	(36)	10	(12)	18	(21)	23	(26)
Number of Transplants									0.79
1		54	(62)	15	(17)	26	(30)	43	(49)
2+		15	(17)	3	(4)	6	(7)	12	(14)
Organ Donor Source									0.05
Deceased donor		41	(47)	7	(8)	13	(15)	32	(37)
Living donor		28	(32)	11	(13)	19	(22)	20	(23)

* As we analyzed the positive and negative experiences separately, the denominator for each group is comprised of the total sample size of 87.

^aTotal n does not add up to 87 because participant(s) did not know or disclose information.

Table 2

Types of Negative and Positive Experiences Interacting with Insurers

	N (%)
Negative Experience Themes (N=32)	
Poor service by insurers results in poor patient care	11 (34)
Processing paperwork is difficult and time consuming	19 (59)
Communication with insurers is poor, inadequate, rude	11 (34)
Concerns about coverage of medical bills	10 (31)
Positive Experience Themes (N=69)	
Adequate coverage of medical bills	44 (64)
Simple application process	17 (25)
Straightforward billing transactions	8 (12)
Helpful, proactive communication by insurers	5 (7%)