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Communication Study

Communication self-efficacy, perceived conversational difficulty, and renal patients' discussions about transplantation

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ABSTRACT

Objective: Many patients with chronic and end-stage renal disease (ESRD) have reported difficulties initiating and managing discussions about kidney transplantation, particularly live donor transplantation (LDT). Limited communication has demonstrable impact on patients' access to transplantation, the duration of dialysis treatments, and the length of time awaiting a transplantable kidney. This formative study sought to identify the specific communicative and conversational elements impeding ESRD patients' discussions about transplantation to inform the design of an educational program facilitating transplant-related discussions.

Methods: From March to July 2012, semi-structured telephone interviews ($n = 63$) were conducted with ESRD patients waitlisted for kidney transplantation at one mid-Atlantic transplant center.

Results: Although 85.7% ($n = 54$) of patients reported holding discussions about transplantation, qualitative analyses of open-ended responses revealed that the majority (66.7%) had limited conversations. Patients reported difficulties managing a variety of logistical and content-related aspects of LDT discussions. Moderate levels of communication self-efficacy were also found (mean = 19.2 out of 28); self-efficacy was highest among respondents having held discussions and was significantly related to perceived magnitude of difficulty handling conversational aspects.

Conclusion: Results support comprehensive communication skills training for ESRD patients awaiting kidney transplantation.

Practice implications: Potential topics to be included in such training are discussed.

1. Introduction

Over the past thirty years, increasing rates of diabetes and hypertension (among other conditions) have led to concomitant increases in the number of Americans afflicted with end-stage renal disease (ESRD). Data indicate that nearly 600,000 patients are currently being treated for ESRD through dialysis or transplantation, with nearly 800,000 projected by 2020 [1]. Although kidney transplantation is often the preferred treatment modality for patients with ESRD, only a fraction of those awaiting a transplantable kidney receive a transplant in any given year [2]. This is primarily due to the severe shortage of transplantable kidneys in the U.S. [2]. As a result, many patients succumb to comorbid conditions such as infections or heart disease, or death while awaiting a transplant [1]. With increases expected in both the number of new ESRD cases, particularly in older and minority populations [1], and the number of patients seeking transplantation, increasing patients' access to kidney transplants and reducing morbidity and mortality in this population are paramount.

Patients' communication about transplantation, living donor transplantation (LDT) in particular, with members of their social networks (e.g., family members, friends, coworkers, neighbors, etc.) has had demonstrable impact on access to transplantation [3]. Transplant-related discussions may also reduce the need for and duration of dialysis treatment, and length of time awaiting a transplantable kidney. Yet, research has revealed patients' reluctance to engage others in conversation about LDT; less than half of patients sampled have found it appropriate to request living donation from others or expressed a willingness to do so [4–7]. Patients have cited concerns about risking donors' immediate and future health; causing pain, inconvenience, and disappointment if the kidney were rejected; potential negative effects of donation on the donor–recipient relationship; and, feelings of obligation to the donor after transplantation as reasons for their reluctance [4,6,8–11]. A host

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of other factors also contribute to patients' reticence to communicate about this topic. For instance, white race, college education, fewer concerns about LDT, and less favorable perceptions of patients' own health status have been shown to predict willingness to talk about LDT, while female gender, a preference for LDT, and a willingness to ask for help were positively associated with self-reported LDT conversations [12,13].

The extant research, however, has limited its focus to communication about LDT and, more specifically, to requests for living donation. Few studies offer insight into specific facets of the discussion that are problematic for patients to manage. To date, initiating the discussion and requesting donation are the only conversational aspects cited as impediments to LDT discussions [14–16]. Yet, patients will also likely face the challenges of providing information about transplantation, both deceased and living donor, and living donation as well as answering questions and responding appropriately to others' fears and/or concerns about donating. Furthermore, no effort has been made to quantify candidates' communication self-efficacy or confidence communicating about LDT [17,18]. The predictive ability of personal appraisals of task performance abilities (i.e., self-efficacy) has been well-documented [19]. Thus, the goals of the current research were twofold. First, this formative study was conducted to identify specific aspects of transplant-related conversations that impede patients' discussions of the topic. The study also sought to quantitatively assess patients' communication self-efficacy. Understanding the discussion-related issues impeding conversations about transplantation as well as patients' confidence holding such conversations is a critical first step toward designing educational programs to coach patients on how to effectively broach the topic of transplantation, including LDT, and manage the ensuing discussion.

2. Method

2.1. Patient sample

Adult, English-speaking patients with ESRD ($N = 172$) wait-listed, in active status (status 1 or 2), for kidney transplantation at one mid-Atlantic transplant center were invited to participate via letters describing the nature and purpose of the research. Two weeks after the letters were mailed, potential participants were contacted by telephone to solicit and address questions about and invite participation in the study. Telephone interviews were completed with 63 (36.6%) kidney transplant candidates agreeing to participate. The low participation rate was largely due to difficulties contacting potential subjects for recruitment. While 26 (15.1%) patients were unable to be reached because of wrong or disconnected telephone numbers, only 15 (8.7%) refused participation and 15 (8.7%) were deemed ineligible due to age (i.e., <18 years), death or incarceration; 53 (30.8%) were unresponsive after multiple attempts to contact by mail and telephone. Interviews were conducted from January to July 2012. Medical record abstractions ascertained participants' time on the transplant wait list, time on dialysis, and past transplant history. Abstractions were performed only for subjects consenting to the review of their medical charts (98.4%; $n = 62$). The study protocols were approved by the university's Institutional Review Board. Verbal informed consent was obtained from all participants prior to beginning the interviews.

2.2. Measures

A semi-structured interview guide was used for data collection. The guide was developed based on a review of the extant literature on this topic and pilot tested with a patient sample ($n = 12$). Modifications to question wording and order were made, as appropriate, before implementation. In addition to capturing sociodemographic information (i.e., age, sex, ethnicity, race, education, marital status, income, transplant preference (living or deceased donor), the interview assessed participants' communication intentions and behaviors, transplant preferences, perceptions of the difficulty and confidence managing various aspects of LDT discussions, and perceptions of the effects of such discussions on interpersonal relationships. Measurement of these constructs is discussed in greater detail below. Higher scores indicate greater levels of each measured variable.

Communication behaviors. One dichotomous item assessed candidates' past communication about transplantation with family members and friends (*yes*/*no*). An open-ended question prompted respondents reporting discussion of transplantation to disclose the content of the conversation(s). A subsequent item gauged past requests for living donation (*yes*/*no*). Respondents reporting discussions or requests were then asked to indicate with whom the discussions were held or requests directed.

Difficulties managing LDT discussions. A series of open and closed-ended questions gauged patients' difficulty managing discussions about live donor transplantation. Eight dichotomous items were used to assess participants' difficulty managing various aspects of LDT discussions including, (1) finding the right person to hold the discussion with; (2) finding the right words to use during the discussion; (3) finding the right time and/or place to hold the discussion; (4) beginning the conversation; (5) answering questions; (6) responding to fears and/or concerns; (7) closing the discussion; and (8) asking the conversational partner to consider living donation. The items were developed based on the SEGUE Framework, a tool developed for the assessment of medical students' communication skills, and modified for the context of interpersonal communication about transplantation [20]. One open-ended item allowed participants to indicate other challenging or difficult aspects of the conversation not included in the list.

Items for which participants acknowledged even a minimal amount of difficulty were followed-up with a probe asking patients to rate the magnitude of difficulty with the conversational aspect using a 5-point Likert-type scale (*1 – slightly difficult, but manageable; 5 – so difficult I cannot attempt this task*). A rating of zero was assigned to all items for which participants indicated no difficulty managing. A global score representing respondents' overall magnitude of difficulty managing LDT conversations was created by summing item scores on the follow-up question; global scores ranged from 0 to 40. The scale's internal consistency reliability, as measured using Cronbach's alpha, was 0.86. A final open-ended item prompted respondents to indicate the *most* difficult aspect to holding LDT discussions.

Communication self-efficacy. Seven 4-point Likert-type items (*1 – not at all confident; 4 – extremely confident*) were used to gauge respondents' confidence in managing aspects of LDT discussions including (1) talking with family (general); (2) talking with friends (general); (3) providing information; (4) answering questions; (5) addressing fears and concerns; (6) beginning the conversation; (7) closing the conversation. Following Bandura's [21] recommendations, these items were developed to reflect the situation under investigation (i.e., transplant-related conversations). Individual items were summed and ranged from 7 to 28. Internal consistency reliability of the scale met acceptable levels ($\alpha = 0.84$).

Impact on interpersonal relationships. An open-ended item ascertained the effects of LDT discussions on relationships with participants' conversational partners. Respondents with no history of LDT discussion were asked to consider how such conversations would likely impact relationships.