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Perceptions of Patient Candidacy for Kidney Transplant in the United States: A Qualitative Study Comparing Rural and Urban Nephrologists

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Abstract

Objectives—To explore different perceptions of urban and rural nephrologists regarding patient suitability for transplant.

Materials and Methods—We conducted 4 focus groups, each consisting of 4 to 6 nephrologists practicing in either a rural (n=9) or an urban setting (n=11). A topic guide was developed and modified according to pilot testing. Broadly stated, open-ended queries probed perceptions about the ideal or suboptimal candidates for transplant, perceived barriers to transplant, views regarding providing information to patients, and strategies that could improve transplant rates. At the sessions, all audio was recorded and professionally transcribed. Responses were pooled, deidentified, and analyzed using qualitative thematic content analysis.

Results—In considering candidacy, urban participants mentioned “age,” “compliance,” and “functional status”; “support” was a more-prevalent theme among rural nephrologists. Urban physicians discussed the expected effect of a transplant on a subject’s quality of life. As barriers to transplant, “evaluation time” was mentioned by urban groups only, and “distance to transplant center” was suggested by rural nephrologists only. To improve transplant rates, urban nephrologists suggested strategies that would increase the donor pool. Rural nephrologists, on the other hand, suggested a collaboration between nephrologists and the transplant center, “limiting listing eligibility” and “financial assistance.” Rural nephrologists suggested providing comparisons of modalities and information about selecting subjects.

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Conclusions—This qualitative study underscores geographic differences in perceptions of nephrologists regarding patient candidacy for kidney transplant, perceived barriers to kidney transplant, and proposed strategies to increase rates of kidney transplant. These differences are potential contributors to geographic variations in referring patients for kidney transplant.

Keywords

Focus groups; Geographic; Disparities

Introduction

The public health burden of chronic kidney disease is substantial. When compared with maintenance dialysis, renal transplant is associated with a better quality of life, improved life expectancy, and lower costs; it is considered the preferred treatment for most patients with end-stage renal disease (ESRD). Despite the well-known advantages of a transplant, not all populations benefit from it. Many studies aim at identifying barriers to renal transplant to understand disparities among different peoples. Nephrologists' perceptions of patient suitability for transplant are important contributors to disparities in transplant.[1,2] Physicians' practice patterns are known to be affected by their own demographic characteristics,[3] which are likely to influence their perceptions about the benefits of transplant for certain patients.

Several studies have examined physicians' views regarding the benefits of transplant compared with dialysis, and their perceptions on posttransplant survival of certain patients.[4,5] In one national survey of 278 nephrologists in the United States, physicians cited patients' preferences, failure to complete evaluations, and comorbid illnesses as reasons for their reluctance to refer patients for transplant.[6] The authors of the study proposed the way transplant is presented by nephrologists as treatment for patients may be reflective of their own perceptions and views.

We qualitatively investigated the relation between the nephrologists' practice location, and their perceptions of patient suitability for transplant and views about barriers to transplant. Focus groups were used often to illuminate key points about the topic and to create comprehensive surveys. They have been widely used by the medical profession to explore opinions, knowledge, and perceptions, and to develop research hypotheses. This method has been used in health disparities research,[7] and is thought to be particularly well-suited for enhancing our understanding of the root causes of inequalities in care.[8] This study forms the basis for a larger quantitative survey instrument intended to study the effect of physician and patient perceptions on selecting transplant for ESRD.

Materials and Methods

Study design and recruiting of participants

The Institutional Review Board of Penn State College of Medicine approved the research protocol. The protocols conformed to the guidelines of the 1975 Helsinki Declaration. Written, informed consent forms were completed by each subject. Two, 2-hour focus group sessions were planned for the nephrologists practicing in urban and rural settings, each.

Eligible participants were nephrologists involved in the care of at least 20 patients with ESRD, willing to participate in group discussion and physically able to attend the focus group meeting. We recruited participants by distributing flyers at the November 2010 annual meeting of the American Society of Nephrology Kidney Week (Denver, CO, USA). The flyers described the purpose of the study, the intended duration, date, time, and location of the sessions, and the honoraria provided for participation. Those interested were asked to directly contact the principal investigator to obtain further details. We recruited 8 participants for each focus group to ensure a group of at least 5 participants. We assigned nephrologists to 1 of 4 focus groups depending on whether their practice site was in a rural or an urban area, based on Rural-Urban Commuting Area Codes, and whether they preferred an early morning or an evening meeting. The first 8 volunteers for participation in each group were included in the focus group. The principal investigator contacted each volunteer by telephone 1 day before the group meeting to confirm their participation.

Topic guide

A topic guide was developed based on investigator discussions and literature review. It was modified according to pilot testing according to 2 nephrology fellows and 2 nephrologists at the principal investigator’s institution. Key questions consisted of broadly stated open-ended queries probing the participants’ perceptions about the ideal and suboptimal candidates for renal transplant, perceived barriers to transplant, views about the process of providing relevant information to patients, and strategies to improve rates of transplant (Table 1).

Data collection

The focus group was initiated by introductions, a description of the research, and completion of informed consent (including consent to audio recording and transcription of the discussion). The participants were reassured that their comments would be confidential and that information collected from them and recorded during the sessions would be anonymous and destroyed upon completion of data analyses. The participants’ right to withdraw from the study at any point was reiterated. All participants completed an anonymous questionnaire to collect basic demographic data. For consistency, the principal investigator moderated all sessions using reflective probes for clarification of statements. All sessions were audio recorded and professionally transcribed verbatim.

Data analyses

Transcript of each session was reviewed for quality. The moderator and the transcriptionist independently reviewed each transcript to identify potential response themes to the main question of the study, “What are the important issues surrounding patient suitability for transplant?” There are variations in the literature about whether the group or the individual should be considered the unit of analysis in focus group studies.[9] In this study, we pooled and de-identified responses from individuals within each category of respondents (urban and rural) for the purpose of analysis. We used qualitative thematic content analysis,[10,11] which involved searching the notes to identify dominant and recurrent themes.

Results

Four separate focus groups were conducted over 4 days with a total of 20 nephrologists. Each focus group consisted of 4 to 6 nephrologists practicing either in a rural setting (n=9) or an urban setting (n=11). Eight of the participating nephrologists (40%) were women. Fourteen participants (70%) identified themselves as white non-Hispanic. Four of the participants were nephrology fellows. The median age among those who reported their age was 58 years old. The mean number of years practicing as a physician was 23.9 (SD 11.4). One of the rural physicians and 4 of the urban physicians held academic appointments. One rural physician and 5 of the urban physicians had an affiliation with a transplant center. The dominant themes and subthemes that emerged during focus group discussions of topics relating to patient candidacy for transplant, patient choice of transplant and perceived barriers to transplant are outlined below and in Tables 2 through 6.

The ideal versus suboptimal candidate for transplant (table 2)

During discussion about the ideal versus suboptimal candidate for kidney transplant, 6 major themes, “comorbidities,” “age,” “compliance,” “functional status,” “patients’ understanding of the transplant process,” and the “support structure” were identified. In all groups, participants mentioned comorbidities as the most important consideration in deciding about patient candidacy for transplant. Compared with rural nephrologists, urban participants mentioned “age,” “compliance” and “functional status” more frequently, while “support” was a more prevalent theme in the discussions for rural nephrologists. Urban physicians believed that the expected effect of kidney transplant on improving the quality of life for the patient should be an important component of the evaluation process.

Why might a patient choose not to be transplanted? (table 3)

When asked to comment on why patients might choose not to be transplanted, participants in all groups believed that issues relating to understanding are the most important. This was followed by “seeing others with poor transplant outcomes” among the urban groups and issues relating to “support” among the rural participants. Other reasons that were mentioned included “age,” “comorbidities,” “doing well on dialysis,” and “religious beliefs.” None of the groups discussed logistics such as, time required for evaluation, and distance needed to travel to the transplant center.

What are some barriers to kidney transplant? (Table 4)

In discussing the nephrologists’ perceptions of barriers to transplant, 5 major themes arouse. Issues relating to “support” and “patient understanding of the process” were noted by both urban and rural nephrologists as being the main barriers to transplant. While “time required for evaluation” was mentioned 4 times in the urban groups, it did not arise during in the discussion among rural nephrologists. In contrast, “distance that is needed to travel to the transplant center” was mentioned only by rural nephrologists.

What can be done to improve rates of transplant? (Table 5)

In all groups, participants mentioned “providing education either to the patients, the providers, or the public” as the main approach to improve rates of transplant. Many urban nephrologists discussed implementing “strategies to increase the donor pool” by programs, such as identifying potential deceased donors earlier and paired donor exchange programs to increase rates of transplant. The need for increased collaboration between nephrologists and the transplant center was mentioned only among rural nephrologists. Other strategies mentioned by rural nephrologists included “limiting the eligibility for the waiting list” and “assistance with finances.”

What type of information do patients need before making a decision about treatment options? (table 6)

When participants were asked about the type of information patients with ESRD need to choose appropriately between the types of treatment, rural nephrologists believed that information aimed at explaining comparison of well-being and quality of life, as well as comparison of complication rates and survival data should be provided. Among urban groups, the need to provide education about all available treatment options was recognized as being crucial for decision making. Only participants in rural groups discussed the need to provide information about the process of patient selection. When asked who should provide information about transplant to patients with ESRD, urban nephrologists suggested only the primary nephrologist and the dialysis nurse. Among the rural groups, while the nephrologist was mentioned by many as being the most appropriate person to provide the information, other suggestions included the nurse, social worker, and providers at the transplant center.

Discussion

In this qualitative study, we found differences in views of urban and rural nephrologists about patient selection for transplant, perceived barriers to transplant, and proposed strategies to improve the rates of transplant. In deciding about patient candidacy for transplant, all participants considered comorbidities as the most important determinant. This finding is congruent with the results of a systematic review of 11 studies, in which physicians’ perception about posttransplant survival of patients was the most commonly identified provider-related barrier.[5] Rural nephrologist also discussed adequate support as a decisive factor. Urban participants mentioned age, compliance, functional status and the expected effect of transplant on quality of life in the individual patient as important considerations in the evaluation process. These findings confirm previous studies. In a systematic review, late referral for transplant by physicians was associated with older patient age, being uninsured, and having from multiple comorbidities.[12]

Participants in all groups believed that inadequate understanding is the most important reasons patients might choose not to pursue transplant. This substantiates the association, found by Navaneethan and associates, between patient’s education and referral for transplant.[12] Insufficient support was, again, mentioned among rural nephrologists as an important determinant for patients. Urban groups mentioned return to dialysis of other patients who had been transplanted as a factor that discourages patients from pursuing transplant. Interestingly, none of the groups discussed time required for evaluation and travel distance as being reasons patients might choose not to pursue transplant.

There was consensus among all groups that insufficient support and patients' inadequate understanding are the main barriers to transplant. Only urban nephrologists mentioned time required for evaluation and only rural nephrologists noted distance from transplant center as additional barriers to transplant.

Providing education was considered the main strategy to improve rates of transplant by all groups. While the urban groups discussed approaches to increase the donor pool, the rural groups suggested limiting the eligibility and thus decreasing the recipient pool as an additional scheme to improve transplant rates. Other suggestions by rural nephrologists included the need for increased collab oration between nephrologists and the transplant center and assistance with finances.

The main difference between the groups regarding the type of information patients with ESRD must be able to choose appropriately between the modality of treatment, was that rural nephrologists discussed the need to provide information about the process of patient selection. Urban participants emphasized the role of the primary nephrologist or dialysis nurse in providing information about transplant; rural participants suggested a more heterogeneous source for the information, including nephrologists, dialysis nurses, social workers, as well as representatives from the transplant center.

The main limitation of our study is selection bias. Recruiting nephrologists from those attending a meeting of the American Society of Nephrology may be source of selection bias. It is likely that nephrologists attending the American Society of Nephrology have different attitudes and practice circumstances than those who do not. While this is a limitation, compared with the alternative strategy of attempting to recruit nephrologists from the community, it was a cost-effective strategy and provided the advantage of selecting from a large sample of nephrologists and conducting the focus group sessions within a short time. Further, the focus group sessions were intended to generate questions rather than to provide quantitative data, minimizing the effect of a selection bias.

Another potential limitation of the study is moderator bias, particularly when the moderator has specific expertise in the topic of interest. The moderator's views may influence the discussion with an emphasis on his/her, rather than the participants', perceptions of the issues.[13] At the same time, it has been suggested that a moderator familiar with the culture of the group is more likely to improve the communication within the group.[14] Nevertheless, to avoid moderator bias, we conducted semi\structured sessions, by using open-ended questions, which had been modified by pilot-testing, and by encouraging all participants to express their opinions and avoiding domination of the group by any individuals.[15] This approach also minimizes the potential for "group think," in which the group tends to conform to the dominant view.[16]

In conclusion, we found urban/rural differences in perceptions of nephrologists about patient candidacy for transplant, perceived barriers to transplant and proposed strategies to increase the rates of transplant. These differences are potential contributors to geographic variations in referral of patients for transplant. The themes identified in this qualitative study will assist in developing questionnaires for quantitative assessment of nephrologists' perceptions of patient suitability for transplant.

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Table 1

Topic Guide

1. Who is the ideal transplant candidate?
2. What are some characteristics of patients that would make them poor transplant candidates?
3. Why might a patient prefer not to be transplanted?
4. What are some barriers to kidney transplant?
5. What can be done to improve rates of transplant?
6. What type of information do patients with ESRD need for making a decision about treatment options?
7. Who should provide the information about transplant to patients with ESRD?

Table 2

The Ideal and Suboptimal Candidate For Kidney Transplant

Themes	**Urban**[*]	**Rural**[*]
Comorbidities	14	14
Age	9	4
Compliance	9	4
Functional status	7	4
Ability to care for self		
Employment		
Understanding of the transplant process	6	5
Education about the process		
Insight about the benefits of transplant compared with dialysis		
Motivation		
Adequacy of support	2	5
Adequacy of social support		
Availability of finances and insurance		

[*] The number of times in which the theme was mentioned in each category of focus groups.

Table 3

Why Might a Patient Choose Not To Be Transplanted?

Themes	**Urban**[*]	**Rural**[*]
Deficiencies in understanding the transplant process	8	6
Inadequate education about the process and the available options		
Fear of surgery		
Fear of medication side effects		
Seeing other patients with poor outcome after transplant	5	1
Lack of support	1	4
Inadequate social support		
Insufficient finances and insurance		
Older age	2	3
Comorbidities	1	2
Doing well on dialysis, does not feel the need to proceed with transplant	2	1
Religious beliefs discourage pursuing transplant	1	1

[*] The number of times in which the theme was mentioned in each category of focus groups.

Table 4

What are Some Barriers To Kidney Transplant?

Themes	**Urban**[*]	**Rural**[*]
Lack of support	6	5
Inadequate social support		
Insufficient finances and insurance		
Inadequate understanding of the transplant process	4	4
Inadequate education about the process and the available options		
Fear of surgery		
Fear of medication side effects		
Time	4	0
Distance	0	2

[*] The number of times in which the theme was mentioned in each category of focus groups.

Table 5

What Can be Done to Improve Rates of Transplant?

Themes	**Urban**[*]	**Rural**[*]
Provide education	8	6
Patient (discussion of transplant at an earlier stage of kidney disease)		
Provider (about the relative benefits of transplant)		
Public (about living and deceased donation)		
Implement and/or improve strategies to increase the donor pool	6	2
Paired donor exchange		
Early identification of potential deceased donors		
Increase collaboration between primary nephrologist and the transplant center	0	4
Regional satellite clinics by the transplant center		
Streamline the referral process		
Limit the eligibility for the waiting list	0	1
Assist with finances	0	1

[*] The number of times in which the theme was mentioned in each category of focus groups.

Table 6

What Type of Information Do Patients Need Before Making a Decision About RxOptions?

Themes	**Urban**[*]	**Rural**[*]
Compare well-being and quality of life between transplant and dialysis	3	6
Provide education about all the available treatment options	6	2
Compare complication rates and survival data between transplant and dialysis	2	6
Explain medication side effects	1	2
Provide more detail about what is involved in the selection and listing process	0	3

[*] The number of times in which the theme was mentioned in each category of focus groups.