

## Medical Provider's Perceptions of ESRD Patients

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### Abstract

Despite changes in the healthcare system, racial and socioeconomic disparities regarding the choice of dialysis among end-stage renal disease (ESRD) patients continue. One possible cause of these disparities in dialysis treatment is the perceptions and observations made by the healthcare provider. This study uses the shared decision-making healthcare model as a framework for examining this possible cause. Five semi-structured interviews were conducted with health care providers, focusing on cultural competency, communication among the provider and their patients as well as their colleagues, the utilization of the shared decision-making model, and the recognition of the disparities in dialysis treatment. Participants included two renal nurses, one nephrologist, one social worker, and one dietician. Audio recordings of each interview were transcribed verbatim and coded using grounded theory principles. Overall, healthcare providers have a good level of communication with their patients. They discuss treatment choices and follow up with patients. They also display aspects of the shared decision-making model in their practice including, "help your patient explore and compare treatment options" and "assess your patient's values and preferences".

**Keywords: End-Stage Renal Disease, Shared Decision-Making Model, Dialysis**

### 1. Introduction

Racial and socioeconomic disparities in end-stage renal disease (ESRD) treatment are evident in the differences between individuals undergoing in-center hemodialysis (HD) and those undergoing peritoneal dialysis (PD). Of the nearly 20 million Americans living with chronic kidney failure, African Americans are 50% less likely to utilize peritoneal dialysis compared to whites<sup>2</sup>. One possible cause of this trend is the lack of knowledge African Americans have about PD. This lack of knowledge is the result of brief and uninformative interactions with their medical provider, possibly resulting from racial discordance. Research has found racial discordance and implicit bias to be a contributor to unsuccessful health interactions between providers and their patients regarding rapport and the use of the shared decision-making model<sup>13</sup>. Unsuccessful health interactions may be exhibited through poor service delivery and the failure to present all treatment options, because of the belief that the patient is incapable of complying with treatment requirements.

When exploring the causes of socioeconomic disparities in dialysis, cost differences between the two modalities were explored. HD has been covered under Medicare for many years, which could explain the higher representation of socioeconomically disadvantaged patients. However, recent changes to Medicare have resulted in equal coverage for both modalities. Prior to the enactment of the Medicare Improvements of Patients and Providers Act (MIPPA), Medicare reimbursed dialysis providers for HD on a per-treatment basis, and reimbursement rates were higher for injectable medication<sup>5,11</sup>. In 2008, the Centers for Medicare & Medicaid Services (CMS) issued MIPPA regulations, resulting in comparable coverage of PD and HD, allowing patients access to both modalities. The purpose of this policy was to reduce the financial incentive for HD use and provide patients with Medicare coverage and equal access

to both treatment options. However, research has shown that low-income patients have a higher utilization of HD, indicating that the disparities continue<sup>15,17</sup>.

This study examines the perceptions that medical providers have of their patients to understand better if this is a contributing factor for ongoing disparities in ESRD treatment. The perceptions of the medical provider were examined, as it may have an effect on the level of communication between the provider and the patient. This lack of communication may prevent the patient from making an informed decision about their ESRD treatment and adhering to the orders of the provider. The shared decision-making healthcare model is used as the framework to explore the level of communication between a provider and their patients.

## 2. Review of Literature

End-stage renal disease (ESRD) is a life-changing disease that requires immediate treatment which can be received through either a kidney transplant or dialysis. There are two forms of dialysis treatment, hemodialysis (HD) and peritoneal dialysis (PD). HD is an in-center treatment that requires patients to undergo treatment three times a week for up to four hours each treatment session. This is an intrusive and time-consuming procedure, requiring its users to make significant lifestyle changes for their treatment. These lifestyle changes include prohibited diet, fluid restriction, and compliance with extensive medical prescriptions<sup>4,10</sup>. HD patients often encounter declining physical, mental, and emotional health<sup>4</sup>. PD is a home-based treatment offering patients more autonomy as treatment can take place overnight. However, PD has extensive requirements including a sterile environment, space to store dialysis materials, and a thorough understanding of how to administer treatment. A concern shared by nephrologists is the risk of its users developing peritonitis, an infection associated with PD complications<sup>5</sup>. However, research has shown that home-based treatments can produce a more positive effect on an individual's well-being than HD<sup>8</sup>. Unfortunately, accessible patient education materials about PD in comparison to HD are scarce. This lack of knowledge can hinder ESRD patients from making an informed decision about their treatment.

To make an informed decision about their healthcare, patients must be educated about the various treatment options available. Education enables patients to participate in making choices about their treatment resulting in a much higher quality of life. A previous study notes that among 104,000 recently diagnosed ESRD patients, over 97,000 patients initiated HD and only 6,875 initiated PD<sup>7</sup>. These findings suggest that PD is either not presented to patients in a way they can understand or not presented at all<sup>7</sup>. This can be the result of implicit biases providers have of their patients. When it comes to patients who are African American or socioeconomically disadvantaged, perceptions can fall on the negative end of the spectrum and negatively influence the communication between the provider and their patient. Implicit bias could manifest as disrespect, poor service, and failure to communicate options and is the result of assumptions, such as the provider believing the patient would not understand or would be incapable of complying with the many requirements of PD because of their circumstances<sup>12</sup>. Implicit bias can negatively affect the communication level between the provider and their patient.

The level of communication between a provider and their patient can be measured with the use of the shared decision-making healthcare model. The shared decision-making model is characterized by equal input between the healthcare provider and their patient. The benefits of shared decision-making include reduced anxiety and depression, increased self-efficacy, improved compliance, and higher satisfaction with the physician. The Agency for Healthcare and Research Quality's SHARE model was used to define the shared decision-making model for this study. The SHARE model is comprised of five steps:

1. Seek your patient's participation
2. Help your patient explore and compare treatment options
3. Assess your patient's values and preferences
4. Reach a decision with your patient
5. Evaluate your patient's decision

The steps of this model include the exploration and comparison of the benefits, risks, and harms of possible treatment options through a meaningful dialogue keeping in mind what is most important to the patient<sup>1</sup>.

### 3. Methodology

This study used qualitative research methods, as it allowed for an in-depth analysis of the data. The qualitative nature of this study allowed for individualism among the responses providing the researcher with the opportunity to interpret the data and identify themes to explore and answer the research question: do the perceptions made by medical providers influence their suggested treatment options?

Semi-structured interviews, approximately 30 to 60 minutes long, were conducted either over the phone or in person. All participants were asked the same questions with the purpose of exploring their previous experiences working with patients of different cultures, their level of communication with current patients as well as colleagues, and their knowledge and utilization of the shared decision-making healthcare model.

Healthcare providers specializing in ESRD care and practicing in Northern Virginia and Washington DC were the target population for this study. Northern Virginia and Washington DC are two locations rich in racial and socioeconomic diversity. Participants in this study have been practicing in the healthcare field from 3-37 years. Identifying information including age and gender of participants were not collected in this study. Professional networks were utilized to identify potential participants using snowball sampling. IRB approval was obtained before contacting potential participants. Participants were contacted through email, and sent information describing the purpose of the study and its intended result. Those who were interested in participating were given a consent form highlighting the research procedures and asking for permission for the researcher to audio record the interview. If the participant agreed, the consent forms were signed and returned to the researcher.

Audio recordings of each interview were immediately transcribed verbatim by the researcher at their conclusion using Microsoft software. The transcripts were then coded by the researcher with the guidance of the primary investigator and two graduate research assistants. Open coding was the initial style, which allowed the essence of each individual interview to be captured. The style of coding then progressed to focused coding, paying attention to similarities among the interviews and those codes were grouped with similar codes. The final stage of analysis involved memoing, which consisted of the researcher giving each grouped code a description and a meaning which then became the themes of the study.

#### 3.1 Interview Questionnaire

1. Could you tell me a little bit about your work with dialysis patients? (alt. with patients with ESRD)
  - Prompt: How long have you worked here?
  - Prompt: What populations do you serve (race, socioeconomic status, age, ethnicity, religion)?
  - Prompt: What was appealing to you about this job?
2. Tell me about how you learned about cultural competency in your professional education and training.
  - Prompt: Were there specific courses available in your school? What were they?
  - Prompt: Have you taken specific trainings or classes related to cultural competency after you completed your education? What were they?
  - Prompt: Are there other non-academic ways that you continue to learn?

I'm interested in your opinions about shared decision-making for your patients. AHRQ's SHARE Approach is a five-step process for shared decision-making that includes exploring and comparing the benefits, harms, and risks of each option through meaningful dialogue about what matters most to the patient (from the Agency for Healthcare Research and Quality website)

Step 1: Seek your patient's participation.

Step 2: Help your patient explore and compare treatment options.

Step 3: Assess your patient's values and preferences.

Step 4: Reach a decision with your patient.

Step 5: Evaluate your patient's decision.

3. Can you tell me what aspects of this shared decision-making model you incorporate into your practice?
  - Prompt: Do your patients give any input when discussing treatment options? Would you prefer the contrary?

- Prompt: If the contrary is preferred how would you go about achieving this?
4. How many patients/clients do you see at once? Do you think this has an effect on the relationship you share with them?
    - Prompt: How long usually does your first meeting with patients/clients last? Do you think this is enough time to really get to know them?
      - a) What things do you look for in this amount of time? What do you take note of?
      - b) How do these observations influence what treatment you think is best for them?
    - Prompt: Do you have a professional relationship with other healthcare providers working with your patient/client? If yes, how beneficial is this to the health of your patient?
  5. Are you aware of the disparities in treatment choice among African Americans and lower socioeconomic populations?
    - Prompt: What do you think are the possible reasons for these disparities?

## 4. Results

The research sample consisted of five healthcare providers: two renal nurses practicing in both acute and chronic settings in North Virginia and Washington DC, and Charlottesville, VA, respectively, one nephrologist and one social worker, both practicing in Fairfax County, and one dietician practicing in Georgetown, Washington, DC.

Overall, results indicate that healthcare providers had a good level of communication with their patients. Differences in professional responsibilities and behavior were noted. The social worker and dietician were more holistic in practice, focusing on the patient's lifestyle (e.g., level of exercise, diet, transportation accessibility) and the effect it has on their treatment. The nurses communicated and were familiar with their patients but noted that their job was to follow procedures and they had no control over the treatment their patients received. The nephrologist displayed both holistic and traditional aspects in their practice, communicating with patients to understand their lifestyle and explain to them how that influences the dialysis treatment they receive. One limitation of this exploratory qualitative study is the sampling methodology and sample size. However, the perspectives of diverse healthcare providers, including a kidney specialist, a dietitian, a social worker, and two nurses provided rich information about their perspectives and how a healthcare provider interacts with his/her patient. Future research could be enhanced by sampling multiple providers of the same type in order to elicit diverse perspectives from healthcare providers specializing in nephrology. One strength of this study is that the participants were very transparent in their responses which allowed for a detailed analysis to be made by the researcher. The themes identified in this analysis were *connecting*, *disconnecting*, and *educating differently*.

### 4.1. Connecting

Healthcare providers such as the social worker and nephrologist, allowed their patients to make informed decisions about their care through many pre-dialysis appointments. They discussed treatment choices and follow up with patients. Participants noted that many patients prefer treatment through HD as it requires less responsibility on their behalf. As ESRD is already a condition that requires significant lifestyle changes, many participants noted that patients would prefer not to be in charge of their dialysis and will accommodate to make time for HD sessions. They also display aspects of the shared decision-making model in their practice including, "help your patient explore and compare treatment options" and "assess your patient's values and preferences". Codes used to define connecting were, *clarifying*, *unassuming*, and *respecting*. This participant's response illustrates this theme:

So you know, everything has its pros and cons and some people yeah their priority is, I don't want to deal with it, I'll let someone else do it. Some people their priority is, I want to be at home. You know, so I can explain the modality, because I think if you- I don't know, I'm not sure why I like doing it that way personally, I like to describe the modality and let them decide then tell them what that commitment means.

## 4.2. Disconnecting

The disconnect is seen through patient blaming and provider frustration with noncompliance. Assumptions about the patient's opinion about hemodialysis and their capability of performing the home-based treatment were made. The assumption was that African American and lower income ESRD patients do not have the requirements to perform PD, including room to store supplies, a partner to assist with treatment, and a clean environment. Codes used to define disconnecting were *blaming*, *assuming*, and *generalizing*.

I think some patients especially African Americans and lower income I think they start hearing ahead of time about PD and they don't really understand it um, plus you have to have room to store your supplies you have to have someone that's going to be there with you and it's you know it's a clean process I mean you got a tube coming out of your abdomen so you have to be very clean.

## 4.3. Educating Differently

Research participants took into consideration the cultural differences between themselves and their patients and were able to tailor their care around that specific patient's culture. One participant had a patient who medicated themselves with a supplement from a flowering plant indigenous to their country of origin. Not understanding the effects of this supplement, the participant conducted research and was able to advise their patient against taking the supplement while respecting the present cultural differences. Codes used to define educating differently were *advising*, *suggesting*, and *following up*.

I knew he was from Africa, I don't remember the actual country. And they were taking something called *moringa*. And I had done some research on that, had seen some claims on the internet about how it's supposed to improve your kidneys, which I don't think is true at all but I did have one patient and I followed up on that and I called him and told him I didn't advise him to take it.

Of the five participants, only two were aware of the disparities found in dialysis treatment. When asked for their perspective on the causes of these disparities, the responses were similar to the information found in the reviewed literature, which highlighted the causes as the lack of information provided by the healthcare provider to the patient about the various types of treatment. Some participants also mentioned financial incentives as a reason for healthcare providers to suggest hemodialysis to their patients. For example, as one participant stated, some nephrologists have their own hemodialysis clinics and will benefit financially if their facilities were being utilized by their patients.

## 5. Discussion

There is an abundance of literature surrounding the effects of patient/provider communication as well as the quality of life of patients with treatment. This study examines how both trends are connected. The importance of patient/provider communication is found in the themes extracted from the data. The level of communication has a significant impact on the patient's quality of life during treatment. Because ESRD is a disease that requires significant lifestyle changes, it is imperative that the healthcare provider inform their patients of the changes associated with treatment to ensure the physical, mental, and emotional well-being of their patient. The themes from this study raise questions that could be used to improve healthcare and ensure patients are receiving information to choose a treatment that best fits their lifestyle and preserve their quality of life.

Participants in this study were welcoming to patient/client questions and comments and indicated that they would make as much time for patients as required. Unfortunately, if a patient has a low level of health literacy, they may be hesitant or even resistant to communicating with their provider about their healthcare. Patients with general literacy concerns also will not disclose their illiteracy to their healthcare provider. This lack of communication can be detrimental to the health of the patient as it promotes poor health outcomes and increased mortality. Health literacy is the ability to read and understand provided information and the ability to engage in the health process. Research has shown that communication can be increased by ensuring health literacy among patients through their understanding of the health process using plain language both oral and written. Health literacy can also be ensured with the use of user testing which checks how well the patient understands the information provided by patients<sup>14</sup>. Although

participants noted that educational materials are distributed to each patient providing information about ESRD and the available treatment options, many patients do not use these materials. One possible way to stop this trend is by evaluating the written materials given to patients, ensuring they are easy to understand and do not contain technical language. The provider could also ensure the patient's understanding of the material by reviewing it with the patient. Possible suggestions to improve educational materials include making the reading level for educational material at a fifth-grade reading level<sup>16</sup>. Also, there should be a limited number of messages in the handout<sup>3</sup>.

The participants in this study represent different helping professions and each participant has varying professional requirements. A remaining question sought to address how each profession could effectively utilize the shared decision-making model while satisfying the requirements of their position. As previously stated, nephrology professionals have the biggest influence on the suggested treatment and patient choice; it is their responsibility to present the options to their patients and allow them to make a decision based on their desired method of treatment. Social work professionals do not introduce treatment options to their patient; however, it is their responsibility to ensure that the patient's quality of life is positive throughout their treatment by asking questions about the patient's lifestyle and preferences. Despite the different professional priorities, one way to improve communication is through more collaborative practices. Research participants stressed the importance of medical rounding, a time in which healthcare professionals from various fields speak with patients during their treatment. This process allows the patient to speak with nephrologists, social workers, and dietitians about any concerns they may have. However, not all professionals are present and speaking with a patient at once. Future research could examine how these professions can better communicate with each other to develop a comprehensive treatment plan specific and beneficial to their patients.

## 6. Conclusion

Through this analysis, the importance of communication emerged as a factor that influences ESRD care among all patients. The communication level between healthcare providers and their patient is greatly influenced by the patient's level of health literacy. Improvements to ensure health literacy can improve the communication between healthcare provider and patient. With an assurance of health literacy, ESRD patients will have the ability to make an informed decision about their healthcare treatment. Communication and collaboration among healthcare providers of different disciplines is also associated with health literacy. This allows the various professionals to have a comprehensive understanding of the patient's needs. The assurance of health literacy through improving educational materials and the communication between healthcare professionals are aspects of patient-centered care, which will greatly improve dialysis care.

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