

Patients' Perceptions Concerning Choice Among Renal Replacement Therapies: A Pilot Study

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Since 1973 individuals with end stage renal disease (ESRD) who are qualified for Social Security benefits have had access to Medicare funding for renal replacement therapies, which include renal transplantation, peritoneal dialysis, and hemodialysis (Social Security Amendments of 1972). There has been rapid growth in both the ESRD population and the program costs since the onset of the ESRD program with the numbers of patients with ESRD increasing from 11,000 in 1973 to more than 450,000 today (ESRD Network, 2005; Murray & Conrad, 1999). Today, the majority of patients with ESRD undergo peritoneal dialysis or hemodialysis with a small percentage being transplanted (ESRD Network, 2005; United Network for Organ Sharing [UNOS], 2005). Both types of dialysis may be safely delivered, but transplantation is considered the best medical option due to less risks and more benefits along with the patient no longer having kidney failure (ESRD Network, 2005; UNOS, 2005).

The primary cause of ESRD today is diabetes; the second main cause is hypertension (ESRD Network, 2005). As with the chronicity of diabetes, the management of chronic renal failure occurs over several months to many years. Patients who are known to be approaching ESRD can be evaluated for either a renal transplant or dialysis. Medicare guidelines provide mechanisms for

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Purpose: The purposes of this pilot study were to determine which replacement therapy group would be most appropriate for exploring the concept of choice and to refine the research question.

Methods: This exploratory, descriptive study used a phenomenological method.

Results: Four themes were derived: (1) uncertainty of long-term health, (2) lack of choice, (3) no memory of making a choice, and (4) lack of information about renal replacement therapies.

Conclusions: No participant remembered actually making a choice regarding their renal replacement therapies.

Goal

To explore the concept of choice perceived by patients receiving renal replacement therapies.

Objectives

1. Summarize the perceptions of queried patients about their perception of having a choice of renal replacement therapies.
2. Analyze the findings of a study of patients receiving renal replacement therapies and their involvement in the choice of that therapy.
3. Recommend future research to determine patients involvement in the choice of renal replacement therapy to be used.

either therapy to be chosen and achieved (Centers for Medicare & Medicaid Services [CMS], 2005). Transplantation can be chosen as an option and be scheduled dependent on the patient's total glomerular filtration rate. Usually, living related and living non-related transplants are better suited for this plan since deceased donor transplants cannot be scheduled several days in advance. The number of living donor transplants has now surpassed deceased donor transplants each

year for the last several years (UNOS, 2005).

There is little documented research on how the choice of renal replacement therapy occurs. This pilot study begins to explore this choice through the perceptions of patients with ESRD.

Synthesis of Science

A literature search of the CINAHL index, PSYCH INFO, and MEDLINE was conducted and

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articles were reviewed concerning perception of choice among renal replacement therapies for individuals affected by ESRD. A search was also done of the major authors in the field who are known to the researcher. Because the topic of renal replacement therapies is published across many types of journals, the review is not necessarily completely exhaustive. The majority of articles included are data-based and several review articles are cited. There were 22 data-based articles in which renal replacement therapies were discussed within the context of several related topics. Also, there were 5 data-based articles in which choice in either the type of dialysis or the type of transplant as the major focus of the study and 3 data-based articles in which the focus was patients' perceptions of choice about either dialysis or transplantation.

What is Known

Research regarding the perception of treatment choice for the patient with ESRD is limited and without clear conclusions. Both the content of the education provided and the timing of providing this information appears to be physician-driven (Rubin et al., 2004). Research by Gordon and Sehgal (2000) documents that dialysis appears to be discussed as the primary plan of care, with transplantation discussed during later conversations. Some patients are not encouraged to consider all options because they are older or from a minority ethnic background (Alexander & Sehgal, 1998; Gordon & Sehgal, 2000; Tell et al., 1995). Older patients, because of their age, may be considered to have too many morbidity reasons, which may incorrectly preclude them from transplant possibility (Holley et al., 1996; Stratta et al., 2003). Additional studies highlight the inadequacy of opportunity for renal transplantation among the black population (Alexander & Sehgal, 1998; Boulware et al., 2005; Tell et al., 1995; Young & Gaston, 2000). These older and ethnically

diverse patients are vulnerable and may require additional or specific information regarding their options for renal replacement therapy (Young & Gaston, 2000).

Patients affected by ESRD may consider mortality and morbidity as important factors to be considered when choosing a renal replacement therapy. Their perceptions of these factors, when making a choice among all renal replacement therapies, have not been reported in the literature. Medical research reveals specific mortality and morbidity rates for each type of renal replacement therapy (ESRD Network, 2005). The mortality among patients using hemodialysis is much higher than that of the general population (Eggers, 1992; Goldfurb-Rumyantzev et al., 2005). Higher rates of mortality and morbidity have been reported for dialysis, when compared to transplantation (ESRD Network, 2005).

Since the U.S. Medicare ESRD Program was enacted, the growth of this patient population has become a large portion of the chronic disease sector. The majority of patients with ESRD are on dialysis even though renal transplantation is usually a viable option (ESRD Network, 2005). Today, with the more than 450,000 patients receiving a type of renal replacement therapy, only 25% of those are awaiting renal transplantation (ESRD Network, 2005).

During the literature review, an inconsistency was noted concerning how and when the options of renal replacement therapies were presented to patients with chronic renal failure and ESRD, which could affect their perception of choice in treatments. Patients with ESRD were not always given options, at the medically appropriate time (Rubin et al., 2004). Medicare recommends transplantation as the first choice of therapy and mandates that every patient with ESRD be evaluated at least yearly (CMS, 2005). Yet, a large majority of patients with ESRD are dialyzed first and remain on dialysis (Mehrotra et al., 2005; Shi, Guo,

Just, & Mujars, 2005). The timing of discussion about renal replacement options, by the nephrologist, is of concern due to a possible affect on the patient's perception of choice (Alexander & Sehgal, 1998; Gordon & Sehgal, 2000). Research indicates that dialysis is usually discussed as the primary plan and there seem to be consistent findings concerning the delay in the discussion of transplantation (Alexander & Sehgal, 1998; Gordon & Sehgal, 2000).

A shift from the paternalistic view in which only the physician made the treatment decision to the view that patients could make their own treatment decisions, has revolutionized patient care issues, patient advocacy issues, and patient rights' issues. This also could affect the patient's perception of choice among renal replacement therapies. Literature supports the position that patients, in general, are capable of participating in treatment choices (Gordon & Sehgal, 2000; Neufeld, Degner, & Dick, 1993). A substantial amount of literature suggests that patients want to participate in their treatment decisions and that the support of health care providers in the choices could lead to improved patient outcomes (Breckenridge, 1997; Degner & Beaton, 1987; Degner & Sloan, 1992). The literature does state that it is considered sub-optimal by decision analysts if all alternatives are not given adequate attention by any patient (Kahneman & Tversky, 1984; Sullivan et al., 1996; Tversky & Kahneman, 1981).

What Is Unknown

Questions abound as to perceived choice of all renal replacement therapies by the patient affected with ESRD. There is little discussion in the review of this literature to explain how a patient with ESRD perceives the choice or evaluates recommended renal replacement therapies (Holley et al., 1996). The lack of research concerning how nephrologists provide information reinforces

the need for this study and future research in this area. Since the nephrologist is the primary physician caregiver, what he/she says may influence the patient's perception of choice.

Nurses are considered patient advocates for this vulnerable population. The literature provides extensive information on providing resources and supports the patient's right to have a choice, but the literature has many gaps in what is actually carried out in practice (Woodle, Boardman, Bohnengel, & Downing, 2005). There are examples of different transplant centers that are grouped as 'aggressive' and 'not aggressive' in the transplant professional community (Abou Ayache et al., 2005; O'Connor & Delmonico, 2005; Stratta et al., 2003). The 'aggressive' transplant centers perform a majority of living related donor transplants and living non-related donor transplants and fewer deceased donor transplants (O'Connor & Delmonico, 2005; Stratta et al., 2003). Also, there are settings in which the majority of patients are on dialysis and very few receive transplants (Boulware et al., 2005). This may raise concern about the patient's perception of choice along with how accurately informed the nurses may or may not be, which may affect patient advocacy in education concerning renal replacement therapies.

Lastly, only one research study was found that spoke to the issue of patients' 'perception concerning their choice' of a specific renal replacement therapy – renal transplant (Gordon & Sehgal, 2000). No studies were found that addressed the specific issue of this research: patients' perception concerning their choice among all the renal replacement therapies. There is a large gap in this area of nursing research. This was an unexpected finding.

Through investigation of these issues, a research question was developed: What are adult ESRD patients' perceptions concerning their choice among renal replacement therapies?

Purpose of the Study

Since ESRD therapies consist of renal transplantation, peritoneal dialysis and hemodialysis, this pilot study was conducted among those patients who have (patients who received dialysis) or have had (patient who had renal transplants) the diagnosis of ESRD and who were treated with one of the three renal replacement therapies. To explore this perception concerning choice, the study sample consisted of two patients who had renal transplants, two patients who received hemodialysis, and two patients who received peritoneal dialysis.

The purpose of this pilot study was to explore how those affected by ESRD perceived choice in their options of renal replacement therapies. The study also served to test the recruitment process for the larger study and to refine the research question. Data from this study also served to determine which replacement therapy treatment group would be most appropriate for exploring the concept of perception of choice among renal replacement therapies in future studies.

Methodology

Research Design

This pilot study was an exploratory, descriptive study using a phenomenological approach to describe the experience of adult patients who had ESRD and their perceptions concerning choice among renal replacement therapies. Based on the review of literature and the lack of research studies examining the perceptions concerning choice among all renal replacement therapies, the research question was developed. The research design included the use of bracketing, intuiting, and identifying essences throughout the study.

The pilot study had two research questions. The first question surrounded each participant's perception of choice regarding each renal replacement therapy. The question

asked was, "How do you perceive your choice of renal replacement therapies?" with the specific probes of "What kinds of choices do you perceive to be options?" and "What information do you have concerning each of your choices?" This additional probing obtained data related to the kind of choice each participant perceived to be an option and what information each participant received regarding treatment choice.

The second question explored the degree that each participant perceived others as influencing their choice of one renal replacement therapy (transplantation, hemodialysis, or peritoneal dialysis). This question asked "To what degree do you perceive others as influencing your choice of one renal replacement therapy (transplantation, hemodialysis, or peritoneal dialysis) over another?" and with specific probes such as "In what ways do you perceive health care providers as influencing your choices?" and "In what ways do you perceive significant others as influencing your choices?" This additional probing served to highlight the ways in which health care providers and/or significant others might have influenced their choice. Because the researcher was unsure of how responsive the participants would be to the questions, open-ended with additional probing questions were asked.

Protection of Human Participants

All data were collected after IRB approval was secured from the researcher's university. The participants in this study were adult volunteers who received both verbal and written explanation of the study prior to signing a consent form. Plans were in place to provide psychological support if participation in this study resulted in participant distress.

Confidentiality and anonymity were maintained during data collection and analysis. Signed consents, audiotapes and transcribed data were secured in the primary investigator's office. Once transcribed, all

identifiers were removed from the data prior to analysis and the audiotapes were destroyed once analysis was complete.

Data Management and Analysis

All data were collected from participants in a southern, metropolitan city. The participants were selected, purposefully, by the head nurse at the dialysis unit and by a nephrologist, at his clinic. These individuals knew each of the participants, solicited their participation, and obtained verbal consent prior to the principal investigator contacting them.

The participants were grouped according to the type of renal replacement therapy they were receiving or had received as treatment of their ESRD. Thus, there were two participants who had received transplants, two receiving peritoneal dialysis, and two undergoing hemodialysis. Participants were all over the age of 18.

Each participant was interviewed once and the interview was transcribed verbatim for the purpose of analysis that remained the same throughout the pilot study. HyperResearch was used for data management (Hesse-Biber et al., 1994). Additionally, the researcher read, analyzed, and synthesized the data using Colaizzi's (1978) techniques.

Quantitative data for this study consisted of specific demographic information, which was used to describe the study population. Qualitative data were obtained by taped interviews, using phenomenological techniques. Data obtained from the interviews were transcribed verbatim and analyzed using Colaizzi's (1978) steps of phenomenological analysis.

Trustworthiness of the Data

Rigor was demonstrated through attention to, and confirmation of, information discovery. Several operational techniques were used to increase the likelihood that credible

findings were produced. First, the use of open-ended interviewing techniques, tape recordings, and verbatim transcriptions increased the accuracy of the description of each of the participant's experience. Also, the researcher incorporated peer debriefings by obtaining feedback concerning collapsing of the data to themes from another qualitative nurse researcher. Confirmability of this study has been objectively grounded by the researcher's use of bracketing along with the researcher's reflexive journal, available audit trail, and peer debriefings.

Findings

All the participants were very responsive to the interview questions. Probing questions appeared to interrupt their description and often they had already answered some of the questions before the researcher used the additional probes.

Data from this study revealed four themes: 'uncertainty of long-term health,' 'lack of choice,' 'no memory of making a choice,' and 'lack of information among renal replacement therapies.' The following comments provide explanation of the process of the collapsing of the data into the four themes.

Participants commented about their long-term health by stating,

- *I don't know how long I'm going to live.*
- *I'm worried about what is going to happen because I'm sick.*
- *What am I going to do because I don't know how long my kidney will last?*

Some of the participants' comments about their lack of choice included,

- *I didn't have a choice in what to do.*
- *The doctor told me I had to do dialysis and that was all I was told.*
- *The doctor said I needed to start dialysis now.*
- *Several participants discussed their lack of knowing they had a choice.*
- *What choice are you talking about?*
- *I don't remember making the choice to do dialysis.*
- *I don't remember who decided that I should do peritoneal dialysis.*

And, lastly, some of the participants commented about their lack of information regarding their therapy.

- *I don't know anything about peritoneal dialysis.*
- *I don't know about getting a kidney.*
- *What is peritoneal dialysis?*

These sample statements provided the description needed to extract themes from the interviews.

Each theme was apparent in all interviews, despite the renal replacement therapy. No participant remembered actually making a choice regarding renal replacement therapy. The participants who were being treated with dialysis mentioned a lack of information about renal replacement therapies and stated that their nephrologist made the choice for them.

Discussion

The literature supports the premise of problems inherent in providing a continuum of care to underserved populations, specifically those patients who have ESRD. These patients are among the vulnerable populations that may be living in the realm of being medically underserved concerning the issue of their perceived choice among renal replacement therapies. Even though progress has been made in understanding how patients make treatment choices, significant gaps in our knowledge remain and need to be addressed for this scientific research to move forward. If and when patients consider the choice of renal replacement therapy, they need support to become more capable of making the choice while possibly having limited physical and cognitive abilities, needing help in avoiding hazards of therapy choices, and needing support in helping them choose therapies which accurately reflect their wishes and needs.

Choice is a cognitive skill that changes over time and through experience. Continued support and current, accurate education is needed for this vulnerable and growing pop-

ulation of patients. Much research needs to be done to provide descriptive models about perception of choice among renal replacement therapies and who makes the choice within this population of patients who have ESRD, in their various settings.

Patients with ESRD are often left with little guidance and/or information as how to make an optimal and timely choice about the renal replacement therapy and its consequences (Gordon & Sehgal, 2000). Physicians have been reported as being the ones who may often make the strong suggestion of the type of renal replacement the patient should receive (Boulware et al., 2005; Gordon & Sehgal, 2000; Stratta et al., 2003). Highly uncertain and often risky choices are often made under extraordinary physical and emotional stress and time constraints, placing a high cognitive demand on an already compromised individual (Hilhorst et al., 2005; Starzomski & Hilton, 2000). Given the ubiquitous nature of human choices along with the perception of choice among renal replacement therapy and the nature of the current health care environment, it is imperative to further develop this knowledge and integrate it into the clinical care of the patient population who have ESRD (Rittman et al., 1993; Woodle, Boardman, Bohnengel, & Downing, 2005).

Future Research

Because the preliminary data from the pilot study was so broad in scope and because the participants who received hemodialysis had the richest descriptions, the recruitment plan for the larger study will be to limit the population sample to those receiving hemodialysis as treatment for ESRD. Data collection and analysis methods appeared appropriate and no plans were made to alter the collection or analysis methods in the future, larger study.

Conclusion

Focused research regarding the perception of choice regarding renal replacement therapy has been lacking. Questions remain as to patients' perceptions of their choices among renal replacement therapies. This vulnerable population exists within our health care system and nursing should provide advocacy for assisting those, who are affected by ESRD, in their health care concerning their renal replacement choices and options.

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ANSWER/EVALUATION FORM

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GOAL

To explore the concept of choice perceived by patients receiving renal replacement therapies.

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Evaluation

- By completing this offering, I was able to meet the stated objectives
 - Summarize the perceptions of queried patients about their perception of having a choice of renal replacement therapies.
 - Analyze the findings of a study of patients receiving renal replacement therapies and their involvement in the choice of that therapy.
 - Recommend future research to determine patients involvement in the choice of renal replacement therapy to be used.
- The content was current and relevant.
- This was an effective method to learn this content.
- Time required to complete reading assignment: _____ minutes.

Strongly disagree

Strongly agree

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

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I verify that I have completed this activity _____

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