Abstract

Caregiver and family engagement in dialysis decisions varies over the end-stage kidney disease treatment trajectory and family preferences are important considerations for patients starting dialysis. Existing literature has not explored the experience of patient and decision partner shared decision-making processes.

Study Design

This interpretive phenomenological study explores how dialysis patients and their partners experience dialysis decisions.

Setting & Participants

A purposive sample of patient-decision partner dyads were recruited from dialysis clinics and online support groups. The dyads participated in a semi-structured interview. Eligible participants were over 18 years old, English speaking, involved with their treatment teams for at least 6 months, and the patient was currently on dialysis. Decision-partners included those who have participated in decision-making with the patient.

Analytical Approach

A five-step iterative process of data analysis occurred concurrently with data collection.

Results

Thirteen dyads (26 participants) were interviewed with patients on ICHD (n=6), PD (n=3), HHD (n=2), and nocturnal HHD (n=2). Decision partner relationships included romantic partners (n=9), a parent (n=2), a sibling (n=1), and a friend (n=1). Fifty-seven percent of participants were White; 46% of patients were women, and 76% of decision partners were women. These interrelated themes were identified: Their body, but not their life; Seeking semi-liberation; and Decision-making is caring.

Limitations

Transferability of findings is limited due to the inclusion of only English-speaking participants and dialysis patients, rather than conservative care or transplant patients.

Conclusions

Dyads are attuned to patient autonomy while managing the collateral effects of dialysis. Shifting the paradigm of dialysis treatment decisions from promoting patient autonomy to dialogues exploring relational autonomy helps providers balance the competing demands of incentivized standards to promote home dialysis with the realities of patients and their decision partners.

Methods and Materials

Interpretive phenomenology provides a framework to explore and describe the relationships and concealed meanings in the phenomenon of modality discernment.

This project aimed to explore the dyadic experience of shared decision-making, so the decision partner and patient were interviewed together. Semi-structured interviews occurred over Zoom or in-person.

The five-step analysis process included an investigation of early focus and lines of inquiry; developing central concerns, exemplars, and paradigm cases; identifying shared meanings; final interpretations; and dissemination of the interpretation.

Table 1 Sample Demographic Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Male</th>
<th>Female</th>
<th>Not Specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Dialysis Modality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICHD</td>
<td>8</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>PD</td>
<td>6</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>HHD</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Nocturnal HHD</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Abbreviations: ICHD, In-center hemodialysis; PD, peritoneal dialysis; HHD, home hemodialysis; NHD, Nocturnal home hemodialysis; RP, romantic partner

Results

Dyadic decision making is intentional and shaped by the history of the relationship. P: And so for me, it’s been difficult to try and think about somebody else to make the decision with. Because for so long, I made them by myself and I trust my gut... So I do my thing and try to make decisions as much as I can and let him know.

Dyadic decision making is caring.

Decision-making is retrospective.

Their body, but not their life

Decision-making is retrospective.

Seeking semi-liberation

Decisions are nested within preserving life and family well-being.

DP: It’s only supposed to be just fitting in it fine.

P: The only thing that was important was I wasn’t going to deny it and just go ahead and die over it because that wasn’t an option.

DP: Truth. You’re not allowed to die.

Limitations in freedom are managed by making smaller decisions and being stubborn.

DP: You’re only supposed to be just fitting in it fine.

P: If I mean, they treat me like that too because for me, “You’d better do your thing.” So I just do it, like every other day just because that way my body is a lot better.

Discussion

The role of informal caregivers in influencing dialysis patient outcomes is generally accepted in ESKD Care. Despite family and caregiver preferences serving as primary motivators for patient decisions, the role of decision partners in modality discernment is not understood. Given the increased incentives for providers to engage patients in home dialysis and transplant therapies, providers need efficient and effective strategies for addressing barriers to home dialysis uptake.

Consistent with Winterbottom et al., our findings indicate that dialysis decision-making is situated across time, indicating that patients and their decision partners deliberate treatment options and choices iteratively rather than episodically.

Treatment decision-making is shaped by the individual’s history of the relationship as well as their personal autonomy, financial, vocational, and social outcomes. The role of informal caregivers in influencing dialysis patient care and outcomes is generally accepted. Shared decision-making provides an established framework for providers to engage in dialogue that integrates the decision partner and acknowledges the shifting experience of dialysis decision-making from a social and relational context.

Collectively, these themes suggest that health care providers should recognize that dyadic decision-making is iterative and shaped by the patients’ social and systemic context. Shared decision-making provides an established framework for providers to engage in dialogue that integrates the decision partner and acknowledges the shifting experience of dialysis decision-making from a social and relational context. Shifting from an episodic paradigm of modality decision-making (e.g., annual assessments) shaped by efficient algorithms to a shared decision-making framework that incorporates patients’ relational and social context may provide a framework to balance the incentives of promoting home dialysis with the realities of the patient experience.

Conclusions

Contact
Renata Sledge, MSW, LCSW
Director of Research and Development
Medical Education Institute, Inc.
rslodge@mei.org
www.mei.org

References

1.renata.1@mei.org
2.somebody@mei.org
3.otherbody@mei.org

1. Family and Community Medicine, Saint Louis University 2. Nephrology, Internal Medicine, Saint Louis University 3. Social Work, University of South Carolina