Barriers and Opportunities to Increase Home Dialysis among African American Patients

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Disclosures

• Karen-Marie Eaton: Employee of DaVita Clinical Research
• Steven M. Brunelli: Employee of DaVita Clinical Research, spouse employee of Astra-Zeneca
• Danelle Radney: Employee of DaVita Inc.
• Francesca Tentori: Employee of DaVita Clinical Research
• Unini Odama: Employee of DaVita Inc., Teaching Faculty- Harvard Medical School, Center for Bioethics
Background & Objective

• Home dialysis is a renal replacement therapy (RRT) option that offers patients more flexibility and possible clinical benefits.

• Home dialysis use is lower in African American patients.

• **Objective**: In this study we sought to understand the experiences of African American patients and care partners in choosing a RRT and uncover motivators and barriers to home dialysis.
Methods

• African American participants (patients receiving either in-center or home dialysis, and their care partners) were recruited at dialysis clinics and by telephone to join focus groups in their cities.

• 90-minute in-person focus groups were held in three cities (Houston, Philadelphia, Washington DC) between December 2022 and February 2023.

• Focus groups were audio and video recorded and transcribed verbatim. Responses were analyzed using inductive thematic analysis.¹

• 29 participants recruited, 21 patients and 8 care givers
• The majority of care partners were female

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Patient</th>
<th>Care Partner</th>
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<tbody>
<tr>
<td>Female, n (%)</td>
<td>11 (52%)</td>
<td>7 (86%)</td>
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<tr>
<td>Age, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤50</td>
<td>8 (38%)</td>
<td>3 (38%)</td>
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<tr>
<td>51-64</td>
<td>7 (33%)</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>65+</td>
<td>6 (29%)</td>
<td>3 (38%)</td>
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Results – Modality Selection Influencers Identified in Focus Groups

**Diagnosis Acceptance** Link between underlying conditions and kidney failure is often unclear before diagnosis, making acceptance more challenging.

**Cultural Lens to Trust** Patients and care partners trust healthcare professionals for information, with reservations.

**Education** Although downstream elements of education such as modality prep were well received and recalled, upstream elements such as comorbidity/modality selection were not always clear.

**Faith** Faith is a critical lens for understanding experience and acceptance of diagnosis and treatment.

**Family Support** Family is important support and caregivers have their own needs, not all of which are being met.
Results – In Their Own Words: Quotes from study participants

**Diagnosis Acceptance**
“Every time I went to the class they talked about diabetes, they never said anything about the kidneys. All they tell you is change the way you eat. You gotta exercise. You gotta do this. You gotta do that. They never said anything about the kidneys [or I would have] changed things quick.” (Home patient, Washington DC)

“I never thought I would catch diabetes. I was too much of a health nut. No sodas, I love water, I never smoked and didn’t really drink. I couldn’t believe this was happening to me... [sometimes] I still don’t.” (Home patient, Washington DC)

**Cultural Lens to Trust**
“My doctor even said that we [AA patients] don’t get the information we should get. But this is a new wave [and] we are gonna get an upgrade for our people.” (Home patient, Philadelphia)

“I’m not taking anything at face value...it’s not a trust thing...but you have to realize that so many people are [being treated for so many things and taking so many medication]...and doctors can’t know everything. So let me go [research] and see for myself. (ICHD patient, Washington DC)

**Education**
“It wasn’t nothing bad about it. We had a good time, but they were telling us things that are known.” (Home patient, Houston)

“Because I’m gonna trust the person that’s going to give it to me 100, 152%. I mean, give the maximum you have. Don’t lie to me. I’m gonna give you the -- the God’s honest truth every time I speak.” (ICHD patient, Houston)

**Family Support**
“They always have something to say about everything and act like they know more than the doctor.” (ICHD patient, Philadelphia)

**Faith**
“What’s gonna get me to where I have to get to is keeping the faith.” (Care Partner, Philadelphia)

“You know, a lotta times people say this, that, or the other. But I put my trust in the Lord Jesus Christ. He only know when your time is up. (ICHD patient, Philadelphia)
Results

• After starting dialysis, most patients and care partners were aware of the benefits of home dialysis; however, broader themes point to fundamental cultural barriers.

• Some barriers specific to home dialysis modality selection included the fear of being solely responsible for a complex procedure, risk of infection, and loss of social interaction.
Conclusions

• Opportunities exist for early and direct linkage of co-morbidities with kidney disease and consideration of patient concerns in home dialysis modality education.
THANK YOU