Care practices for patients with advanced kidney disease who forgo maintenance dialysis

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Dialysis Is a Way of Life for Many Older Patients. Maybe It Shouldn’t Be.

So-called conservative management can ease symptoms without dialysis in some people with kidney disease. But many of them are never given the option.

Elderly who don't want dialysis often pressured to get it

Listening to older patients who want to stop dialysis
Background
Saying ‘NO’ to dialysis

• The burdens and harms of dialysis outweigh the potential benefits of life prolongation in some patients.

• It is uncommon for patients with advanced CKD not to be treated with dialysis.
  • In the national VA health system, 1 in every 7 Veterans with advanced CKD forgo initiation of dialysis

• Decisions against dialysis tend to occur late in the disease trajectory, during acute illness, and with a minority patients enrolling in hospice.

Wong, JASN 2014; Wong CJASN 2016; Wong AJKD 2018
Study aim

• To elucidate how decisions to forgo initiation of maintenance dialysis unfold in clinical context.
Study
Study overview

- **Design**: Qualitative study.

- **Population**: 851 Veterans with sustained eGFR <15 in the VA health system in whom there was a documented decision not to pursue dialysis between 2000-2011.

- **Sources**: VA electronic medical record, VA and Medicare files.
Qualitative content analysis of chart notes

Medical record of 851 patients

SPYW coded ALL patients

AMO and LM coded 20% patients

Independent open coding

Review Deliberation Consensus Iteration

Final thematic schema
Results
<table>
<thead>
<tr>
<th>Characteristics of patients (n=851)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics at eGFR &lt;15</strong></td>
<td></td>
</tr>
<tr>
<td>Age ≥ 75 years</td>
<td>61.3</td>
</tr>
<tr>
<td>White</td>
<td>66.6</td>
</tr>
<tr>
<td>Severe comorbid burden (Gagne score &gt;6)</td>
<td>42.1</td>
</tr>
<tr>
<td>No renal clinic visits in year prior</td>
<td>45.8</td>
</tr>
<tr>
<td>Mean eGFR, SD</td>
<td>11.7, 2.5</td>
</tr>
<tr>
<td><strong>Care during follow-up</strong></td>
<td></td>
</tr>
<tr>
<td>Median follow up, IQR (months)</td>
<td>5.7, 1.1-17.2</td>
</tr>
<tr>
<td>Received palliative care consultation</td>
<td>51.6</td>
</tr>
<tr>
<td>Enrolled in hospice</td>
<td>38.0</td>
</tr>
<tr>
<td>Died during follow-up</td>
<td>95.4</td>
</tr>
</tbody>
</table>
Dynamics relevant to not pursuing dialysis

- **Dialysis as the Norm**
- **Not a candidate for dialysis**
- **Having little to offer beyond dialysis**
Dynamics relevant to not pursuing dialysis

- Dialysis as the Norm
- Not a candidate for dialysis
- Having little to offer beyond dialysis
Repeated questioning about preferences
Repeated questioning about preferences

Admission 1: “The patient again refused dialysis…I discussed the case with all the nephrologists at [nephrology practice].”

[inpatient renal]

Admission 2: “Patient was contacted on the phone by [cardiologist] to discuss dialysis. He categorically refused and thought that all this had been settled during his previous admission.”

[inpatient medicine]
Repeated questioning about preferences

“repeatedly every time asked says he will never agree to dialysis, and will die first. He gets angry, belligerent when asked this question, and says it is his right to refuse any care he chooses.”

[renal clinic]
Deliberating about patient’s competency
Deliberating about patient’s competency

“lack insight”

“not ready”

“suicidal”

“in denial”

“irrational”

“emotional”
Deliberating about patient’s competency

“lack insight”
“not ready”
“suicidal”
“in denial”
“emotional”
“sending conflict messages”
“irrational”
“depressed”
“mental illness”
Deliberating about patient’s competency

“I did discuss the risk factors with him again regarding the kidney failure and death, and I explained this to the patient, and he still refused, and he has signed a release of responsibility which is in his chart.”

[primary care clinic]
Encouraging dialysis
Encouraging dialysis

“willing to offer dialysis as bridge to wedding or chemotherapy...He said quite clearly that he did not want dialysis or chemotherapy, he just wanted ‘to be comfortable.’”

[inpatient medicine]
Encouraging dialysis

“Writer did tell patient however that if the doctor wants him to go through dialysis then it would be the right thing to do as the doctor says. Patient then again stated... ‘I already told him I don't want it, I just want to die’.”

[community living center]
Expecting patients to change their minds
Expecting patients to change their minds

“Patient confirmed that he wants a referral for home hospice...He was educated that he can change his mind at any time and let us know if he wants to discontinue hospice and start dialysis”

[outpatient social work]
Expecting patients to change their minds

“He does not want to go on hemodialysis... We'll try to convince him of doing so, at least to have the information in the event we need to plan for creation of a fistula once he agrees.”

[nephrology clinic]
Dynamics relevant to not pursuing dialysis

- Dialysis as the Norm
- Not a candidate for dialysis
- Having little to offer beyond dialysis
Determining candidacy

Figure 3. The Seattle Artificial Kidney Center Admissions and Policy Committee, in a photograph taken by Lawrence Schiller for Life magazine (image reproduced with permission, copyright © Polaris Communications, Inc.).
Determining candidacy

“The patient is 83 years of age. She has declining functional status and dementia. She is not considered to be a candidate for dialysis”
“patient had refused hemodialysis in the past... Overall, patient remains a poor candidate for dialysis, anyway.”

[inpatient renal]
Dynamics relevant to not pursuing dialysis

Dialysis as the Norm

Not a candidate for dialysis

Having little to offer beyond dialysis
“patient continues to refuse hemodialysis... Since we cannot offer him any assistance from a renal standpoint other than hemodialysis at this stage of his disease, he will be discharged from renal clinic. Urged patient that should he change his mind about hemodialysis, to call us back to arrange this.”

[renal clinic]
Hospice as the only alternative

“he really ought to go into hospice and I tried to impress that on him...He really does not want to until he gets to the point where he really needs that kind of help.”

[primary care clinic]
Discussion
Summary of findings

• When patients refused dialysis, providers:
  • repeatedly questioned patients’ preferences
  • deliberated about their competency to make this decision
  • encouraged patients to start dialysis; and,
  • expected patients to change their mind and start dialysis.

• Determining candidacy for dialysis had little to do with patients’ values or preferences.

• Providers often feel that they have little to offer patients who would not be starting dialysis and signed off from their care.
Not a patient-centered process

Pre-dialysis pathway

Patient-defined goals
Not a patient-centered process

Nephrology Clinical Practice Guidelines:

• “education to begin early…and to be continually reinforced”
• “greater choice of treatment options”

Brow-beating?

Acceptable
Not acceptable

KDIGO 2012; KDOQI, 2015; Grubbs, CJASN 2014; Kalanter-Zadeh, Sem Dial 2017; RPA 2010
Conclusion

• Our findings reveal an all-or-nothing approach to dialysis decision-making

• Dialysis initiation is a powerful default difficult for patients to resist.

• Greater efforts are needed to develop the cultural and clinical infrastructure to proactively support patients who choose not to initiate dialysis.
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