An Exploratory Needs Assessment For AKI Patient Education: Results from a Focus Group

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On behalf of the ASN AKINow Education and Awareness Workgroup.

Project Aims
- To engage stakeholders in AKI education: patients, nephrologists, hospital providers, primary care providers, nurses, pharmacists, social workers, etc.
- To identify domains of AKI education described by the focus group.
- To identify potential opportunities for future research and development of educational tools in this area.

Methods
- We recruited patients or their advocates and health care workers from the U.S. & U.K. for a virtual event.
- We selected 4 topics for discussion in four virtual breakout rooms with participants each assigned to one room.
- We are now applying formal, qualitative techniques to derive additional themes and development of educational tools in this area.

Results
- Across 4 breakout groups with different foci regarding the AKI experience and education to be poor and inconsistent.
- Desire education on choices they can make to improve recovery-chances.
- Desire multiple approaches and modalities for education, multiple mechanisms to support asking questions (e.g., suggested questions, online access to providers, etc.), and education tailored to their case (incl. their current degree of understanding).

Summary and Conclusions
- We are now applying formal, qualitative techniques to derive additional themes and domains from the transcripts of these discussions among AKI stakeholders.

Table 1. Main domains/themes in education that are lacking, according to the stakeholders, identified by the moderators

<table>
<thead>
<tr>
<th>Group</th>
<th>AKI in the hospital</th>
<th>AKI-recovery</th>
<th>AKI-dialysis</th>
<th>risk for AKI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>key signs/symptoms to monitor for AKI-course</td>
<td>recommended steps to improve or protect health after AKI, including medications or a diet to use or avoid</td>
<td>inconsistency in provider messaging around the evolving assessment of AKI-recovery vs. ESKD</td>
<td>no real education around kidneys up until that point… the kidneys weren’t the priority</td>
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<tr>
<td>Group 2</td>
<td>clear directions to navigate clinical changes in a patient’s AKI-course</td>
<td></td>
<td></td>
<td>“told me there might be a possibility of them not waking up. Like, what, what does he know? He’s not the team that I trust.”</td>
</tr>
<tr>
<td>Group 3</td>
<td></td>
<td></td>
<td></td>
<td>“There wasn’t coordinated care and coordinated communication between the teams that were taking care of her.”</td>
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<tr>
<td>Group 4</td>
<td></td>
<td></td>
<td></td>
<td>“found education to be poor and inconsistent.”</td>
</tr>
</tbody>
</table>

Table 2. Exemplar quotes from focus group participants

- “I would get conflicting info… one would be telling me ‘you’re gonna get better.’ The others were saying ‘you need a transplant’.”
- “We don’t talk to people about kidney injury very well before they leave, and we know our follow-up isn’t very good.”
- “if I ate the wrong thing I would die.”
- “most… patients remember seeing us vaguely but don’t remember the information, advice, and support”
- “’it’s very hard, actually, to work out where that responsibility lies’
- “hard when… aren’t sure if it’s AKI or… permanent”
- “There wasn’t coordinated care and coordinated communication between the teams that were taking care of her.”
- “no real education around kidneys up until that point… the kidneys weren’t the priority”
- “told me there might be a possibility of them not waking up. Like, what, what does he know? He’s not the team that I trust.”
- “There wasn’t coordinated care and coordinated communication between the teams that were taking care of her.”
- “We don’t talk to people about kidney injury very well before they leave, and we know our follow-up isn’t very good.”

Background
Literature on the type, content, and effectiveness of patient education regarding acute kidney injury (AKI) is scarce. The American Society of Nephrology AKINow Education Workgroup conducted a focus group of relevant stakeholders with AKI experience to discern major themes in the educational needs, level of resources, and opportunities in the realm of AKI education.