

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

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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.

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: Group 1, *AKI education inside and upon leaving the hospital*; Group 2, *AKI education in the dialysis center*; Group 3, *AKI education for the long-term and based on degree of recovery*; and Group 4, *pre-AKI education for those at heightened risk for AKI*.
- Focus group breakout room conversations were recorded, deidentified, and transcribed.
- Initial overarching codes and themes were identified by the breakout room moderators (three nephrologists and one intensivist, each a stakeholder as well).

RESULTS

FIGURE 1. FOCUS GROUP PARTICIPANTS.

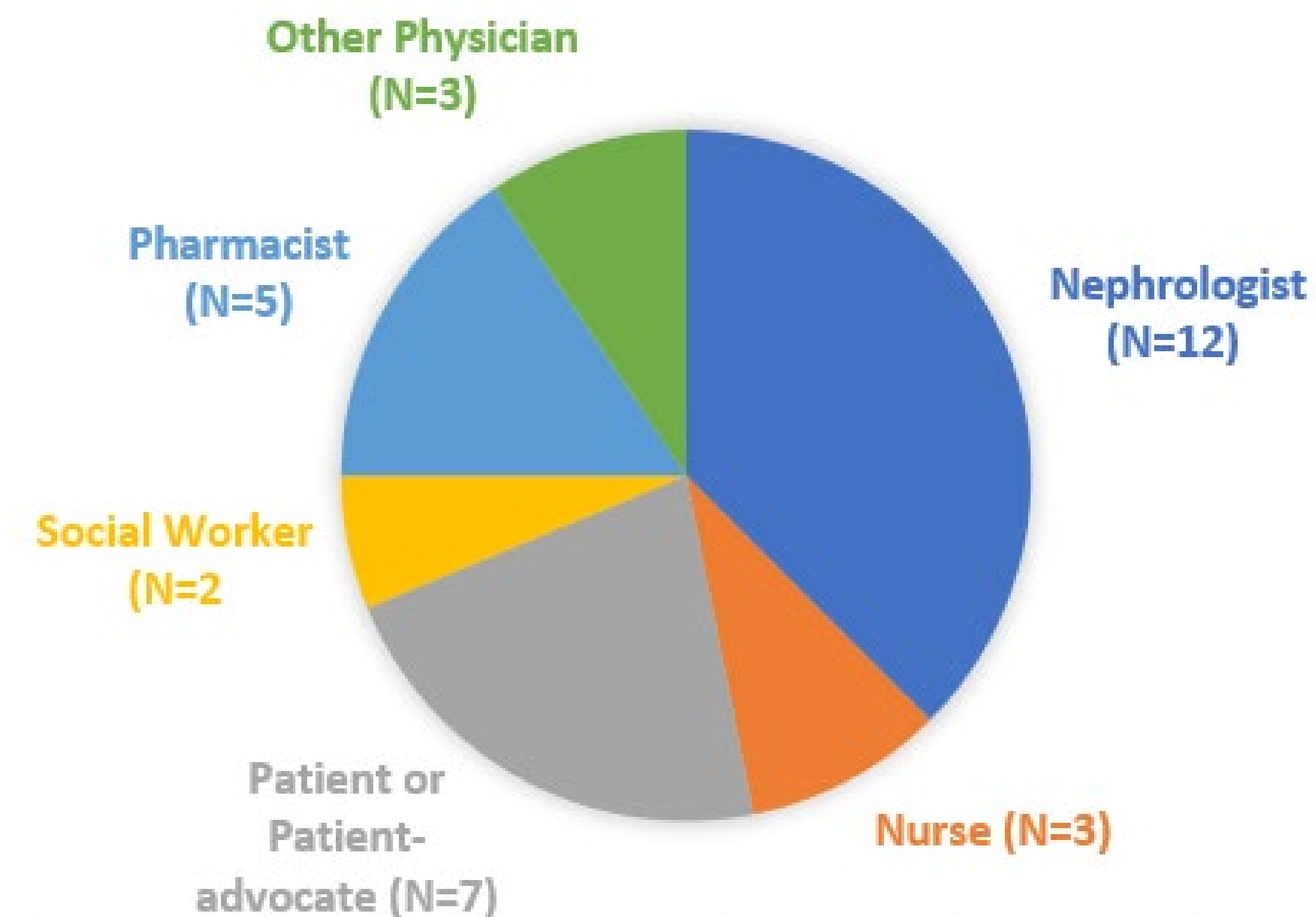


Table 1. Main domains/themes in education that are lacking, according to the stakeholders, identified by the moderators

Group 1 (<i>AKI in the hospital</i>)	<u>key signs/symptoms to monitor for</u>
Group 1 (<i>AKI in the hospital</i>)	<u>clear directions to navigate clinical changes in a patient's AKI-course</u>
Group 2 (<i>AKI-recovery</i>)	<u>recommended steps to improve or protect health after AKI, including medications or a diet to use or avoid</u>
Group 3 (<i>AKI-dialysis</i>)	<u>inconsistency in provider messaging around the evolving assessment of AKI-recovery vs. ESKD</u>
Group 4 (<i>risk for AKI</i>)	<u>the need for multimodal patient education [e.g., written & multimedia resources] in addition to education from trusted providers</u>
All Groups	<u>general lack of knowledge regarding "what kidneys do"</u>
All Groups	<u>uncertainty of what questions patients should be asking</u>
All Groups	<u>desire for improved and/or more frequent communication to patients and amongst their medical team regarding updated, germane AKI-related information</u>

Table 2. Exemplar quotes from focus group participants

Group 1 (<i>AKI in the hospital</i>)	"We don't talk to people about kidney injury very well before they leave, and we know our follow-up isn't very good."
Group 1 (<i>AKI in the hospital</i>)	"I was so scared to mess up... if I ate the wrong thing I would die."
Group 1 (<i>AKI in the hospital</i>)	"most... patients remember seeing us vaguely but don't remember the information, advice, and support"
Group 1 (<i>AKI in the hospital</i>)	"it's very hard, actually, to work out where that responsibility lies"
Group 3 (<i>AKI-dialysis</i>)	"hard when... aren't sure if it's AKI or... permanent"
Group 3 (<i>AKI-dialysis</i>)	"I would get conflicting info... one would be telling me 'you're... gonna get better.' The others were saying 'you need a transplant'"
Group 4 (<i>risk for AKI</i>)	"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."
Group 4 (<i>risk for AKI</i>)	"no real education around kidneys up until that point... the kidneys weren't the priority"
Group 4 (<i>risk for AKI</i>)	"There wasn't coordinated care and coordinated communication between the teams that were taking care of her."

- Breakout Group 2 (*AKI-recovery*) failed to record. Contemporaneous notes reported patients:
 - Found 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

- Across 4 breakout groups with different foci regarding the AKI experience and opportunities for AKI education, common themes were observed.
- They included: **improving and expanding communication with both patients and healthcare team members**, *addressing fears*, *building trust*, and *empowerment*.
- We are now applying formal, qualitative techniques to derive additional themes and domains from the transcripts of these discussions among AKI stakeholders.