Identifying and integrating patient and caregiver perspectives in clinical practice guidelines for percutaneous renal biopsy

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On behalf of the KHA-CARI Renal Biopsy writing group
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Background

“Gold Standard” for diagnosis/management

Safe and efficacious

Invasive – fear/anxiety/stress provoking

Scant evidence of patient experience

Development of evidence-based guideline informed by Consumer Perspectives
Aims

- To identify topics and outcomes important to patients and caregivers to be included in renal biopsy guidelines
- To describe reasons for their choices
- To compare topics and outcomes identified with those selected by guideline writing group
Methods

Data collection
- Purposive sampling
- Workshop consisting of 3 simultaneous focus group discussions + group feedbacks

Descriptive analysis
- Extract list of topics raised by patients and caregivers
- Compare to topics covered by writers

Thematic analysis
- Audio-recorded and transcribed
- Line-by-line inductive coding in HyperResearch
# Results

- 17 participants attended
- 10 patients
- 7 carers

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>10</td>
</tr>
<tr>
<td>Caregiver</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Aged 30-49</td>
<td>7</td>
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<tr>
<td>Aged &gt;50</td>
<td>10</td>
</tr>
<tr>
<td>Did not finish secondary school</td>
<td>5</td>
</tr>
<tr>
<td>Completed tertiary qualification</td>
<td>11</td>
</tr>
<tr>
<td>Employed</td>
<td>9</td>
</tr>
<tr>
<td>Unemployed/retired</td>
<td>7</td>
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</tbody>
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## Topics prioritised by writing group:

1. Cessation of antiplatelets
2. Use of DDAVP
3. Imaging modality
4. Needle type/size
5. Positioning
6. Bleeding
7. Post-Op care

## Guidelines

<table>
<thead>
<tr>
<th>Subtopic</th>
<th>Interventions</th>
<th>Priority</th>
<th>Relevant comments from Consumer group</th>
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</thead>
<tbody>
<tr>
<td>Patient care</td>
<td>*Reduce impact on family</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>*Clinician / patient partnership</td>
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<td></td>
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<tr>
<td></td>
<td>*Multidisciplinary</td>
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<td></td>
<td>*Anxiety management</td>
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<td></td>
<td>*Carer support</td>
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<tr>
<td>Patient and carer information</td>
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*Carers should be allowed in the procedure room to support the patient.

*It is not just the biopsy taking place. There are many unknown factors.
“How much damage does biopsy do to my new kidney that I’ve waited so long for?”

Patient, Male

“They said ‘don’t move’, and I’m shaking. They said ‘you’re nervous’.

Patient, Male

“We had two different sets of information for post-biopsy care.”

Patient, Male

“It’s that context of it’s a whole person and a whole family.”

Caregiver, Female

“We were in the dark about everything.”

Patient, Male
Establish visit plan
• Deliver information for self-management pre/post procedure
• Conduct thorough consent process outlining risks and necessity for biopsy

Pre-biopsy

Admission: explain expected schedule
• Pre-procedure: introduce operator to patient, check patient comfort
• Post-procedure: explain restrictions/timing, contact caregiver
• Recovery: check in with patient at expected time
• Discharge: explain post-procedure care, notify caregiver
• All: Keep informed of delays, multidisciplinary communication

Biopsy

Delivery of results: schedule clinic to deliver results as soon as possible

Post-biopsy
Impact and Conclusions

• Health professionals and patients/caregivers have different priorities and concerns
  – Health professionals prioritised clinical topics e.g. cessation of medication, biopsy techniques, equipment
  – Patients focused on psychosocial and emotional topics e.g. education, communication

• Patient and caregiver involvement in development of the guideline ensured their concerns and needs were met

• Guideline scope expanded to include new topic – “Patient Education”
Developing the consumer guideline:

KHA-CARI guideline group

- Teleconference
- Develop FAQs
- Update with feedback
- Draft guidelines
- Update
- Finalise guidelines

Patient/Carers

- Review and feedback
- Review guidelines
- Public consultation
- Review and publish
Acknowledgments

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