

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

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Background

Percutaneous renal biopsy is often essential for providing reliable diagnostic and prognostic information for people with suspected kidney disease, however the procedure can lead to complications and concerns among patients.

Objectives

This study aims to identify and integrate patient priorities and perspectives into the Kidney Health Australia – Caring for Australasians with Renal Impairment clinical practice guidelines for renal biopsy, to ensure patient-relevance.

Method

We convened a workshop, consisting of three simultaneous focus groups and a plenary session, with ten patients who had undergone a renal biopsy and seven caregivers. Topics and outcomes prioritised by patients and their caregivers were compared to those identified by the guideline working group, which was comprised of seven nephrologists. Transcripts and flipcharts were analysed thematically to identify the reasons for participants' choices.

Results

In total, 34 topics/outcomes were identified, 14 of which were common to the list of 28 previously identified by the guideline working group. Most of the new topics identified by patients/caregivers were related to communication and education, psychosocial support, and self-management. We identified five themes underpinning the reasons for topic and outcome selection: alleviating anxiety and unnecessary distress, minimising discomfort and disruption, supporting family and caregivers, enabling self-management, and protecting their kidney. A new topic on patient care and education was added to the guideline as a result.

Conclusions

Patient and caregiver involvement in developing guidelines on renal biopsy ensured that their concerns and needs for education, psychosocial support, and self-management were explicitly addressed; enabling a patient-centred approach to renal biopsies.