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WHAT A PATIENT WANTS: A CONSUMER PERSPECTIVE OF KIDNEY SUPPORTIVE CARE

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Aim: To evaluate benefits patients and carers derive from a kidney supportive care (KSC) program, integrating renal and palliative medicine.

Background: Patient and carer perspectives are vital for developing healthcare strategies that are equitable, accessible, effective and patient-centred. This is especially important in the context of end-stage kidney disease (ESKD), where treatment options can be extremely burdensome while, in many cases, providing little long-term benefit. KSC is emerging as an effective way to care for patients with ESKD—whether on dialysis or not—who need help with symptom management, advance care planning and/or complex decision-making around dialysis options.

Methods: Patient and carer satisfaction with a new KSC program in the north of Brisbane and symptom scores were assessed using self-reported questionnaires. Place of death data were collected from medical records. To obtain detailed information about patient and carer perceptions of the program and their healthcare needs, semi-structured interviews based on the Consolidated Framework for Implementation Research were conducted with 10 patients and 5 carers receiving KSC.

Results: KSC patients and carers were highly satisfied with the program (96% and 91% satisfaction, respectively). Reasons for this included feeling supported, having enough time for detailed discussions and the program’s focus on wellbeing rather than biochemical markers. Patients and carers reported that they valued receiving care that they perceived to be tailored to them and their circumstances. Overall symptom burden decreased in 69% of those who had attended >1 KSC visit. Among patients who died, 75% died in their preferred final place of care.

Conclusions: Patients and carers receiving KSC derived benefits including improved symptom control and self-determination, and valued the quality of care they received.