

An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in End-Stage Kidney Disease

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Key messages

1. ACP is confronting (ie emotionally difficult) for patients with end-stage kidney disease and their caregivers
2. ACP fosters acceptance of the inevitability of death
3. ACP alleviates existential tension

Methods

Recruitment

- CKD patients and caregivers from 3 renal services in Melbourne, Australia
- Purposive sampling (ie a range of experience with ACP)

Data collection

- Semi-structured interviews
- Topics: Initial reactions, decision-making, personal experiences of ACP

Data analysis

- Thematic analysis

Demographics (N=39)

Patients aged 55-91 years (median 67 years), and 16 (41%) were men. Caregivers aged 36-78 years (median 62 years), and six (40%) were men. Eleven spouse/ partners, 2 parents, 1 child or 1 sibling.

Characteristics	Patients (n=24)	Caregivers (n=15)
	N (%)	N (%)
Treatment type for ESKD		
Hemodialysis	21 (88)	13 (87)
Peritoneal dialysis	1 (4)	1 (7)
Transplant	1 (4)	1 (7)
Conservative care	1 (4)	-
Patient ACP status		
Completed	20 (83)	12 (80)
In progress	1 (4)	1 (7)
Not commenced	3 (13)	2 (13)

Articulating core values | Avoiding futile and undignifying treatment, reevaluating terms of dialysis, framing a life worth living, and refusing to be a burden

"I thought the diet, the drugs and the kidney dialysis were adequate to keep her alive for an indefinite period but the [ACP nurse] said that everyone on dialysis has a much shorter lifespan and you need to plan for it." –Caregiver, Male, 70s

Confronting conversations | Signifying death and defeat, accepting inevitable death, and alleviating existential tension

"[ACP] made me depressed for about three days because they were touchy subjects. No-one likes to die, so it brought it home. If when I first started [dialysis] they started talking about, where you want to die, I would've said 'Get lost' but as you get on in life things change and you become more realistic with what is going to happen eventually." –Patient, Male, 60s

"It was like a weight being lifted from my shoulders because I hated dialysis so badly, you've got no idea. So when [the ACP nurse] came to me and said, 'You can choose', I thought, 'Fantastic'! So I chose [to withdraw from dialysis]. It felt fantastic, and I mean it. Fantastic." –Patient, Male, 70s

Negotiating mutual understanding | broaching taboos, and assisting conflicted caregivers

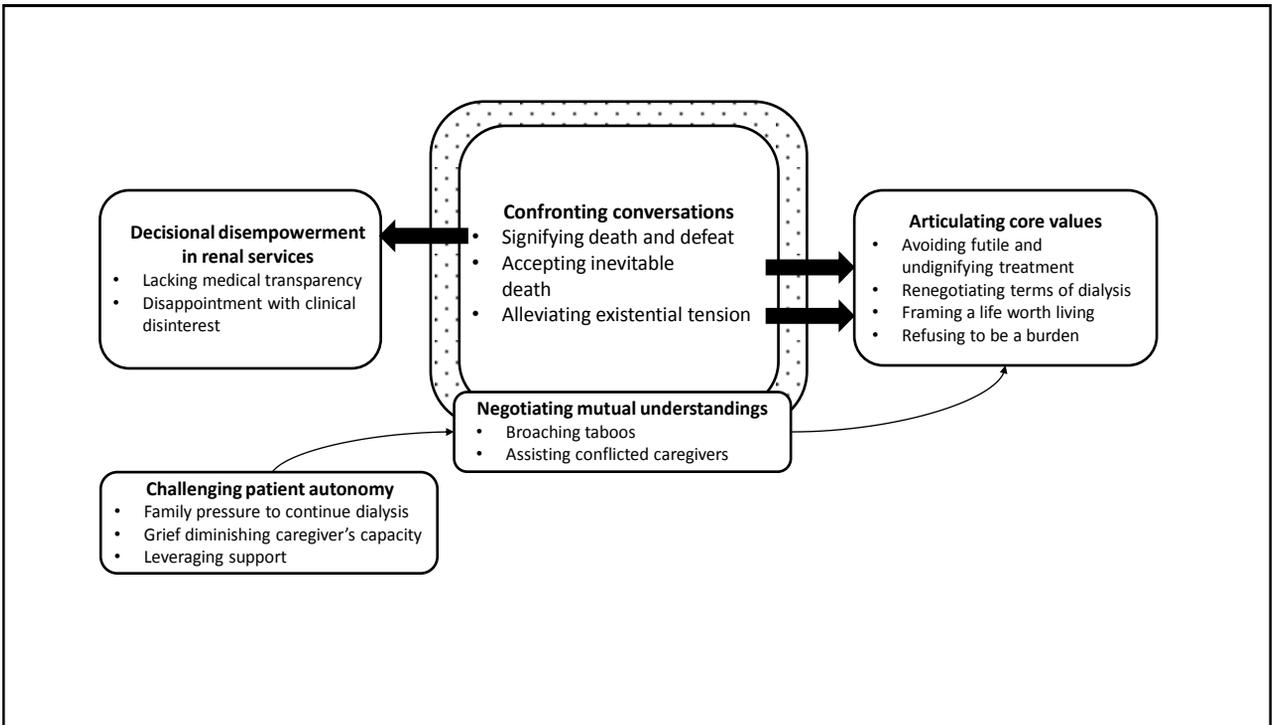
"We don't have these conversations in my house, my dad's pretty traditional. We have a lot of taboo topics in our family. We are more non-confrontational. We don't tackle issues head on like that; we talk around them. Even though I'm different in my life, it was a bit awkward, uncomfortable, because I would never talk about that [with him], no way." –Caregiver, Female, 30s

Challenging patient autonomy | Family pressures to continue dialysis, grief diminishing caregivers' capacity, and leveraging support

"Before I got out the door [the doctor] rung back and said, '[the patient has] really gone down and we're not even going to ask you basically, you can overrule us, but we've decided to just make [the patient] comfortable and stick with his wishes'. Even though [the patient] had asked me not to let them do that to him again I was relieved that he had told them. I don't know if I would have been able to follow the advance care plan. I didn't want to and I doubt that I would have been able to do it at the time." –Former caregiver of patient who had died, Female, 70s

Decisional disempowerment in renal services | Lacking medical transparency and disappointment with clinical disinterest

"The trouble is when you're attached to a dialysis unit you see so many doctors. They change – they rotate; you don't have that meaningful discussion with any of them because half the time they don't even know you." –Caregiver, Female, 60s



Conclusions

- For end-stage kidney disease patients and caregivers, ACP was considered emotionally difficult
- ACP fostered acceptance of the inevitability of death
- ACP alleviated existential tensions

Recommendations

- Clinicians who are involved in ACP to be empathetic and to attend to patient and caregiver needs as they navigate difficult concepts, such as accepting the inevitable death of the patient and broaching taboos
- Support systems available for caregivers who feel unable make end-of-life decisions on behalf of the patient due to their own grief

Future research

- Examine whether a diminished capacity to make decisions affects caregivers at end-of-life, and to develop and evaluate interventions to minimize this effect during ACP
- Future trials of ACP interventions consider illness acceptance as an outcome measure in patients and their caregivers (eg the Illness Cognition Questionnaire)

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