

Treatment preferences of older people deciding between dialysis and comprehensive conservative care – the UNPACK qualitative study

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Background

Older people with comorbid conditions deciding how to prepare for kidney failure face preference-sensitive decisions: the ‘right’ path depends upon what they consider important. Eighty-percent of UK older adults starting kidney replacement therapy receive haemodialysis.[1] Half die within three years,[1] and less than 20% receive a transplant.[2] Life-extension averages 18-months compared with conservative care (CC), but the least-well gain less.[3] Treatment is burdensome and quality of life - and death - are often poor.[4] Knowing what drives decisions between kidney failure treatment pathways could inform development of better-fitting care. This qualitative study supplements existing evidence by focussing on older adults with stage-5 chronic kidney disease. A future discrete choice experiment will quantify the trade-offs individuals make between the treatment characteristics identified as important.

Methods

Participants with eGFR<15 aged over-80 years, or over-65 with ≥ 2 comorbidities/a WHO performance status ≥ 3 were recruited from three UK renal centres. Purposeful sampling maximised variation in participant clinicodemographics.

Semi-structured interviews were conducted in participant’s homes by an interviewer unknown to them (BH). Interviews were audio-recorded and anonymised transcripts were thematically analysed using constant comparative techniques, derived from grounded theory. Preliminary analysis is presented.

Results

Fifteen interviews (eight male, seven female) were conducted before saturation was identified (no new themes emerging). Participant age ranged from 65 to 90 (median 81); with a median eGFR of 12 (IQR 9.8-13.8). Nine participants were preparing for dialysis, six CC. Four relevant themes were identified: death, uncertainty/inevitability, decisions and trades (table).

- ‘Death’ reflects participants’ descriptions of acceptance of the end-of-life. Especially those anticipating CC expressed a sense of readiness.
- ‘Uncertainty/inevitability’ reflects descriptions of unavoidable kidney failure which may yet be preceded by death. The uncertain onset of kidney failure was acknowledged as a source of frustration and confusion.
- ‘Decisions’ reflects descriptions of deciding between treatments for kidney failure. Some participants described being steered towards clinical courses of action. Others reported autonomous decisions. Some individuals expressed reservations about whether they were preparing for the right treatment.
- ‘Trades’ reflects evidence of weighing-up treatment aspects. Trades were often framed in terms of ‘being able to do things’. Life-expectancy, treatment location and frequency, and functional ability were key characteristics.

Conclusion

Older people with comorbid conditions anticipating kidney failure recognise uncertain futures and closeness to death. They appreciate treatment benefits and burdens and weigh them up. They experience differing levels of agency during planning, but appear able to express their treatment and health outcomes preferences. This work provides qualitative information about their preferences for kidney failure

treatments, but does not quantify importance. Quantitative work building on the themes identified is underway, using a discrete choice experiment.

1. www.renalreg.org/reports/
2. www.odt.nhs.uk
3. Foote, C. et al., Survival outcomes of supportive care versus dialysis therapies for elderly patients with end-stage kidney disease: A systematic review and meta-analysis. *Nephrol*, 2016,21(3):241-253.
4. Da Silva-Gane, M., et al., Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. *Clin J Am Soc Nephrol*, 2012.7(12):2002-9.