Understanding pre-dialysis modality decision-making: a meta-synthesis of qualitative studies

Harwood L, Clark, Alexander M

CRD summary
The authors concluded that decisions about dialysis options in patients with chronic kidney disease were highly personal and strongly influenced by patient and family values, the context of the patient's life and a desire for minimal intrusiveness. No single option was perceived as superior. This review was largely well conducted and the conclusions seem justified.

Authors' objectives
To examine how people with chronic kidney disease make decisions about the delivery and type of dialysis. The review aimed specifically to identify influences on decisions relating to home dialysis.

Searching
In collaboration with a health sciences librarian, MEDLINE, EMBASE, CINAHL, Web of Science, Scopus, Cochrane databases and Joanna Briggs Institute Library of Systematic Reviews were searched to 2009. The search was updated (including PsycINFO) to January 2012. Search terms were reported. Only articles published in English were eligible for inclusion.

Study selection
Eligible studies were qualitative studies that focused primarily on adults with chronic kidney disease and explored factors that influenced the decision-making process about place and type of dialysis. Studies had to include face-to-face data collection methods and provide exemplars of text.

Studies were located in the United States, Australia, Canada, Taiwan and Europe; two were in the United Kingdom. Studies included people with chronic kidney disease who were not on dialysis, people who were already on dialysis and provided retrospective views on starting treatment and a mixture of those on dialysis and not yet on dialysis. Some patients were renal transplant recipients; others received haemodialysis or peritoneal dialysis. Reported mean ages of participants were 51 to 73 years (range 20 to 87 years). There were approximately equal numbers of men and women.

It appeared that more than one reviewer was independently involved in study selection.

Assessment of study quality
Study quality was assessed using the Critical Appraisal Skills Programme tool. Studies were rated as low, moderate or high quality and the main reasons for categorisation were recorded.

One reviewer carried out the quality assessment and this was checked by a second reviewer. Discrepancies were resolved by consensus.

Data extraction
Data extraction was carried out by one reviewer and checked for accuracy by a second reviewer.

Methods of synthesis
Data extraction and synthesis followed the meta-ethnography approach. This involved the recording of concepts in each study relating to dialysis decision-making followed by an exploration of themes and relationships across the studies. Frequently occurring concepts were then applied to a re-review of all the identified themes, culminating in a final synthesis containing three main headings. Findings were discussed by reviewers at each stage.

Results of the review
Sixteen qualitative studies were included (410 patients, 29 family members, 38 health care professionals; sample size range six to 95). Eight studies used interpretive description (two of these were mixed methods studies), four used
grounded theory, three used phenomenology and one used ethnography. Study quality was moderate (two were classed as low, 10 were medium and four were high quality; further details not reported).

Across the studies, decisions about dialysis options were embedded within the context of the patients' life and their situation. Three main themes emerged.

**The illusion of choice – a matter of life or death**: In many studies patients perceived that choices about dialysis were available but these were not genuine choices. Instead, they were stressful decisions (often forced by unforeseen medical circumstances) to be made about life or death.

**Personal factors and minimisation of the intrusiveness of dialysis**: No single mode of dialysis was perceived as superior and in many studies decision-making was influenced by a desire to improve quality as well as length of life. Travel distance to the dialysis centre was a strong influence in choosing home dialysis. Patients' wishes to maintain autonomy to preserve their values and identity, often drawing on past experiences of dialysis, were further factors impacting on decision-making.

**Knowledge and social support: essential and context bound**: Patients derived knowledge about dialysis from family, health care professionals and other patients on dialysis. Knowledge was seen by patients as essential to decrease misunderstandings about treatment. Acceptance of medical advice/information was aided by a trusted source (health care providers). The importance of education applied not only to the patient but also to help the wider family in collaborative decision-making. Social support was important, particularly from families, given that decisions about dialysis modality would affect them too.

**Authors' conclusions**
Dialysis modality decisions in patients with chronic kidney disease are highly personal and strongly influenced by patient and family values, the context of the patient's life and a desire for minimal intrusiveness. No single mode of dialysis was perceived as superior, given the personalised nature of decision-making.

**CRD commentary**
The review question was clear, inclusion criteria were replicable and the decision to include qualitative studies was justified by the authors. Various appropriate data sources were searched for studies published in English. The authors acknowledged that the restriction to published studies in English meant that relevant studies may have been missed. The review process included appropriate checks for reliability between the reviewers.

Methods of data collection and synthesis were reported clearly and appropriate quality assessment criteria were applied (although details beyond aggregate scores were not reported and study quality was not incorporated into the synthesis). Results were presented systematically according to the stages of meta-ethnography and the findings seemed plausible from the raw data presented. However, it is important to note that weaker studies appear to contribute to the overall findings in the same way as more robust studies. Reporting of study characteristics enabled some evaluation of applicability. The authors acknowledged several limitations of the review but did not comment on potential biases arising from their own roles in the research process.

This review was largely well conducted and the conclusions seem justified.

**Implications of the review for practice and research**
**Practice**: The authors stated that home dialysis should be presented as an option in the context of planned and timely discussions about dialysis. Professional support should include patient and family preparation for dialysis, knowledge about the different options and implications for lifestyle. The authors noted that some of the studies were conducted more than 10 years ago and the approach to treatment has changed in that time.

**Research**: The authors stated that further research was needed to explore the complexity of decision-making with wider social factors in mind. Specifically, research should be conducted with patients at the active decision-making stage to understand more clearly the influences specific to home dialysis.

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