

Decision making about home dialysis: What are the voices of renal patients approaching end stage kidney disease?

Mr Christopher Duncan¹, Dr Jyoti Baharani¹

¹University Of Wolverhampton, Wolverhampton, United Kingdom, ²Heart of England Foundation Trust, Birmingham, United Kingdom

Introduction

Patient preference to modality choice requires further exploration in the literature. This aspect of inquiry is pertinent because other than those patients who experience life limiting physical and cognitive states, it is unclear why patients approaching end stage kidney failure change their mind about dialysing at home. Access to home dialysis therapies should be an achievable option to many¹. A critical literature review was therefore undertaken to elicit the extent of inquiry about decision making in predialysis patients approaching end stage kidney disease.

Method

Databases used in the search strategy were: Cochrane Library- all years; Cumulative index to Nursing and Allied Health literature (CINAHL) 1970 – 2019, Medical literature On-line (Medline) 1970 – 2019, Psychological Information Database (PsycINFO) 1970 – 2019.

Key search terms used: Home therapies', 'Haemodialysis', 'Peritoneal Dialysis', 'Shared decision making' 'Culture', 'Ethnicity' and 'identity'. A search of the Electronic Theses Online Service (ETHoS) for renal theses yielded 2 relevant results with relevance to the review.

Results

Three key themes emerged from the data extraction tool.

1. Patient empowerment in the shared decision process

There is robust evidence in the literature linking effective and timely patient education to empowerment, and this finding is translated to the notion of modality decision making in the predialysis setting irrespective of age, education level and health literacy. Of significant note is that empowerment and quality of life among peritoneal dialysis (PD) patients is enhanced compared to haemodialysis (HD), but the literature is very limited in order to give credibility to these findings. What is striking is that despite the apparent superiority of PD in this regard, the 'take up' rate of this modality is consistently poor.

2. Addressing decisional conflict

The complex nature of decision conflict is a renowned concept across many healthcare disciplines. Decision conflict has potentially serious repercussions for CKD patients approaching ESKD because a decision made and missed opportunity to self-manage dialysis at home will compromise superior clinical outcomes and the treatment flexibility that home dialysis affords.

Decisional conflict is complex in nature. Level of education and the ability to understand the information presented can influence decision making conflict and participation in the shared decision making process ²

3. Cultural influences in decision making

There is a relative paucity of research literature available to elucidate the effectiveness of shared decision making among cultural groups. It is clear that empowerment in decision making must apply to each individual irrespective of patients' existence within cultural groups. Tailored predialysis information and education is equally important across all cultural groups ³

Conclusion

There are significant, albeit limited findings which link enhanced shared decision making and patient empowerment to the peritoneal dialysis modality. ⁴⁵⁶⁷⁸⁹ Of continued uncertainty is why, despite evidence of CKD patient willingness to engage in home dialysis preparation, particularly PD, the enthusiasm for independence and autonomy is lost at end stage kidney disease when the final decision to commit is required. Research evidence supports conclusively that home dialysis therapies improve clinical outcomes and quality of life, but it is already elicited in the evidence that patient uptake to home dialysis therapies is notoriously under recruited to 10, 11