

“Haemodialysis is nothing like it was portrayed”. An exploration of shared-decision making in haemodialysis initiation.

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Background

Older, unwell patients often have multiple comorbidities and decisions about treatment options can be complex¹. As part of the ePISTLE (Perceptions of Illness Severity, Treatment goals and Life Expectancy) study, we sought to explore whether patients felt they were involved in shared decision-making when starting on haemodialysis, their subsequent reflections and experiences of treatment.

Methods

Seriously unwell patients at three hospital-based haemodialysis units were invited to take part in the study. ‘Seriously unwell’ was defined as a 1-year mortality risk of >20%². Patients were invited to take either part in a semi-structured interview or to complete the same questions independently via a questionnaire. Ethical approval was granted (18/LO/1386).

Results

“I didn't particularly want to do it. You think it's going to make you feel better but I've found it really debilitating. Sometimes you have good days but a lot of the time I'm existing rather than living at the moment. “

43 patients were recruited into the study (14F, 29M). The median age of participants was 76 years (interquartile range, IQR 65-83) and they had been on dialysis for a median of 34 months (IQR 20-56). 37 patients took part in a semi-structured interview, 6 patients chose only to complete the questionnaire.

Only 29/43 (70%) felt that they had been actively involved in the decision to start dialysis. Patients who did not feel involved in the decision-making process were significantly more likely to regret starting dialysis and wish they had opted for conservative care ($p=0.03$).

“The lack of freedom, the quality of life. Not being able to do things I would want to do. Not being able to work. Not being able to travel. I would have done anything I could to avoid dialysis.”

Analysis of the factors considered when starting dialysis has revealed four major themes: lack of choice ($n=19$), a desire to stay alive ($n=11$), symptom control ($n=7$) and family pressures ($n=5$) (Table 1). Despite a perceived lack of autonomy in dialysis initiation, 12/19 patients citing lack of choice felt actively involved in the decision-making process (63%). In these patients, the perceived beneficence of treatment may have outweighed the lack of control they felt at the outset of therapy.

5 patients in this study would choose no dialysis if they could go back in time. Most patients ($n=22$, 51%) were happy with hospital haemodialysis (reasons given included reassurance, perceived safety of the hospital environment and social aspects). 16 patients (37%) would prefer a home-based treatment modality (home haemodialysis or peritoneal dialysis). The most common reason cited for this was difficulties with patient transport.

Conclusion

Whilst over nearly half of the patients involved reported having no choice in the decision to start dialysis, nearly two thirds of these patients felt actively involved in the decision-making process. This highlights the importance of the manner in which dialysis initiation is managed. Actively involving and empowering patients in the decision-making process may result in less regret amongst older hospital haemodialysis patients.