End of Life Decisions

“IT’S A LOT EASIER TO SAY YES THAN NO” - DECISION MAKING IN END STAGE KIDNEY DISEASE

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Background Individuals with chronic advanced diseases such as end stage kidney disease (ESKD) are offered a growing number of choices regarding life-prolonging treatments. Health care teams (HCTs) play an important part in helping patients make decisions about with-holding and withdrawing such treatment.

Aim To explore the similarities and differences in the decision-making process for patients with ESKD and their healthcare team (HCT), with regards to dialysis.

Method A systematic review of qualitative studies. The search strategy was peer-reviewed and two independent researchers were involved in screening, data extraction, quality appraisal and synthesis. The Hawker et al (2002) appraisal checklist was used to provide an assessment of quality. The synthesis was conducted using thematic analysis.

Results Eleven studies were eligible for inclusion, including 177 patients and 53 HCT members. With-holding dialysis: Factors weighed up by patients included peer experience, being a burden on family and wider society, and maintaining normal social roles. Some individuals instinctively opted for life-prolonging treatment at all costs, whereas others accepted death as a natural course. HCTs on the other hand prioritised biomedical factors and relied on their own objective deliberation rather than patient preference. How individuals coped with their emotions was an important mediating factor. Problem-focussed copers sought various levels of input where as emotion-focussed individuals delegated choice.

Dialysis withdrawal Problem-focussed individuals viewed the option to withdraw treatment as a ‘tremendous control’ to stop their suffering. Emotion-focussed copers however passively continued dialysis. HCTs struggled with the dilemma of determining when dialysis was prolonging suffering rather than improving quality of life and therefore continued to err on the side of life-prolonging treatment until dialysis was no longer physically possible.

Conclusions Patients and HCTs are influenced by different factors when making decisions about dialysis. Informed shared decision-making requires greater transparency of the impact of such factors on choice.