

What information do staff use to involve patients in decisions about conservative management? A critical review of leaflets used in UK renal services.

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Background: When patients transition from chronic to advanced kidney disease healthcare professionals begin conversations with patients to plan for the next treatment phase. Conservative management is increasingly offered to older patients who have co-morbidities, increased symptom burden and/or frailty, as the clinical benefits of dialysis may not outweigh the burden of treatment. Pre-dialysis education prepares patients to make changes to their illness management and aid decision making. Providing good quality written information is essential to supplement this educational process. No guidelines on the development of treatment information about CM/RRT options exist and it is not known if information meets quality and health literacy standards and/or is able to assist patients in decision making.

Aim: Our study (i) surveyed the provision of information provided to patients about CM via an audit of UK renal units and national UK renal charities and (ii) examined the quality of written information about CM via a formal quality assessment using a selection of written information.

Methods: A cross-sectional survey of written information about conservative management including all 72 main UK and Northern Ireland renal units and three leading UK-based renal charities. Ethical approval was not necessary as this was an audit of information. Questionnaires were posted to members of staff identified as being responsible for pre-dialysis education. Respondents were asked to include copies of their written information on CM when returning their questionnaire. A coding frame in the form of a checklist was systematically applied to each leaflet by the first author (AW). Data were managed using the Statistical Package for the Social Sciences. Frequency and descriptive data summarized the responses from the audit questionnaire and leaflets' content analysis.

Results: Fifty two (72%) renal units returned the questionnaire. Unites reported that they patients discuss the CM decision with a: nephrologist (99%), nurse (100%), palliative care (47%) or elderly care specialist (14%). Conversations were supplemented with: written leaflets (98%) and DVDs (27%). Decision aids were used in n=18 (35%) units: Dialysis: Making the Right Choices For You (KRUK; n=6, 33%); NHS Rightcare Shared Decision Making (n=4, 22%); in-house decision aid (n=1; 5%); not named and/or incorrectly labelled as a 'decision aid' (n=7; 41%). Seventeen leaflets were included in the quality assessment. Conservative management was referred to by a variety of names, most commonly 'conservative kidney management and choosing not to have dialysis'. Leaflets framed the choice as being between CM and dialysis (n=10, 59%) or CM, dialysis and transplantation (n=5, 29%); two leaflets (12%) referring to CM as 'renal supportive care' did not include details of other treatment options. The readability score for each of the leaflets was 53/100, meaning the leaflets were fairly difficult to understand.

Discussion: Leaflets were the main source of information used to supplement discussions with nephrologists and nurses about choosing CM. Eighteen services provided 17 different leaflets, 11 (65%) of which were developed by renal services. This suggests considerable time and resources are put in to producing the same

information driven by the lack guidelines and/or a centralized system to guide renal services in the design and development of information resources. Findings will help identify how we can develop a patient decision aid resource (YoDCA) to support staff and patients making the CM/dialysis choice.