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EDITORIAL COMMENT

Dialysis modality selection: physician guided or patient led?*

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* The results presented in this article have not been published previously in whole or part.

Abstract

The process of choosing dialysis modality for patients is complex and requires input from the expert renal team. Although it is commonplace for nephrologists to recommend dialysis modalities to patients, this might not always lead to the patient receiving treatment which they regard as most suitable. Nephrologists should consider whether it is appropriate for pre-dialysis education to be directive, or whether the choice between treatment options should be led by the patient.

Key words: dialysis, end-stage kidney disease, haemodialysis, peritoneal dialysis, pre-dialysis

How do patients choose between treatments for end-stage kidney disease? The process and method of dialysis modality selection by patients is complex, nuanced and subject to multiple influences. How do patients then receive the treatment they have chosen? Even after modality selection, the process of then delivering this treatment to patients can be challenging and renal services frequently fail to start patients' renal replacement therapy using their stated chosen treatments [1, 2].

Whatever the process, Registry data tell us that dialysis modality choice alters between geographical areas and over time, and all analyses show a reduction in uptake of home therapies over the last two or three decades [3, 4].

Although nearly all nephrologists and patients would regard transplantation as the superior modality of renal replacement therapy, the relative advantages of dialysis modalities over each other continue to be debated [5–7]. There are some strong advocates for home therapies, and reasons cited for such a point of view often contain a mixture of individual clinical indications and utilitarian principles of maximal usage of limited resources [7, 8]. On the whole, however, guidelines broadly recommend that selection between these options should be a

shared decision-making process between health care professional and an informed patient [9]. Shared decision-making takes into account the best clinical evidence available, as well as the patient's values and preferences. It needs patients and professionals to understand what is important to the other person when choosing a treatment [10].

For example, the European Best Practice Advisory Board [11] recommend that patients '... should receive well-balanced information about the different RRT modalities by means of a structured education programme', thereby '... [making] sure that all patients can select the modality that is most suitable for them'. Although such statements are inarguable, the devil is in the detail, and defining what constitutes 'well-balanced information' and 'modality that is most suitable' is extremely challenging. Even though it is well established that how options are framed or presented affects the choices people make [12], recent reports indicate significant variation in the delivery and content of pre-dialysis education programmes [13].

In this issue of CKJ, De Maar et al. [14] describe 'GUIDE, a structured pre-dialysis program that increases the use of home dialysis'. In the article, the authors describe a retrospective

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analysis of outcomes in patients with advanced chronic kidney disease subject to a novel structured pre-dialysis education programme, termed 'GUIDE'. Over a 12-month period following introduction of 'GUIDE', the uptake of home dialysis modalities among patients with advanced chronic kidney disease who progress on to dialysis was higher than in historical controls from the same centre.

For those nephrologists wishing to increase uptake of home therapies, adopting a process resembling 'GUIDE' would appear to be a method of doing so.

At the heart of 'GUIDE' are six things—first, the programme has a home-focused approach in which, if transplantation cannot take place in a timely fashion, home dialysis is advised above centre-based treatment by a team who aspire to increase uptake of home therapies; secondly, patients are visited at home by a case manager, who reviews the patients circumstances and completes a questionnaire indicating their view of the patient's suitability for home dialysis; questionnaires are also completed by the patient and their nephrologist, the latter indicating the nephrologist's treatment preference; thirdly, there is a multidisciplinary meeting (MDM) (in the patient's absence) where the most suitable treatment for this particular patient is chosen; fourthly, after the MDM, the patient is educated, usually in a single session, about their dialysis options; fifthly, after a second MDM, patient and nephrologist choose the modality, and finally the patient is prepared for and started on dialysis.

A strength of the 'GUIDE' process is the transparency of the policy, goals and actions of their programme, and further transparency about how they have involved the patient in their professional and service infrastructure. However, within this structure the patient is educated and chooses their modality after an MDM has determined what is most suitable for them. Although this may reflect practice in many nephrological centres, it is a directive process, and it should be recognized that there may well be tensions between the view of a health care professional (subject to service delivery frameworks/initiatives/other incentives) [8] and the view of the patient about what is best for them.

Although consultant nephrologists are highly trained and experienced practitioners, it has been demonstrated that the views of individual practitioners about patient suitability for dialysis vary widely. When presented with patient scenarios in experimental conditions, nephrologists practising in the same nephrological service vary in their assessment of suitability from completely suitable to completely unsuitable [15]. Similar results have been described in other similar experiments [16].

In addition, in a series of highly revealing discrete choice experiments conducted among health care professionals, patients and those close to them, Morton *et al.* showed us that the views of patients about the trade-offs necessary to choose dialysis modality can also be different from those looking after them, being either professionals or loved ones [17–19].

Education can inform patients about treatment choices and preparation for care [20], and if appropriately designed might enable patients to make treatment choices reflecting their lifestyle preferences in the context of their disease [21]. However, patient information can also enable understanding, help with coping or adjusting and develop self-management skills including adherence [22]. One interpretation of the 'GUIDE' process would be that it aims to increase adherence of patients to their health care team's favoured treatment choice, and patients who choose not to take up a home therapy might be seen as non-adherent. When implementing the 'GUIDE' process, it is interesting that the MDM view of suitability for home therapy was

1.5–2 times the rate judged by the patients. The ability of a patient to challenge the recommendation of a health care professional is variable, but studies of a decision aid introduced to support patient modality choice has shown that use of such materials lead to patients being less dependent on others to make such decisions [21]. Furthermore, such information was also shown to make patients more likely to challenge the view of a health care professional when it does not match their personal beliefs and values [21]. Although patients may report satisfaction with their dialysis team's care of them, they also report valuing help to make an informed decision, rather than being encouraged to adhere to a choice given to them [23].

Leaving aside the issues of education and modality selection for a moment, there are also interesting results with regard to service delivery.

It is interesting to note that even with the 'GUIDE' programme in place, there was not an increased uptake of home therapies at dialysis start compared with historical controls. In addition, the numbers choosing a home therapy fell between discussion and declaration of modality choice, and fell further when patients actually started renal replacement therapy. Furthermore about one-quarter of patients did not start with the treatment of their choice. It appears that even in a renal centre with a desire to promote home therapy, a patient who has chosen home therapy may not start treatment this way but instead commence in-centre dialysis.

The authors cite a lack of training capacity as one of the issues underlying this problem. This is a very objective issue, and another recent study identified similar practical barriers—including perceived medical contraindications and lack of space—which prevented patients starting dialysis at home even after choosing it among the options [24]. Addressing these issues through service design is required by all nephrologists, and patient flow analyses may be very helpful in identifying barriers to the practical implementation of home therapies [2]. Such flow analysis might also identify where extra numbers of home therapy patients were recruited from in programmes where this is promoted. Reproducing the flow diagram as from the current article may be an instructive undertaking for many renal services [14], and similar previous initiatives have suggested this [2].

However, in both studies, other much more subjective barriers to starting home dialysis were identified, even after this modality had been chosen. These include a feeling of fear, insufficient education or lack of confidence leading to ultimately declining home therapy when recommended or failing to start on it even having apparently chosen it [14]. These latter reasons would appear particularly amenable to intervention by structured pre-dialysis education; however, if patients are reporting such problems even after structured pre-dialysis education then the programme itself would seem to require at least some adjustment. It is important to recognize that even apparent difficulties with service delivery may at least have some of their roots in the more complex and subtle issues raised by the patient pre-dialysis education programme.

The important point is that the educational programme should be one that is directed towards producing patients who are informed and activated, to enable shared decision-making to properly take place [25, 26]. The ingredients necessary to produce activated, informed patients have been well defined by health psychologists and decision-scientists. Patients need to be prompted to understand that 'they' have a decision to make; 'they' need to learn the required information without bias and assimilate the facts with 'their' existing values to make 'their' own decision [26].

The authors of the article presenting the 'GUIDE' pre-dialysis education programme describe a directive educational programme that can increase home therapy uptake. What is unclear is whether it is appropriate for clinicians to guide patients to the clinicians' preferred treatment or if we should allow the patients to lead the clinicians to the patients' most suitable treatment.

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