

PDI Commentary 1633

Title: “Do dialysis decision aids improve treatment decision making?”

Rachael Morton, PhD

Many of us have contemplated decisions about our health like whether or not to have the flu vaccine, whether or not be screened for breast or prostate cancer, or whether or not to have surgery for lower back pain. Patients with end-stage kidney disease face a number of important health and treatment decisions such as: Should I have a transplant? Should I keep taking statins? Should I go on dialysis? The answers to these questions are not straightforward because they depend on a multitude of factors including clinical indications, availability of the treatment options, potential harms and benefits of each treatment, and alignment of the treatment options with patients’ values, goals and beliefs. The process of shared decision making¹ brings together evidence-based decisions about healthcare and informed decisions about patients’ lives, to create shared decisions about health, illness, treatment and care delivery.² Informed decision-making on the other hand, is slightly different in that it refers to making decisions based on accurate information, which can be made independently, and/or with family members, and/or with staff providing that care.

Several studies report people with advanced kidney disease are dissatisfied with the amount and type of information they receive about dialysis treatment options.³ A systematic review of patients’ perspectives about treatment option information found 10 of 18 studies in which patients and family members felt they had

insufficient information on which to make informed treatment decisions.³

Furthermore, many patients found the timing of information provision to be problematic, as it often occurred when they were acutely unwell and unable to make best use of the information, or it was delivered just as a decision needed to be made, causing a rushed, time-pressured decision.^{3,4} Patients with advanced kidney disease and their families, who are naïve to the world of dialysis, and who carry varying degrees of health literacy, rely on accurate information from health professionals about peritoneal dialysis and haemodialysis treatments in order to make informed choices. Patient decision aids are one evidence-based method to achieve this.⁵

Decision aids in healthcare are designed to encourage patients and clinicians to consider information about treatment options and their consequences, evaluate this information in accord with their values, make a decision accounting for trade-offs and discuss this reasoning with others to agree upon and implement a preferred choice.⁵ A recent PubMed search identified >460 hits for 'dialysis decision aid', including eight patient decision aids listed for a variety of chronic kidney disease health decisions, with five of those relevant to dialysis modality decision making;(My Kidneys, My Choice [Australia]);⁶ Dialysis: Making the right choices for you – the dialysis decision aid booklet YoDDA[UK];^{2,7} Kidney failure: What type of dialysis should I have[US];⁷ My Life, My Dialysis Choice [US]; and Chronic kidney disease: Treatment Options[UK].

Winterbottom and colleagues² recently evaluated their decision aid, Dialysis: Making the right choices for you – the dialysis decision aid booklet (also known as the

Yorkshire Dialysis Decision Aid (YoDDA)), in a prospective non-randomised study among 189 participants. Importantly this evaluation was undertaken from two perspectives: i) patients making dialysis treatment decisions and ii) implementation of the decision aid into usual practice, in a busy and varied group of renal units which would be considered representative of many units in the UK.

Briefly, the YoDDA decision aid is a booklet that contains information about chronic kidney disease, conservative care and renal replacement therapy; differences between specific dialysis options; and a decision-attribute summary table that prompts a patient rating of whether centre-based haemodialysis, home haemodialysis, continuous ambulatory peritoneal dialysis or automated peritoneal dialysis best fits their lifestyle at the current point in time. The final section is a glossary with useful additional links for support. A number of countries have translated the YoDDA booklet into their own language.

<http://www.kidneyresearchuk.org/file/health-information/kr-decision-aid-colour.pdf>

The prospective study by Winterbottom et al.² compared usual pre-dialysis care for newly referred patients at six Yorkshire renal services between February - August 2012, to usual care plus the YoDDA booklet, for patients referred between September 2012 - March 2013. The main outcomes from the patient perspective were the usefulness of written information; decision making processes; and decisional conflict measured at the initial pre-dialysis consultation and then again six weeks later. Acceptability of the decision aid from a health service perspective was measured by the proportion of new patients at each centre who were given the

YoDDA booklet intervention; and the number of centres continuing to hand out YoDDA booklets following study completion.

The main findings showed that at six weeks, those in the YoDDA intervention group had significantly higher information scores, higher decision clarity and feelings of control, and higher levels of shared decision making among their family. Importantly, the YoDDA significantly improved patients' considerations of the advantages and disadvantages of each option (including harms and benefits of each dialysis modality). YoDDA improved all measures of autonomy in decision-making although this difference was not statistically significant. Preparedness for decision making scores were higher in the YoDDA group compared to the usual care group directly following the pre-dialysis education and six weeks later. Interestingly, there was no difference between YoDDA and usual care groups in decisional conflict, which the authors interpreted as participants not experiencing conflict and /or the measure used (decisional conflict scale) was not sensitive to detecting decisional uncertainty. In contrast to other studies,^{3,8} the YoDDA evaluation found the views of family and professionals were important in treatment decision-making, but not the views of other patients. Forty-five percent of referred patients in the intervention group were given the YoDDA booklet with a by-center variation of 14%-49%. Four of six centres continued giving out YoDDA booklets after the study closed.²

Some important limitations of the YODDA evaluation are worth mentioning. The study was not randomized and therefore subject to selection bias, whereby characteristics of participants in the usual care and YoDDA groups may be different.

There was a moderate amount of missing data (as evidenced by a <60% survey completion rate for both groups at initial consultation and six weeks); and potentially a larger sample size may have been needed to confirm evidence of effect in some of the measured outcomes.

However, the authors are to be commended for their study evaluating the acceptability and usefulness of a dialysis decision aid. YoDDA itself was developed through an extensive, systematic process that included reviews of clinical guidelines, service frameworks and analysis of existing patient information; using decision analysis and behavioural decision support guidance; and testing face validity. It is well grounded in decision-making theory, and was designed with an emphasis on removing 'dialysis modality biases' from the information presented.² This type of decision aid evaluation is rarely undertaken and published.

Implementation of the decision aid into usual practice

Perhaps one of the greatest strengths of this study is the knowledge it generates about a complex health service intervention and the explicit evaluation of study engagement by health professionals and the feasibility of incorporating this decision aid into current practice. The authors reported a variation in the rate of uptake of YoDDA across the six renal units, and proposed reasons for this including a limited health service infrastructure, differing views towards research about shared decision making, or possibly limited benefits of dialysis decision aids for patients with

worsening health.² Either way, these reasons for a lack of engagement are interesting and important, as they may speak to something broader about the judgments made by health professionals on behalf of new patients. In one sense this represents a 'gatekeeper' effect, where health professionals act as information agents, and 'control' the type of information being delivered.⁹ This can have both positive and negative consequences including the avoidance of 'information overload' to anxious or overwhelmed patients by delivering the right amount of information at the right time, or it may lead to a lack of information provision about all available courses of action. The fact that YoDDA is now directly accessible through consumer organisations like Kidney Research UK, may help overcome this barrier.

A Cochrane review of decision aids for people facing treatment or screening decisions,⁵ found high-quality evidence that decision aids compared to usual care improved people's knowledge regarding options, and reduce their decisional conflict related to feeling uninformed and unclear about their personal values. There was moderate-quality evidence that decision aids compared to usual care stimulated people to take a more active role in decision making, and improved accurate risk perceptions when probabilities were included in decision aids, compared to not being included. There was low-quality evidence that decision aids improved congruence between the chosen option and the patient's values.

Other health service benefits of dialysis decision aids have been reported.

Decision aids can change service provider behavior and this is a fundamental contribution to improvements in patient care. Fortnum et al,¹⁰ in an implementation

study of the My Kidneys, My Choice decision aid, claims that staff variations in pre-dialysis education practices were minimized through staff training in shared decision making and implementation of the decision aid. Further changes may be uncovered such as the nature of conversations with patients, through a process evaluation study, with benefits to be gained by health services just as much as by patients.

Returning to the main question posed in the title – do decision aids improve decision-making? There is good evidence that YoDDA helps patients think differently about the problem of choosing between treatment for advanced kidney disease. Of equal benefit I would argue is that the use of a decision aid like YoDDA also helps clinicians think differently about the treatment they recommend for individual patients.

Associate Professor Rachael Morton, PhD

Director of Health Economics,

NHMRC Clinical Trials Centre,

The University of Sydney, Australia

Note: The Ottawa hospital – Research Institute maintains a list of available patient decision aids with a quality assessment of each according to International Patient Decision Aid Standards (IPDAS). (<https://decisionaid.ohri.ca/AZlist.html>)

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