The introduction of the paper is based on the assumption that heuristic choices are less favourable than logical and ‘informed’ ones. However, this point of view conveys another philosophical hypothesis, namely that a Cartesian approach is superior. Yet, as far as we know, there is no demonstration of this assumption, and it should probably still be seen as a working hypothesis, in line with the structure of our evidence-based medicine and with a logical probabilistic approach [4].

The heuristic approach has been defined as an efficient cognitive process (conscious or unconscious) that ignores part of the information. The hypothesis that heuristic decisions involve greater errors than decisions defined by logic or statistical models is not uniformly accepted, and heuristic methods may indeed allow one to find ‘good’ empirical solutions where an exhaustive search is impractical or hardly feasible, as in the vast field of dialysis modalities [4]. Furthermore, as the paper states, the two main dialysis choices are depicted as equivalent in terms of survival, and thus, the choice between haemodialysis and peritoneal dialysis necessarily relies on side effects, specific risks and the setting of treatment [1]. Therefore, the most objective part of the question on dialysis treatment (survival figures) is equivalent, and an empirical experience-based heuristic approach may indeed be more apt to allow each individual to identify the pros and cons of the dialysis modality tailored to his/her case. The conclusion that ‘scientific’ information alone is insufficient may be rather obvious in a context in which the choice profoundly interferes with daily life.

Indeed, this brilliant study focussing on the importance of the role (you are the patient, you suffered, therefore you know better) may also suggest a conclusion that at least partially differs from the reported conclusions, which state that providing the opportunity for patients considering dialysis options to speak with others on dialysis may discourage them from making informed dialysis modality decisions. However, why not implement the heuristic decisional pathway by providing the opportunity to discuss different types of experiences with different types of patients as a means to supplement the often cooler and detached technical information, thus ensuring the highest attention and value to our patients’ experiences?

Our experience in this regard may be of some interest. Our teaching programme was based on the ‘exposure’ of patients both to extensive written material on dialysis and to different experiences of peers on peritoneal dialysis, haemodialysis, transplantation and home haemodialysis, both in written form (interviews) and in direct talks during lessons held in the Centre. This approach was the basis for restarting a home haemodialysis programme in the last decade and more recently for starting a new home haemodialysis project, recruiting nine patients in 10 months (six presently in training, with different schedules; three in the pre-dialysis phase) in a new dialysis Unit. While it may be argued that expert patients may exert a ‘too strong’ influence on their peers, home haemodialysis may be a good marker of the importance of continuous education and peer support since in our setting the training is long and the patients may drop out of the programme at any time [5, 6]. Lastly, the suggestion that patients (or individuals in the overall population) may place more trust in other patients.


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On the impossibility to translate experience and the role of patient narratives in dialysis choices

Sir,

In a time in which the importance of narrative medicine is being rediscovered, the elegant study by Winterbottom et al. underlines the role of the narrator in the decision process. In fact, in the different combinations of the presentation of dialysis modality, patients are more apt to choose the type of dialysis presented by their ‘colleagues’ in disease, instead of the one presented by the doctors [1].

The paper recalls the ancient philosophical concept of the impossibility to translate experience into words and words into experience as well as the possible dichotomy and complementarity, between ‘truth’ (which we might identify with science, in our context) and experience. As in the words of Parmenides, a pre-Socratic philosopher, ~2500 years ago:

‘It is right that you learn all things, Both the unshaking heart of well-persuasive truth, and the beliefs of mortals, in which there is no true trust.’ (B1.28–30) [2].

The impossibility to fully translate experience is a concept that makes the modern informed consent a never-ending task and a continuous challenge [3]. We may actually wonder if we, as physicians who do not experience the fear of dialysis or the changes in body appearance due to increased fluid in the abdomen or the curiosity of neighbours in summer when they look at the scars on the arms, are really able to convey the pros and cons of dialysis.
than in their physicians provides a valuable opportunity to critically reflect on our role as physicians and masters [7].

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Reply

Sir,

We would like to submit the following response to the letter entitled: ‘On the impossibility to translate experience, and on the role of patients’ narratives in dialysis choice’ (G Piccoli). We welcome the opportunity to respond to this letter and we are pleased to receive positive feedback. Our findings are open to a number of different interpretations and we acknowledge the authors comments about the value of looking back retrospectively to find that apparently new ideas have often been visited before, even as far back as classical times. Our letter underlines three main points raised by the author.

Firstly, the author states that there is no evidence that heuristic decision making is less superior to those choices that can be said to be more ‘informed’. Indeed, the authors acknowledge the work of Gigereiser et al. that describes the use of ‘fast and frugal’ heuristics whereby judgements are based on the decision maker’s environment, which lead to accurate decisions [1, 2]. Piccoli argues that using heuristics to guide decision making may be an acceptable approach for the dialysis decision where an ‘exhaustive approach is impractical and hardly feasible’. We would argue, however, that the majority of patients have time to prepare for their impending dialysis and be provided with comprehensive information about dialysis thus facilitating informed decision making, which is based on the relevant treatment information. It is well documented that encouraging patients to make more informed decisions leads to better quality decision making in terms of increased satisfaction, less decisional conflict, less regret, encourage active participation in the decision making process, improve agreement between values and choices, lead to a decrease in the numbers of those who remain undecided and involve more realistic evaluations of the decision (for a review, see [3]).

Secondly, the author states that patients’ experiences might meaningfully be incorporated into the decision-making process. We agree with this point but feel that at present there are a number of outstanding issues that must be addressed through research before we can confidently incorporate the patient experience into decision making without fear of it biasing patients’ choices. Our study corroborates previous evidence that suggests that patients bypass some of the facts about treatment options and make biased choices when it is presented from the perspective of the patient [4]. Through the development of a clear definition and taxonomy of what constitutes a patient narrative and through the analysis of theory driven explanations of why narratives might influence choice, we can better understand how they might be effectively implemented into practice. We are currently exploring these issues while updating the International Patient Decision Aid Standards document (H. L. Bekker, A. Winterbottom, P. Butow, D. Feldman-Stewart, A. Dillard, M. Jibaja-Weiss, J. Fowler, V. Shaffer and B. Volk, in preparation).

Finally, we thank the author for drawing our attention to their work on peer support for patients with haemodialysis and acknowledge the important role that patients may play in supporting other ‘newer’ dialysis patients. We would like to make a distinction between the role that patients play through peer support and their role in facilitating dialysis decision making. While ‘expert’ patients may be useful in terms of helping others to cope and adjustment to their illness, in contrast, patients need to make a dialysis choice based on their own values and judgements rather than those of another patient. We do not think that receiving information in the form of patient narratives necessarily means the decision will not be ‘informed’ but that this powerful intervention can be harnessed more effectively and with less bias by training patients in the way they impart information.

We are currently exploring such ideas using experimental research designs in hypothetical dialysis decision-making scenarios with student populations (A. Mooney, T. Gavaruza, B. Sumner, G. Latchford, A. Stigglebout, M. Willkie, A. Winterbottom and H. L. Bekker, oral presentation).

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