End stage renal failure and assessment of health related quality of life

The management of renal failure has developed from experimental status to the point that haemodialysis, continuous ambulatory peritoneal dialysis, and renal transplantation are commonly used and relatively straightforward procedures to administer for patients with end stage renal disease. However, while contributing to the continued survival of patients, these treatments may impose adherence to various demands that may reduce wellbeing and health related quality of life. Some studies have suggested, for example, that patients with end stage renal disease have very high levels of depression and considerably impaired social activities. Patients with renal failure will be reliant on healthcare for life, and both health professionals and the patient will end up living with the consequences of all decisions that are made. The patient has many issues to come to terms with (for instance controlled diet, fluid intake, medications, and operative procedures) and how well these adaptations can be made by the patient is likely to have major effects on how successful treatment is. Therefore although the technical challenges can, on occasions, be considerable, the nephrologist also has some other tough calls to make. We might consider two broad responsibilities; firstly, to strive to offer the best quality of life to individual patients, and secondly to consider the costs involved. Can the information offered by patient based assessments of health related quality of life help us in these areas?

Firstly, a caveat; we should be very careful about drawing conclusions from cross sectional data sets of the kind reported in this issue by Wight et al; as there will inevitably be bias and difficulties of adjusting for case mix and baseline characteristics that result in patients receiving different treatments. However such data do provide evidence that dialysis patients have impaired quality of life compared with the normal population. This is hardly surprising; after all, dialysis involves the loss of many hours a week, a loss of control over a patient’s own destiny. Furthermore, the level of renal replacement, although adequate for life and the prevention of frank uraemic symptoms, is certainly far from physiological. The quality of life gap can be measured, and at least potentially, be filled. Such evidence is thought provoking for the dialysis physician, and provides a stimulus (if one is required) to consider aspects of the patient’s health not directly related to the mechanics of dialysis. Across the population with end stage renal failure, or in individual renal units, survey data might be helpful in focusing physicians on areas of anxiety for patients—such as sexual dysfunction—without loss of attention to variables—such as serum phosphate.

When considering individual patients, questionnaires might well be used to focus the efforts of qualified counselling staff on the most vulnerable patients. However, the evidence from other areas of medicine is not entirely encouraging. Although clinicians find the evidence available from health status measures interesting and informative, clinical trials seem to suggest that availability of such data does not significantly alter treatment decisions and, more importantly, outcomes for patients. Notably the information will be much more reliable and powerful when used to assess an intervention in a trial. We should also be able to use such methods to assess the benefit of other changes in provision affecting availability of service, convenience, and support staff. It is likely that patients’ quality of life is more sensitive to these changes than to a higher target haemoglobin or increased dialysis prescription. For instance, the impact of a new satellite dialysis unit on this kind of outcome measure may be substantial, even though it may be almost cost neutral because of savings on transport.

Wight et al consider the role of a so called generic measure of state of health. It may be that questionnaires with content designed more specifically to consider experiences of patients with renal failure will prove more clinically meaningful answers. For example, the haemodialysis stressor scale examines how patients cope with stresses of haemodialysis in terms of two scales, psychosocial and physiological. The haemodialysis quality of life scale assesses five aspects of patients’ experience: symptoms from haemodialysis, symptoms of end stage renal failure, mood, social and vocational factors, and family. Alternatively clinicians may use measures of psychological wellbeing—such as the Beck depression inventory—which has been extensively used in a wide range of patient groups to assess specific experiences—such as depression. The user needs to think carefully about the advantages of a generic measure—such as SF 36. It is argued that such measures have the advantage of comparing effectiveness of diverse treatments across disease groups. However, those concerned with services for renal failure have reason to distrust such crude comparisons of treatments, especially when put to use in the form of the cost per quality assisted life-year league table. Such comparisons seem insensitive to the critical state of health of patients with renal failure. Indeed measures of health generally struggle to capture the ways in which patients with renal failure accept considerable limitations in health related quality of life in return for the prospect of further life.

Thus, at present, such measures may prove useful in providing aggregated data of health related quality of life about groups of patients, particularly where study design and other evidence make it possible to attribute problems identified to sources in the service that can in principle be improved. However, there is little evidence at present to support their widespread use in individual patient care in the field of end stage renal failure. Trials are needed in this field of health care, and indeed, elsewhere to examine the additional benefits for health professional decision making and ultimately for patients’ health related quality of life.

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