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Which patients choose to stop dialysis?

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In 1986, Neu and Kjellstrand [1] reported that 22% of all end-stage renal disease (ESRD) deaths in a large regional dialysis programme resulted from discontinuation of dialysis therapy. Since then, several retrospective studies in the US have confirmed this observation. Two separate analyses of the US Renal Data System database in two time periods showed that ~20% of patients who die withdraw from dialysis at some time preceding their death [2,3]. While some nephrologists accept these statistics as consistent with their experience, others are sceptical and claim that they virtually never see voluntary withdrawal from dialysis. How can we understand this disparity?

Incidence and patient characteristics

While there have been few studies describing the incidence and characteristics of patients who choose

withdrawal, the reports from many locations around the US describe consistent findings. In one prospective study, patients who withdrew from dialysis were older, were more likely to live in nursing homes, had more comorbidity and suffered more severe pain than other dialysis patients [4]. Another report describes patients who choose withdrawal as more likely to have severe physical impairment and severe restriction of activities of daily living [5]. In another large retrospective review, patients who died of chronic diseases (e.g. dementia and malignancy) were much more likely to withdraw from dialysis before death [6].

While many patients who choose withdrawal are acutely ill and face imminent death, others are stable with no technical dialysis complication or new medical illness. Mailloux *et al.* [7] retrospectively studied 716 patients over a 20 year time span. They found that 18.5% of all deaths were attributed to withdrawal, in the absence of active medical disease, rapid deterioration or imminent death. However, cancer, malnutrition, catabolism and dissatisfaction with life were associated with the decision to withdraw. In another study of 1766 patients and 704 deaths, 26 stable dialysis patients (4% of all ESRD deaths) chose to stop treatment [8]. When compared with 40 competent patients who chose to stop dialysis when a medical complication arose, these stable patients were more often on home dialysis.

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A patient's decision to withdraw from dialysis should be considered in the context of his/her psychological state. It is important to remember that depression is the most common psychological problem presented by dialysis patients [9]. Nearly half of all dialysis patients have scores on standard psychological instruments that suggest symptoms of clinical depression. Furthermore, studies have shown a relationship between depression and mortality in both the US and Europe [10,11]. Could depression contribute to a patient's decision to terminate dialysis? Recent studies indicate that depression in dialysis patients is potentially treatable with standard psychotropic medication [12].

Do cultural and educational factors play a role?

Withdrawal from dialysis is rarely described in Europe [13,14]. Might cultural or educational differences among patients and dialysis professionals explain the disparity? In the US, Cohen *et al.* [15] studied a sample of patients on maintenance dialysis and reported that the majority of patients never discussed with their nephrologist or family the circumstances in which treatment should be discontinued. Sekkarie and Moss [16] reported that academic nephrologists who had received education in the ethics and law of stopping dialysis withdrew therapy from a greater percentage of patients than those in private practice.

Changing attitudes toward life-sustaining therapies

Withdrawal from dialysis must be viewed within the context of changing attitudes toward other life-sustaining therapies. One study of critically ill patients from intensive care units (ICUs) found a surprisingly high incidence of withholding or withdrawing life support [17]. They found that 90% of patients who died in ICUs during 1992–1993 did so following a decision to limit therapy, up from 51% during 1987–1988. In addition, recent studies have shown that the burden of treatment as well as the treatment outcome influences treatment preferences [18]. An accurate assessment of the burden of treatment for patients requiring not only dialysis, but also treatment for other multisystem diseases, may direct patients to choose stopping dialysis treatments. For some, the relatively small probability of return to normal function in addition to the treatment burdens may press the decision to cease treatments.

Shared decisions among physician, patient and family

There is still no clear explanation for the disparate descriptions of withdrawal, ranging from virtually

non-existent to the second leading cause of death on dialysis. Different cultures approach critical illness and death in different ways. Patients, families and caregivers have widely varying comfort levels and desires to discuss these issues or to consider withdrawal. The US Renal Physicians Association (RPA) and American Society of Nephrology (ASN) published a clinical practice guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis [19]. Following a structured review of the research evidence, case and statutory law and ethical principles, the authors make several recommendations. Shared decisions between physician and patient and, if the patient consents, with the family, is recommended. The physician should provide prognosis and treatment options, including stopping dialysis and receiving end-of-life care. They further recommend that informed decisions should follow estimations of prognosis, including chances for survival. The renal care team should attempt to obtain written advance directives from all dialysis patients. The guideline outlines the specific conditions where it is appropriate to withhold or withdraw dialysis.

Conclusion

We believe that a more comprehensive understanding of withdrawal from dialysis will require prospective analysis of dialysis patients, families and caregivers in many different geographical and cultural settings. Such investigations will need to include study of attitudes, cultural, ethical and religious training and beliefs, and communication practices. Are the RPA/ASN guidelines appropriate for all dialysis patients? The understanding of where and when withdrawal is considered, discussed and performed or is specifically avoided will be needed to answer this question.

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