

Illness trajectories: an important concept in the management of kidney failure

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to aid the planning of services to support patients in the terminal phase of their disease.

Introduction

The number of patients diagnosed with chronic kidney disease (CKD) is increasing, with recent studies suggesting that >10% of the population may have CKD [1,2]. This high prevalence is due to a variety of factors. A major contributor, in developed countries, is the increasing age of the population; epidemiological studies show that the prevalence of CKD increases dramatically with advancing age [2]. As the population lives longer and the proportion of older people increases, so the prevalence of CKD increases. In addition, use of estimated glomerular filtration rate (eGFR) has contributed to increased recognition of CKD [3]. Improved accessibility to renal services has also meant that many patients previously not referred are now being seen by nephrologists.

The presence of CKD has many implications for the patients, including increased morbidity and all-cause mortality, in particular increased risk of death from cardiovascular disease [4]. The majority of patients with CKD will die of a non-renal cause, and although their renal disease may contribute, it is not directly responsible. A proportion of the CKD population will progress to stage 5 CKD and need renal replacement therapy, either dialysis or renal transplantation. But even with optimal renal replacement therapy, the life expectancy for patients with stage 5 CKD is significantly reduced compared to healthy populations. In the presence of advanced age and significant co-morbidity, prognosis may be short [5]. In addition, a growing number of patients are opting not to have dialysis [6].

Irrespective of dialysis decision, most of these patients will die under the care of a nephrologist. It is critical therefore that we understand this phase of patient management, not only to provide optimal care for individuals but also

Disease trajectories

The concept of distinct patterns of functional decline over time leading to death is well established in palliative care [7]. Four distinct trajectories have been described (Figure 1) [8,9]. First, sudden death can occur at any stage without a prior diagnosis or symptoms of underlying disease (Figure 1A). Secondly, after the diagnosis of a terminal illness, there is preservation of function followed by a rapid decline in the advanced stages (Figure 1B), typical of a patient with cancer. The third pattern is one of acute episodes, frequently requiring hospital admission, and often without recovery to the previous level of function (Figure 1C). Eventually, death occurs during one of these acute episodes. This pattern is typical of patients with organ failure, such as end-stage cardiac or respiratory disease. The final pattern is one of gradual decline in already poor function prior to death and is typically seen in the very elderly and those patients with diseases such as dementia (Figure 1D).

Implications of disease trajectories

For patients with advanced renal disease and their families, and for medical professionals planning and delivering their care, it is vital to understand disease trajectories towards the end of life. This is increasingly important for nephrologists as the age and co-morbidity advanced renal failure population increases.

First, many patients will want to know their prognosis [10]. Questions frequently asked by patients include: How long do I have to live? What will happen at the end? The answers to these questions will inform the patient's expectations for the future and may influence their choice of treatment. Nephrologists need not only more evidence about survival times [5] but also better insights into the most likely course or trajectory of illness the patient might expect [11], so as to best advise patients as end of life nears. Sensitive end of life discussions help patients maintain hope and realistic expectations, rather than removing hope, as

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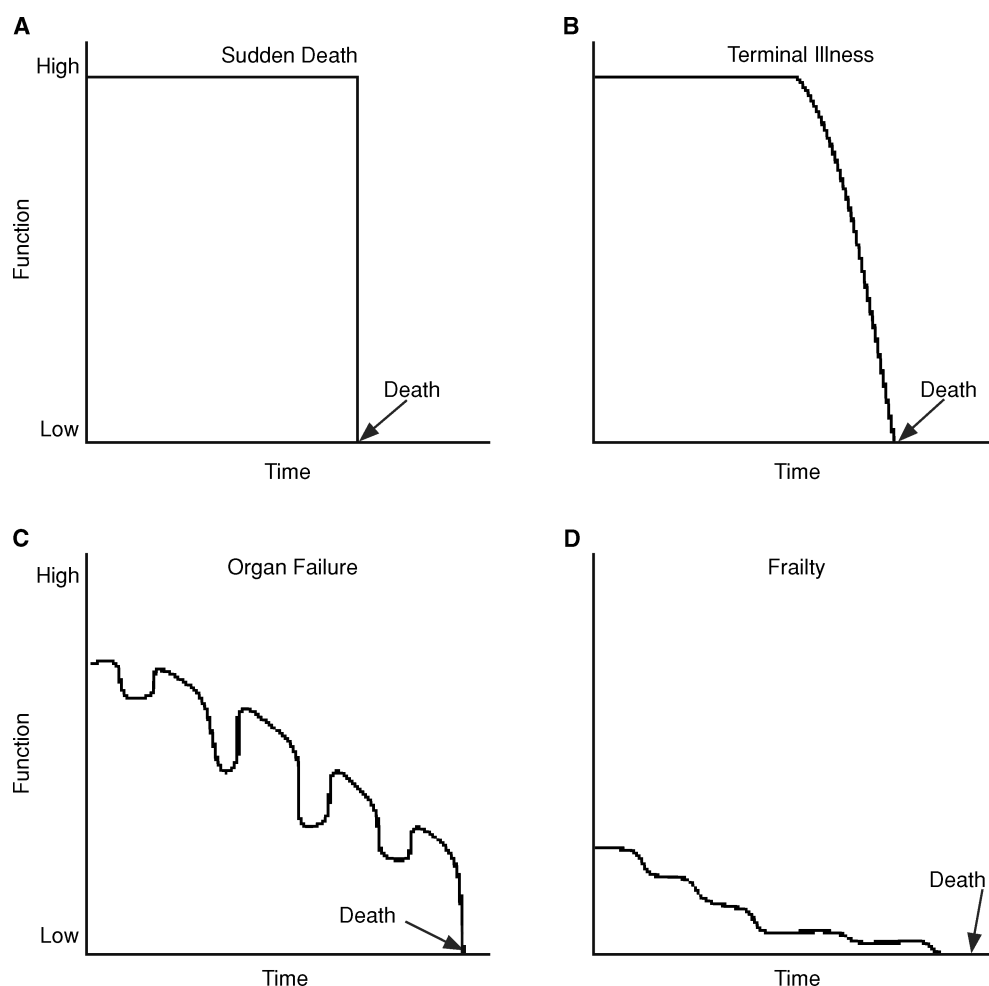


Fig. 1. The typical disease trajectories identified in patients with different diseases. From Lunney *et al.* [8].

professionals often expect [12]. Evidence also shows that, alongside good symptom control, patients give high priority to the opportunity to prepare for death [13,14].

Second, an understanding of trajectories is needed to underpin service provision. Not only functional trajectories but also symptoms and other components of disease trajectories need to be mapped. Predictors of change in functional or symptom trajectories also need to be determined. Knowing when patients are likely to experience rapid functional decline, high symptom burden and become most dependent on health and social services has major implications for the planning and delivery of their care.

Trajectories in renal disease

Is it appropriate to extrapolate disease trajectories developed in other end-of-life populations to renal patients? There are aspects of renal disease, in particular the availability of dialysis, which differentiate renal failure from other end-stage disease, and it is likely that the functional trajectories of patients with advanced renal disease will vary, largely according to whether dialysis is undertaken,

and according to the presence or absence of co-morbid conditions.

Some will follow functional trajectories similar to end-stage cardiac or respiratory disease (Figure 1C). Renal patients often have recurrent acute episodes, such as cardiovascular events, infective episodes, or problems with fluid overload. Dialysis patients may have specific acute episodes relating to dialysis access. After each acute episode, patients are left with greater functional deficit or increased problems with the ongoing delivery of dialysis. These episodes become increasingly frequent and refractory to treatment as the patient nears the end of life. Recognition of this pattern enables those at risk of imminent death to be managed more appropriately, and to have the chance that most (but not all) patients prefer, to plan and prepare for death, together with their families.

The trajectory of sudden death (Figure 1A) may occur for some renal patients, most commonly due to a cardiovascular event, although even for these patients, preceding events may have heralded decline. Withdrawal from dialysis is an increasingly frequent cause of death among the dialysis population; those who withdraw from dialysis likely have a much shorter period of decline in their illness trajectory, closer to the pattern described for malignant

disease (Figure 1B). However, many patients who withdraw from dialysis experience considerable functional decline well before withdrawal, and some may follow the more episodic trajectory (Figure 1C).

Conservatively managed patients can remain stable for long periods of time with a rapid decline in the late stages of their disease. This decline can be difficult to predict and without obvious precipitant. Services need to react rapidly to respond to such abrupt change in patient needs. A slower decline in function may be seen in other conservatively managed patients [15], with increasing frailty and dependence over several months prior to death. These patients may be very symptomatic during this period [16], needing good symptom control as well as psychological and social support for optimal outcomes. For this group, knowledge of the trajectory, how the disease will progress, what to expect and provision of adequate community support may prevent inappropriate and expensive hospital admissions.

Summary

With increasing numbers of patients reaching stage 5 CKD, it is vital that we understand the terminal phases of renal failure. The concept of disease trajectories provides a useful way to do this. Care for the renal patient in the last months of life has received much less attention than many other areas of nephrology. Yet this phase of illness needs equal levels of attention if we are to ensure good quality of death for all [17].

Collaboration between nephrology and palliative care provides the best chance for rapid improvements in care. The data available on disease trajectories are one example of the useful cross-fertilization between these specialities that can inform both patients and health care professionals, and allow us to improve quality of care. Although there is little evidence available as yet on trajectories in the renal population, the disease trajectories developed in other end of life populations are a useful way of conceptualizing and understanding care in the last months and weeks of life, to provide a basis for further research, and rapidly identify ways to improve care towards the end of life.

Conflict of interest statement. None declared.

References

1. Zhang QL, Rothenbacher D. Prevalence of chronic kidney disease in population-based studies: systematic review. *BMC Public Health* 2008; 8: 117
2. Stevens PE, O'Donoghue DJ, de LS *et al.* Chronic kidney disease management in the United Kingdom: NEOERICA project results. *Kidney Int* 2007; 72: 92–99
3. Courtney AE, Maxwell AP, Fogarty DG. Using estimated glomerular filtration rate (eGFR) to help manage patients with chronic kidney disease. *Ulster Med J* 2007; 76: 154–156
4. Go AS, Chertow GM, Fan D *et al.* Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. *N Engl J Med* 2004; 351: 1296–1305
5. Murtagh FE, Marsh JE, Donohoe P *et al.* Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant* 2007; 22: 1955–1962
6. Smith C, Silva-Gane M, Chandna S *et al.* Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract* 2003; 95: c40–c46
7. Glaser B, Strauss A. *Time for Dying*. Chicago: Aldine, 1968
8. Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. *J Am Geriatr Soc* 2002; 50: 1108–1112
9. Lunney JR, Lynn J, Foley DJ *et al.* Patterns of functional decline at the end of life. *JAMA* 2003; 289: 2387–2392
10. Murray SA, Kendall M, Boyd K *et al.* Illness trajectories and palliative care. *BMJ* 2005; 330: 1007–1011
11. Murray SA, Sheikh A. Palliative care beyond cancer: care for all at the end of life. *BMJ* 2008; 336: 958–959
12. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006; 333: 886–889
13. Steinhauser KE, Christakis NA, Clipp EC *et al.* Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001; 22: 727–737
14. Steinhauser KE, Christakis NA, Clipp EC *et al.* Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476–2482
15. Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. *Clin Med* 2004; 4: 39–44
16. Murtagh F, Addington-Hall J, Edmonds P *et al.* Symptoms in advanced renal disease—a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *J Palliat Med* 2007; 10: 1266–1276
17. Department of Health. *The End of Life Care Strategy*. London, UK: Department of Health, 2008

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