

# Contrasting approaches to end of life and palliative care in end stage kidney disease

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## ABSTRACT

With increased numbers of the elderly, including nursing home patients, being accepted for end-stage kidney disease (ESKD) management, there is heightened interest and focus on end of life decisions, advanced care planning and directives, withdrawal from dialysis and palliative care in this setting. Despite this, care at the individual patient level can vary greatly. Here, we present two contrasting cases to highlight the importance of early and ongoing involvement of palliative care in patients with ESKD. In the first case, a high quality of life was preserved before the patient died with dignity, with early interdisciplinary palliative care involvement. In the second case there was a long protracted period of poor quality of life prior to death. This was associated with resistance to the involvement of palliative care, mainly from the family. Addressing end of life care issues early in the chronic kidney disease (CKD) trajectory and ensuring patients, their families and health care providers are well informed, may contribute to a better outcome for the patient and their family.

**Key words:** conservative therapy, kidney failure, morbidity, mortality, palliative care

## Introduction

Mortality in patients with ESKD is 10- to 100-fold greater than age and gender-matched controls in the general population.<sup>[1,2]</sup> With the greater life expectancies, the prevalence of those aged over 75 years undergoing dialysis has doubled in the last 20 years<sup>[3]</sup> and the number receiving dialysis is increasing by up to 10% annually.<sup>[4]</sup> The increase in the number of elderly people who are accepted onto dialysis, many with co-morbidities means that patients, nephrologists, families and multidisciplinary teams, is often faced with end-of-life decisions and the provision of palliative care.

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Whether dialysis offers better quality and quantity of life compared with conservative management is debatable and may vary depending on a patient's health, emotional status, and associated co-morbidities.<sup>[5]</sup> Randomized controlled trials that evaluate the benefits of dialysis in the elderly are lacking. The decision to continue or to withdraw from dialysis falls to patients and families and it is vital they are fully informed about the benefits and burdens of each choice with the all options adequately supported by an interdisciplinary palliative care team.

The contrasting approaches to end of life and palliative care are explored in these cases with the aim of highlighting the importance of pre-ESKD education and the change in focus required from the life extending goal of dialysis care to relief of symptom burden and palliative care. Early palliative care involvement, integrated into routine ESKD management, is proposed.

## Case Reports

### Cases

#### Patient A

Patient A was a 62-year-old woman who developed kidney failure in her late teens secondary to mesangiocapillary glomerulonephritis. She had a live donor kidney

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transplant aged 34, which failed 13-years later and a cadaveric transplant the year after lasting 8 years. Her past medical history included hypertension, acute myocardial infarction, and a cerebrovascular accident. After 5 years of hemodialysis following the failed cadaveric transplant, the idea of withdrawing from active therapy was discussed at a time she described as “the low point in my life.” Psychiatric care through this period had no effect on her functional state. She reiterated her desire to withdraw from therapy because of the combination of physical symptoms of recurrent brachiocephalic thrombosis, nausea, vomiting, and a decline in overall functional status. With her family closely involved, discussions around prognosis and quality of life were raised and a joint decision was made to continue management in a palliative care setting. This family meeting, along with ongoing follow-ups with the renal team reinforced the relationship where Patient A felt that she was supported in her decision to discontinue dialysis therapy. An interdisciplinary approach was facilitated by referrals to social work and pastoral care.

During this period the patient underwent some palliative ultrafiltration sessions, which helped in the resolution of her progressive breathlessness. The patient had a planned admission to a specialist palliative care unit immediately following her complete withdrawal from dialysis. She experienced some episodes of nausea, shortness of breath and agitation, all managed effectively by the palliative care team. Food and drink were provided and consumed as tolerated. She was well supported by her family during her admission and there were no unrealistic expectations of her family with regards to the aims of palliative therapy. She understood and even stated that “I only have a few days of life left” and spent quality time with her loved ones towards the end. The patient passed away in the palliative care unit 10-days after withdrawing from dialysis.

#### *Patient B*

Patient B was a 65-year-old woman who developed ESKD secondary to diabetic nephropathy, managed with hemodialysis for 5 years. She was a bilateral amputee due to peripheral vascular disease, had hypertension, congestive heart failure, a history of vascular dementia, and a cerebrovascular accident. She lived at home with her husband who was her full time caregiver assisting her in all her activities of daily living.

In this case, there were no discussions regarding palliative care documented on initiating dialysis or during the latter phases of treatment. The patient’s sole support was her husband who was not well informed about the possible outcomes, prognosis and role of dialysis in ESKD. In

several instances it was documented that he believed stopping dialysis was equivalent to “pulling the plug.” These unrealistic expectations on his behalf lead to disagreements and sub-optimal care delivery.

On her last in-hospital admission, the nephrologist made the decision to withdraw dialysis on medical grounds, as further dialysis was unlikely to lead to any improvement in patient comfort or survival. Even after discussing the decision with the husband 3 weeks prior to her death, he wanted to reverse this decision because he felt that she “took a flight into health.” During this admission, the decision was made to feed the patient only as tolerated and the family filed a formal complaint as they felt that the hospital was trying to starve the patient.

Palliative care assessment and review was only initiated a week prior to her demise and their suggestions of achieving effective sedation and managing the pain were not well received by the patient’s family. The inherent distrust that developed between the patient’s family and the health professionals led to a turbulent end of life situation that could have potentially been alleviated with counseling and palliative care involvement at an early stage.

## Discussion

The 5-year survival for ESKD patients is less than 33%; which is comparable or worse than patients with many types of cancer.<sup>[6]</sup> Palliative care in ESKD encompasses the effective management of pain and other symptoms, advance care planning and directives, psychosocial and spiritual support, and ethical issues in dialysis decision making; with end-of-life care being just one of the aspects in this spectrum of care.<sup>[6]</sup> Given the anticipated decline in patients’ health, it follows that palliative care should begin with the diagnosis of CKD as the care should shift from a curative to a supportive focus.<sup>[7]</sup>

The integration of palliative care into the advanced care planning in ESKD can be complicated by the personal beliefs and values of health professionals.<sup>[8]</sup> Farber *et al.* showed that internists were much more likely to withhold treatment than withdraw it; as the latter could be viewed as leading to the death of the patient.<sup>[9]</sup>

Some studies report a prolongation in life among the elderly patients with ESKD who underwent dialysis as opposed to conservative management.<sup>[10]</sup> However, a retrospective review by Murtagh *et al.* found patients ESKD patients with ischemic heart disease or more than one comorbidity who chose not to accept dialysis

treatment had the same survival as those that started dialysis.<sup>[11]</sup> This data makes the decision of assessing the benefit of dialysis in the elderly difficult. It also highlights the questionable value of dialysis among elderly patients with comorbidities who experience the medical interventions associated with dialysis therapy without any survival benefit.<sup>[12]</sup>

Renal replacement therapy has been shown in some studies to have minimal influence on longevity and a resultant sharp decline in functional status.<sup>[4]</sup> Retrospective analysis and even some prospective trials have confirmed the impression that dialysis discontinuation provides an opportunity for maximal application of palliative care and a better quality of death.<sup>[13]</sup> It is therefore vital that patients and their families receive adequate predialysis education where discussion should focus not just on dialysis modalities and transplantation but also on not undertaking dialysis treatment and supporting this decision with palliative care.

In Patient A's case, early predialysis education, which reinforced a palliative approach, helped to ensure that both the patient and family had no misconceptions about the prognosis or the efficacy of renal replacement therapy. A planned decision to stop dialysis ensured a timely referral to a multidisciplinary palliative care setting and a "good death" for both the patient and those around her. This outcome may have been achieved even without palliative care but it most likely had a significant impact. In stark contrast, Patient B's case was one where the lack of early and ongoing patient and family education about withdrawal from dialysis led to the breakdown in communication and unrealistic expectations regarding treatment outcomes. Considering her poor functional status and multiple comorbidities, an earlier discussion with family regarding offering palliative care support and discussions regarding withdrawal of dialysis therapy could have potentially avoided such a turbulent end of life situation.

In the cases where a non-dialysis management pathway is suggested, an interdisciplinary team providing palliative care best supports management.<sup>[14]</sup>

## Conclusion

The two cases presented here display contrasts in outcomes, which may be due to many factors one of which may have been the timing of palliative care involvement. Given the importance of the patient and family in the decision to withdraw from treatment, their understanding of the issues surrounding CKD and palliative care is

critically important. The case studies suggest that leaving it too late to discuss the issues may lead to patients and family developing unrealistic expectations and making under-informed decisions on that basis. The issues are best confronted with palliative care involvement at the time of pre-ESKD education, with ongoing palliative care support whichever pathway is chosen. This would allow a shared understanding between patient, family and health care team to develop and to promote the best outcome for the patient.

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