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Riordan, J. O., Smyth, A., Kane, P. M., Noble, H., Beatty, S., Mannion, E., ... Harnett, I. (2017). 'When less is more; Optimising care for elderly patients failing to thrive on dialysis.'. *Journal of Pain and Symptom Management*. <https://doi.org/10.1016/j.jpainsymman.2017.12.475>

Published in:

Journal of Pain and Symptom Management

Document Version:

Peer reviewed version

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

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Accepted Manuscript



‘When less is more: Optimising care for elderly patients failing to thrive on dialysis.’

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PII: S0885-3924(17)31226-5

DOI: [10.1016/j.jpainsymman.2017.12.475](https://doi.org/10.1016/j.jpainsymman.2017.12.475)

Reference: JPS 9676

To appear in: *Journal of Pain and Symptom Management*

Received Date: 27 April 2017

Revised Date: 7 December 2017

Accepted Date: 8 December 2017

Please cite this article as: Riordan JO, Smyth A, Kane PM, Noble H, Beatty S, Mannion E, Murtagh C, Harnett I, ‘When less is more: Optimising care for elderly patients failing to thrive on dialysis.’, *Journal of Pain and Symptom Management* (2018), doi: 10.1016/j.jpainsymman.2017.12.475.

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'When less is more: Optimising care for elderly patients failing to thrive on dialysis.'**Introduction**

As the prevalence of end-stage renal disease (ESRD) has risen significantly over the last ten years, renal replacement therapy (RRT) remains a limited resource. In addition, 25% of new dialysis patients in the United Kingdom are over 75 years of age, and have the greatest increase in uptake of RRT.¹ For the majority of patients with ESRD, RRT prolongs life and alleviates symptom burden. However, in those aged ≥ 75 years when first commencing RRT, the survival advantage may be substantially reduced by comorbidity, in particular, by ischaemic heart disease,² with probability of survival of 71% at one year and 54% at 2 years in Europe³, 59% and 43% respectively in the USA.⁴ More than 10% of patients aged over 75 years commencing RRT, die within three months^{3,5} and are more likely to die in hospital than at home or in a hospice.⁶ While patients in receipt of RRT may be at a survival advantage, they are almost 50% more likely to be hospitalised than those receiving conservative management⁶, including active and supportive care without the use of dialysis or renal transplantation. Additionally, despite enduring the burden of RRT, these patients often have little perceived benefit on quality of life, as symptom burden often remains high.⁷ Indeed almost 30% of those aged ≥ 75 years reportedly withdraw from dialysis suggesting dissatisfaction with quality of life on RRT and limited tolerance of RRT.^{8,9} The following case illustrates the importance of establishing goals of care, in a timely manner, to ensure the delivery of optimal patient centred care¹⁰. Importantly, this also requires ongoing review throughout a patient's course on dialysis to identify patients no longer thriving and for whom dialysis withdrawal may be appropriate. At this stage, consideration should be given to specialist Palliative Care input to ensure optimal end of life care for these patients.

Case description

An 83 year old gentleman with a history of ESRD due to diabetes mellitus, receiving intermittent haemodialysis (HD) for 2 years, was admitted to hospital with worsening dyspnoea and dizziness for several weeks. His medical history included type II diabetes mellitus (also complicated by diabetic retinopathy) dependent on insulin for two years, peripheral vascular disease (PVD) with previous pedal arterial ulceration, congestive cardiac failure (CCF, with an ejection fraction of 30%) and severe aortic stenosis. Functionally, he was restricted by bilateral osteoarthritis of his hips and knees, frequent episodes of gout, obesity and exertional dyspnoea. Prior to this hospitalisation, his family described him as 'jolly, easy going and sociable.' A widower, he lived alone, with his daughter close by who visited two to three times per week. He travelled to his dialysis sessions by taxi three times per week, and he received one hour of home help five days a week. He reported increasing fatigue in the preceding months, which largely confined him to his home, except for his weekly attendance at Mass.

On this occasion he was admitted with CCF. Coronary angiography demonstrated significant triple vessel disease; - stenoses of 70%, 50% and 99% at the proximal, mid and distal points of the left

anterior descending coronary artery (LAD), respectively; 60% stenosis at the mid left circumflex and proximal right coronary artery. The trans-aortic pressure gradient was 40mmHg, pulmonary hypertension was diagnosed and he was scheduled for percutaneous coronary intervention (PCI). However he found the coronary angiography distressing; he struggled to breathe when supine, he found the application of pressure to his groin very painful and he subsequently developed a femoral haematoma. Consequently he was fearful about the proposed PCI and had developed trouble sleeping.

Two weeks later, given the complexity of the case, he was discussed at a cardiology/cardiothoracic multidisciplinary meeting. As he was considered high risk for Aortic Valve Replacement (AVR) and unsuitable for coronary artery bypass grafting (CABG), medical management was optimised, including an increase to four weekly haemodialysis sessions of 3.5hours duration, targeting a reduced dry weight. However, he tolerated this poorly due to intra-dialytic symptomatic hypoglycaemia, hypotension and leg cramps (limiting fluid removal) and he continued to gain 2.5-3.0kg in weight between dialysis sessions. Clinically, he remained in CCF, and complained of pruritus, persistent anxiety, poor sleep and nocturnal agitation. He was assessed by Liaison Psychiatry and reported 'being constantly on edge', 'unable to sleep', 'unable to articulate himself' and 'lacking the concentration to read', a past time he had previously enjoyed. Mild cognitive impairment was noted. He was diagnosed with adjustment disorder and mild anxiety, and commenced promethazine 25mg at night.

After two months in hospital, he requested discharge but was advised to remain as an inpatient as his condition was deemed 'high risk.' One week later, on Christmas Day, he was permitted day leave but was contacted and requested to return to the hospital early as his potassium level was $>7\text{mMol/L}$. This normalised with medical management. One week later he was discharged home and he returned to his usual dialysis regime.

Unfortunately, six weeks later he was hospitalised with an infected arterial pedal ulcer and gangrene of his right great toe. He refused vascular input, as he could not tolerate the pain associated with measurement of his ankle brachial index (ABI). Since his previous discharge, his sleep remained poor (initial insomnia and frequent waking); he remained anxious and continued to experience nocturnal agitation. Consequently, his daughter had begun staying with him at night. Given this presentation, the medical team declared him 'not for resuscitation in the event of cardiopulmonary arrest' and commenced transdermal buprenorphine 10mcg/hr for control of ischaemic limb pain.

One week later, during a Palliative Medicine assessment, for management of pain and pruritus, his respiratory rate was reduced (6 per minute) and he was somnolent with frequent myoclonus, consistent with opioid toxicity. The buprenorphine patch was removed, he responded to IV naloxone and haemodialysis was arranged to reverse opioid toxicity. However, he tolerated only two hours of haemodialysis due to symptomatic hypotension. The following day his level of consciousness had improved, but he was now in severe pain from an ischaemic digit. He commenced a continuous subcutaneous infusion of alfentanil and increased gabapentin dose. A few hours later he suddenly became acutely short of breath, his breathing became laboured and his oxygen saturation decreased to 74%. He died thirty minutes later.

Comment

This case highlights many clinical and ethical dilemmas when considering dialysis in older patients with multiple comorbidities. In many cases, dialysis does not confer a survival benefit² and significantly, may not improve quality of life⁷ and so the approach must differ from younger patients or those with less comorbidity. Thus, the importance of Shared Decision Making (SDM), the 'pinnacle of patient centred care', cannot be overstated. Successful SDM, between physician and patient (or a legal representative where patients lack decision making capacity) implies that physicians understand patients' values, goals and preferences, while patients are afforded the opportunity to understand prognosis and disease trajectory¹⁰. This process should result in a clear statement of goals of care, including circumstances where dialysis withdrawal should be considered^{11,12}. If, as physicians we fail in this endeavour, we risk depriving our patients of the opportunity to 'live as long and as well as possible and die gently.'¹³ In practice, however, SDM is poorly integrated into the clinical care of elderly patients with ESRD, as illustrated by our case¹⁰.

In addition, many patients perceive that the decision to initiate dialysis was not theirs, but rather that of their family or physician¹⁴. A retrospective American study of patients with ESRD (mean age 60 years and duration of RRT of four years) showed that 67% of patients felt they had 'no choice about initiating dialysis or modality as the alternative would be death' and one third perceived the decision on starting and mode of dialysis had already been made by the doctor¹⁵. Only one patient (1%) was given the option of not starting dialysis and only 20% of patients were asked about their values and preferences. 67% of patients said that the risks and burden of dialysis were not mentioned and only 13% felt part of a collaborative decision making process. The majority of patients reported that what was 'most consistently conveyed was the certainty of death without dialysis and the life-long need for dialysis.' Over 60% of patients interviewed would like to have received more information, experienced more sensitive delivery of 'bad news' and wished they had been powerful enough to resist/delay dialysis. These poor decision making experiences are linked to low satisfaction with RRT.¹⁴

Identifying older patients likely to benefit from RRT is challenging. Guidelines consistently recommend that a fully informed patient and his/her family participate in treatment decisions for stage 5 chronic kidney disease (CKD)^{11,16,17,18} and the (Renal Physicians Association / American Society of Nephrology (RPA/ASN) guideline recognises the importance of advance directives and patient refusal to commence dialysis for Acute Kidney Injury (AKI) or ESRD.¹⁹ In particular, it is reasonable to forego dialysis in patients with irreversible profound neurological impairment (they lack signs of thought, sensation, purposeful behaviour and awareness of self and the environment), life-limiting illness (from a non-renal cause) or in cases where a medical condition may preclude the technical process of dialysis (e.g. co-existent heart failure or liver failure, where prognosis must also be considered in terms of the other failing organ). Other important factors include dyspnoea secondary to heart failure or angina, and patients with a very poor functional capacity.²⁰

Despite these guidelines, a study of older patients established on RRT with an expected 3-month mortality of >40% showed a preponderance of male gender, age >85 years, congestive cardiac failure, severe peripheral vascular disease, dysrhythmia, behavioural disorders (dementia, psychosis or severe neurosis likely to affect functional status or adherence to treatment), active malignancy, low serum albumin and impaired mobility.²¹ It is noteworthy that 58% of this 'high risk' group

commenced RRT on an emergency basis. In practice, decision making is rarely straight forward and merits in-depth consideration of each patient's individual circumstances. Although discussion around foregoing RRT in patients with progressive CKD can be done in the outpatient setting, advocating conservative management is particularly challenging when patients present for the first time with an urgent need for haemodialysis.

Little is known of the factors which influence either patient or physician choice of therapy in older patients with ESRD. Discrete choice experiments, which mimic real life decision making, show that nephrologists are more likely to recommend RRT in older patients with preserved cognition, low comorbidity, likely to increase life expectancy, quality of life(QOL) is high and if both the patient and family are inclined towards RRT²². Interestingly, nephrologists were willing to forego 12 months of patient survival in order to avoid a decreased QOL with RRT initiation. Doctors also vary considerably in their propensity to offer dialysis and their perceptions of patient benefits²³. In a 'clinical judgement analysis' the perceived gain in life expectancy varied from 24-264months; for most the patient's age had little influence on decision making. The most important non-renal factor in dialysis decisions was the patient's mental state.

The role of the nephrologist in offering conservative care is critical. A retrospective study showed that 93% of nephrologists considered 'patient preference' and 'severe clinical condition' as extremely or quite important factors influencing their decision; 84% considered 'vascular dementia' and 75% considered the presence of 'frailty' as extremely or quite important²⁴. Interestingly, social support was considered least important, with only 41% of nephrologists rating this as extremely or quite important. Finally, 14% of nephrologists indicated that they always offered RRT to all patients.

In contrast to the nephrologist, social isolation appears to be one of the most significant factors influencing patients. Patients choosing conservative management are more likely to be older, to be unmarried or living alone, have higher levels of comorbidity or lower functional status²⁵. The ability to cope with RRT, physical ability, the modality best fitting with the patient's lifestyle and distance to the dialysis centre are additional factors influencing the decision. Interestingly, no participant from this study had attended a RRT education day. Another study also highlighted the importance of fewer hospital visits and less travel restrictions²⁶.

Recently, the Standardised Outcomes in Nephrology (SONG) initiative used a Delphi survey to generate a list of prioritised core outcomes for haemodialysis patients, from the perspective of patients in receipt of haemodialysis, care givers and health care professionals²⁷. By the third round, core outcomes prioritised by patients/care givers centred on dialysis adequacy, time free of dialysis, fatigue and the ability to travel. In contrast, those prioritised by health care professionals focused on the factors likely to adversely affect the mechanics of dialysis, and mortality. Patients and carers prioritised quality of life over death.

Our gentleman tolerated haemodialysis reasonably for some time prior to this hospitalisation, but he was experiencing significant decline. By this stage haemodialysis was likely contributing to his fatigue and social isolation. The prolonged hospital admission was causing psychological distress which further eroded his independence and QOL. He requested to go home twice during his hospitalisation, after he was deemed unfit for cardiac intervention and was clearly struggling with haemodialysis. This scenario should have prompted a discussion of the goals of care and more specifically withdrawal from dialysis. At this point referral to Palliative Medicine should have been

offered to the patient to optimise symptom control and maximise the opportunity for successful end of life care including the opportunity to involve family members in this final phase of his life. Sadly, this did not happen and despite his poor prognosis and escalating symptom burden, he remained on haemodialysis. The request from the medical team that he return early from leave on Christmas Day further highlights the disproportionate focus on biochemical indices despite the impact on his QOL.

In the absence of advance care planning, it was inevitable that this gentleman, with such a degree of medical complexity, would die in hospital. This situation could have been avoided had a goals of care discussion taken place and if he had transitioned to conservative management in a timely fashion. It is also likely that such advance care planning would have allowed him the opportunity for important life closures with his family.

There is considerable international variation in rates of withdrawal from dialysis. Nephrologists report feeling uncomfortable in managing end of life scenarios, partially due to inadequate training in this area. The likelihood of withdrawal is further influenced by the acceptability of withdrawal to the physician, and whether or not shared decision making took place²⁸. For patients, religious beliefs and practices feature prominently in the decision to withdraw²⁹, as many see the availability of RRT in religious terms ('God made it available'), but there was no sense of a religious obligation to continue it. Another common belief is that 'there was a time to die' and faith countered fear in patients who knew they would die within days of stopping dialysis. A recent qualitative study, though not restricted to older patients, showed that patients prefer modalities that enhance their freedom and autonomy, minimise confinement and risk, and were convenient, effective and simple³⁰.

We are in a situation where an increasing numbers of older patients initiate RRT and knowingly or otherwise, are faced with the day-to-day impact of RRT. Furthermore it is not clear that patients are involved in this decision making process in a meaningful way. The 'decision ecology' model of autonomy acknowledges the importance of the wider social context as well as individual patient narratives^{31,32}. This model requires that patient autonomy be supported at the level of everyday care as well as decisions regarding further care. Hence SDM, which encompasses advance care planning (including when to consider dialysis withdrawal) and the physician's understanding of patients' values, goals and preferences is crucial to ensure patient autonomy and well-being is prioritised and preserved at all levels of care. Indeed, resource and financial constraints may well become a factor in decision making, even in higher income countries. Further research is needed to facilitate the development and delivery of patient-centred care to older patients with ESRD for whom the burden of RRT may outweigh benefit. Patient perceived outcomes and healthcare satisfaction would also be expected to improve with a service tailored appropriately to patients' needs and wishes.

Declaration

Each of the authors declares no conflict of interest.

There was no funding received in support of this article.

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