Clinical Kidney Journal, 2022, vol. 15, no. 8, 1622–1625

https://doi.org/10.1093/ckj/sfac089
Advance Access Publication Date: 7 April 2022
Exceptional Case

EXCEPTIONAL CASE

Half a century of haemodialysis: two patient journeys

Drasko Pavlovic[1], Tania Salehi[2], Giorgina B. Piccoli[3] and Patrick T. Coates[2,4]

[1]Polyclinic for Internal Medicine and Dialysis B. Braun Avitum, Zagreb, Croatia, [2]Central Northern Adelaide Renal and Transplantation Service, Adelaide, Australia, [3]Centre Hospitalier Le Mans, Le Mans, France and [4]The University of Adelaide, Adelaide, Australia

Correspondence to: Patrick T. Coates; E-mail: toby.coates@sa.gov.au

ABSTRACT

The history of renal replacement therapy (RRT) for end-stage kidney disease (ESKD) started in 1960 and has reached, in these six decades, goals initially unforeseen. This report describes two patients who commenced dialysis at the age of 17 and 27, for 53 and 45 years, respectively, whereby the modality of RRT was mostly in the form of home haemodialysis. The history of these two patients, who started RRT in distant parts of the world, Australia and Croatia, highlights not only the advances made over time, to significantly delay the onset and reduce the morbidity and mortality associated with ESKD, but also underlines the importance of empowerment and commitment, added values in home haemodialysis.

Keywords: end-stage kidney disease, haemodialysis, home-HD, nocturnal HD, renal replacement therapy

BACKGROUND

Sustaining life with a machine or a device replacing the function of a vital organ is one of the most important medical advances of the twentieth century [1].

Since the first session of haemodialysis (HD) for end-stage kidney disease (ESKD) was successfully achieved in Seattle in March 1960, renal replacement therapy has developed at an unpredicted speed, and presently more than 3 million people are treated by HD or peritoneal dialysis (PD).

At the beginning of the history of HD, home-HD was strongly encouraged and by 1964 it had become one of the major dialysis treatment modalities in the USA [1, 2]. Over time, enthusiasm for home-HD diminished, due to changes in the dialysis population, older and at higher comorbidity, in the society, with long hours working out of the home, and changes in the delivery of dialysis, organization of which is deeply influenced by economic factors that often penalize home-HD.

While in some settings, such as Australia and Canada, home-HD has always continued to be widely used, it is only recently that home-HD has regained support from both patients and nephrologists over the world, profiting also from some innovative approaches in dialysis machines specifically defined for home-HD [3].

One of the main advantages of home-HD is patient empowerment, and the possibility of adapting treatment to individual needs with flexible approaches may play a vital role not only in achieving a better quality of life, but also in prolonging its duration [4]. The two cases herein described, probably amongst the longest survivors on HD, may teach an important lesson in this regard.

THE CASES

Case 1

In 1967, a 15-year-old Australian female presented with malaise, fever, abdominal pain and cutaneous rash involving upper and lower limbs. She was found to have haematuria and proteinuria, together with elevated erythrocyte sedimentation rate and high serum creatinine. A kidney biopsy demonstrated focal glomerulonephritis (GN), several sclerotic glomeruli, fibrin thrombi in capillary loops and an inflammatory cell infiltrate. There was no basement membrane thickening and tubular areas were infiltrated with fibrous tissue. She was diagnosed with possible

Received: 4.3.2022; Editorial decision: 1.4.2022

© The Author(s) 2022. Published by Oxford University Press on behalf of the ERA. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (https://creativecommons.org/licenses/by-nc/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

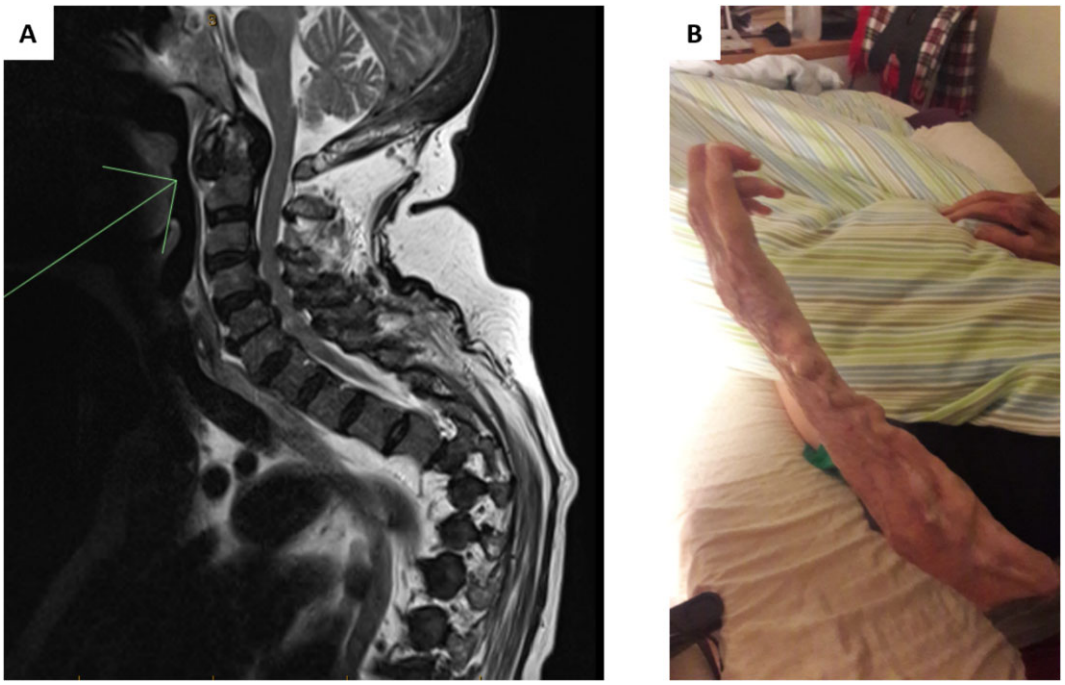

FIGURE 1: (**A**) Amyloid deposition at the atlantoaxial joint (DRA: destructive dialysis-related amyloidosis). (**B**) β2M amyloidosis of the hand and left upper limb AVF.

systemic lupus erythematosus and lupus nephritis. She was treated with oral cyclophosphamide and prednisolone but renal function continued to decline and by the age of 16 she had established ESKD.

Given the patient's young age and the lack of clinical experience with RRT at the time, initiation of HD was delayed for over a year during which time she received psychiatric assessment to evaluate her suitability for future RRT. Due to worsening renal function, she was commenced on PD, but throughout the early stages of 1969 she had recurrent hospital admissions relating to azotaemia and symptomatic anaemia and was bridged to HD. An arteriovenous Scribner shunt was positioned in her right leg and she started HD on 28 May 1969 at The Queen Elizabeth Hospital, Adelaide, South Australia. Later that year she underwent bilateral nephrectomy for management of refractory hypertension.

Dialysis employed Kiil Boards, primed with normal saline and occasionally blood products. Dialysis sessions typically ran for 14 h, twice weekly over a period of 18 months. She later transitioned to the 'Drake Willock' home-HD machine, where nocturnal HD was implemented thrice weekly for the next 18 years. With advancements in dialysis equipment, dialysis duration was progressively reduced from 10 to 4 h per session. At the age of 30, a left arm brachiocephalic arteriovenous fistula (AVF) was created; she learnt self-needling and due to her commitment to optimal care, this AVF remained her single access until early 2019, when the fistula was removed due to recurrent infections, and replaced by a tunnelled catheter (in the preceding years, she required multiple fistula interventions, including thrombectomy and fistuloplasty). Now in her 54th year of uninterrupted HD, the dialysis schedule is 3 h and 45 min thrice weekly.

Our patient was never wait-listed for renal transplantation due to personal preference, intolerance to corticosteroid therapy and immune sensitization following repeated exposure to allogenic blood products, used both for treatment of anaemia and priming of the first dialysis machines. Over time, she developed metabolic bone disease, including osteomalacia and severe secondary hyperparathyroidism requiring parathyroidectomy. In addition, beta2 microglobulin (β2M) amyloidosis led to deforming polyarthropathy, predominantly involving the small joints of the hands. Advanced amyloid deposition has also been noted along the spine, including the odontoid process and atlantoaxial joint, contributing to cervical central canal stenosis, which poses a significant future risk of cord compression (Figure 1A).

Her steadfast adherence to dialysis regimes, dietary restrictions and a strict daily fluid limit of 600 mL was probably the reason why she has circumvented cardiovascular complications and despite long-standing ESKD has preserved systolic and diastolic ventricular function.

Her ability to endure over 53 years of HD, whilst maintaining quality of life, is the result of a strong commitment to optimal self-care. Our patient, now 69 years of age, reports: 'I had 50 years of life living with an artificial kidney and without it I would not be here'.

Case 2

A 27-year-old male who started HD in Croatia in 1976, for ESKD presumed to be secondary to GN, in the absence of a kidney biopsy. A left forearm AVF had been created a few weeks prior to initiating therapy. In 1978, he went to London seeking a further opinion regarding his illness and became aware of the possibility of home-HD. Upon his return to Croatia, he continued to explore this option; his training from both nursing and medical staff in his early years of in-hospital HD enabled him to become confident with the concept of home-HD, and with great personal effort and after overcoming a number of bureaucratic hurdles, he began home-HD in 1983, the first patient in Croatia to do so.

The first dialysis machine he used was a 'Drake Willock' with an acetate solution. In 1989, he shifted to a bicarbonate solution,

ahead of most Croatian in-hospital HD patients. His dialysis machines were subsequently changed to Fresenius 2008 and later Fresenius 4008, which he still uses today. Various capillary dialysers were employed over the years.

The patient prepared his dialysis machine and punctured his AVF at home in Zagreb, later at home in a small town on Adriatic coast, and only in the last two years, due to significant functional impairment of his hands caused by β2M amyloidosis (Figure 1B), he needed needling assistance from his wife. He emphasizes that the support and understanding from his wife throughout his ESKD journey is what enabled him to successfully undertake home-HD. The original left forearm AVF created in 1976 was used for 44 years. Eventually, his access was transitioned to a tunnelled catheter due to fistula thrombophlebitis. Since 2020, he has returned to in-hospital HD.

When asked about the advantages of home-HD, the patient's answer is short and clear: 'Freedom… all aspects of freedom!' Home-HD did not impose constraints on his lifestyle, with need to travel three times per week for in-hospital dialysis, which he regarded as a significant burden. His home-HD regime consisted of two or three sessions per week, 4 or 3 h at a time, respectively, often whilst watching television in the evening.

He often ignored nephrologists' advice about the need for dialysis three times a week, saying that he desires to have as much of 'free' time for himself and his family as possible. As he was satisfied with dialysis from the beginning, especially at home, he never seriously apprehended recommendations for a kidney transplant.

This provided him with the liberty and ability to continue working. Before commencing HD, he was a software programmer for a large company. In-hospital HD prevented him from having regular full-time employment and as a result he started a personal business, which he ran successfully for 30 years. He emphasises that the flexibility of adjusting home-HD regimes to personal needs enabled him to successfully continue working and provide for his family of three. He retired in 2010, following 27 years of home-HD.

During his 37 years of home-HD, the patient remained physically active and independent. In more recent years, his functional status has slowly declined, with bilateral hand β2M renal amyloidosis and the requirement for a walking aid. Anaemia was initially a feature in the early days of home-HD, requiring blood transfusions and a short period of erythropoietin-stimulating agents. In more recent years, cardiovascular complications have emerged in the form of ischaemic heart disease, managed with medical therapy. In all, our patient, now 73 years of age, has been on HD for over 45 years, 37 years of which on home-HD. His case outlines a patient's ability to adapt home-HD treatment to daily needs, enabling him to lead a fulfilling life.

DISCUSSION

The evolution of RRT over the last 60 years has been so impressive that the draconian selection of the early years is often forgotten. Indeed, in the 1960s, a panel of nephrologists screened potential recipients. Ideal candidates were <45 years of age and had no significant comorbidities. In addition, they needed to be deemed emotionally stable and able to adhere to demanding dialysis regimes and dietary requirements. Dependent children and young adults were generally excluded [1]. In such a context, home-HD was also a mean to 'rescue' some patients, allowing them to be treated, and, almost at the opposite of nowadays, home-HD was often chosen for patients with comorbidities. The advantages of self-management (what we now call 'empowerment') were, however, rapidly evident, leading to the endless question of whether or not home-HD was a better treatment as compared with hospital dialysis [5, 6]. The recent revival of this dialysis option may not only be a way to allow personalized, adapted treatment for empowered patients, but also a way to reduce costs and increase availability of RRT in settings where dialysis is not available or is available only at high, and often unaffordable, costs [7].

The story of our patients somehow summarizes the history of HD and the progressive discovery of its long-term complications [1, 8]. The advances in technology, along with an improved understanding of the pathogenesis, treatment and prevention of complications from RRT, have contributed to reduction in morbidity and mortality in chronic kidney disease (CKD) populations.

The patients' history traces the evolution of vascular access: the first patient started dialysis with a 'Scribner shunt' while the second was initially treated via a Cimino Brescia fistula; both are presently treated by tunnelled central venous catheters in these last periods. However, it is conceivable that the availability of a well-functioning fistula throughout most of their life has played a major role in their longevity, as vascular access still merits the title of the 'Achilles' heel' of dialysis treatment.

Renal bone, joint and mineral disorders are common in dialysis patients and were pronounced in both our cases in the form of β2M renal amyloidosis [9, 10]. The development and use of better-performing dialysis membranes with higher depuration of middle molecules has significantly enhanced β2M clearance, 215 slowing deposition within osteoarticular structures and viscera, and reducing the incidence of amyloidosis as a complication of long-termHD [4]. The prevention and treatment of boneand mineral diseases remains a major challenge in ESKD [11]. Severe lesions, including destructive spondiloarthopathy are still found in long-term dialysis patients (12-13). Unfortunately, cardiovascular complications of long-standing HD 220 have persisted despite the improvement in CKD management and RRT strategies [12, 14, 15]. Such complications are highlighted in our second case.

In spite of all the problems and challenges they faced during their life with dialysis, both patients are optimistic and show that dialysis is not incompatible with freedom.

Indeed, it is often underlined that implementation of home-HD requires the support of local health authorities, funding and specific policies. Without minimizing the importance of these issues, the two stories also show the role of determination and independence also in changing the general policies. Our patients commenced home therapy at a time when only conventional HD machines existed, connections to hospital-HD centres were poor and adequate medical support was not always available. This lesson of self-care may be useful for many patients with ESKD, as well as for caregivers, often dedicating more time to prescription than to shared decisions, the basis for allowing patients engage in self-care.

CONCLUSION

We report the cases of two patients who remained on uninterrupted, dialysis-only therapy for in excess of 53 and 45 years, mostly in the form of home-HD. We believe they are amongst the longest surviving home-HD patients in the world.

Whilst their survival can be partly attributed to the evolution in dialysis technology, their commitment to self-care and disease management has undoubtedly been a major contributing factor to their endurance, a lesson not to be forgotten by patients and caregivers.

CONFLICT OF INTEREST STATEMENT

No conflict of interest for any of the authors.

FUNDING

No funding was received for this article.

PATIENT CONSENT

The authors would like to thank the patients and declare that they have obtained their consent for publication of the information that appears within these cases.

REFERENCES

1. Blagg CR. The early history of dialysis for chronic renal failure in the United States: a view from Seattle. *Am J Kidney Dis* 2007; **49**: 482–496
2. Blagg CR, Hickman RO, Eschbach JW *et al*. Home hemodialysis: six years' experience. *N Engl J Med* 1970; **283**: 1126–1131
3. Strauss FG, Weintraub J. Over four decades of life with dialysis: a tale of self-empowerment. *Clin J Am Soc Nephrol* 2021; **16**: 993–995
4. Marshall MR, Polkinghorne KR, Boudville N *et al*. Home versus facility dialysis and mortality in Australia and New Zealand. *Am J Kidney Dis* 2021; **78**: 826–836.e1
5. Vinson AJ, Perl J, Tennankore KK. Survival comparisons of home dialysis versus in-center hemodialysis: a narrative review. *Can J Kidney Health Dis* 2019; **6**: 205435811986194
6. Konner K. History of vascular access for haemodialysis. *Nephrol Dial Transplant* 2005; **20**: 2629–2635
7. Cozzolino M, Mangano M, Stucchi A *et al*. Cardiovascular disease in dialysis patients. *Nephrol Dial Transplant* 2018; **33** (suppl_3): iii28–iii34
8. Heaf J, Nielsen AH, Hansen HP. Long-term haemodialysis survival. *Clin Kidney J* 2012; **5**: 168–169
9. Piccoli GB, Mezza E, Anania P *et al*. Patients on renal replacement therapy for 20 or more years: a clinical profile. *Nephrol Dial Transplant* 2002; **17**: 1440–1449
10. Malgaj Vrečko M, Ponikvar R, Gubenšek J *et al*. Clinical and dialysis-related characteristics of extremely long-term hemodialysis survivors: three case reports. *Hemodial Int* 2021; **25**: E29–E32
11. Scarpioni R, Ricardi M, Albertazzi V *et al*. Dialysis-related amyloidosis: challenges and solutions. *Int J Nephrol Renovasc Dis* 2016; **9**: 319–328
12. Santagati G, Cataldo E, Columbano V *et al*. Positron emission tomography can support the diagnosis of dialysis-related amyloidosis. *J Clin Med* 2019; **8**: 1494
13. Kuo CH, Tu TH. Dialysis-related amyloidosis cervical vertebral body destruction and cord compression. *Radiology* 2022; **302**: 28
14. Nakamura H, Anayama M, Makino Y *et al*. An ethical discussion on a long-term peritoneal dialysis patient. *J Nephrol* 2021; **34**: 1559–1560
15. Piccoli GB, Mesiano P, Mezza E *et al*. Twenty years of renal replacement therapy in a type 1 diabetic patient: advantages of a multiple choice dialysis system. *Int J Artif Organs* 2003; **26**: 442–445
16. Tomori K, Okada H. Home hemodialysis: benefits, risks, and barriers. *Contrib Nephrol* 2018; **196**: 178–183