

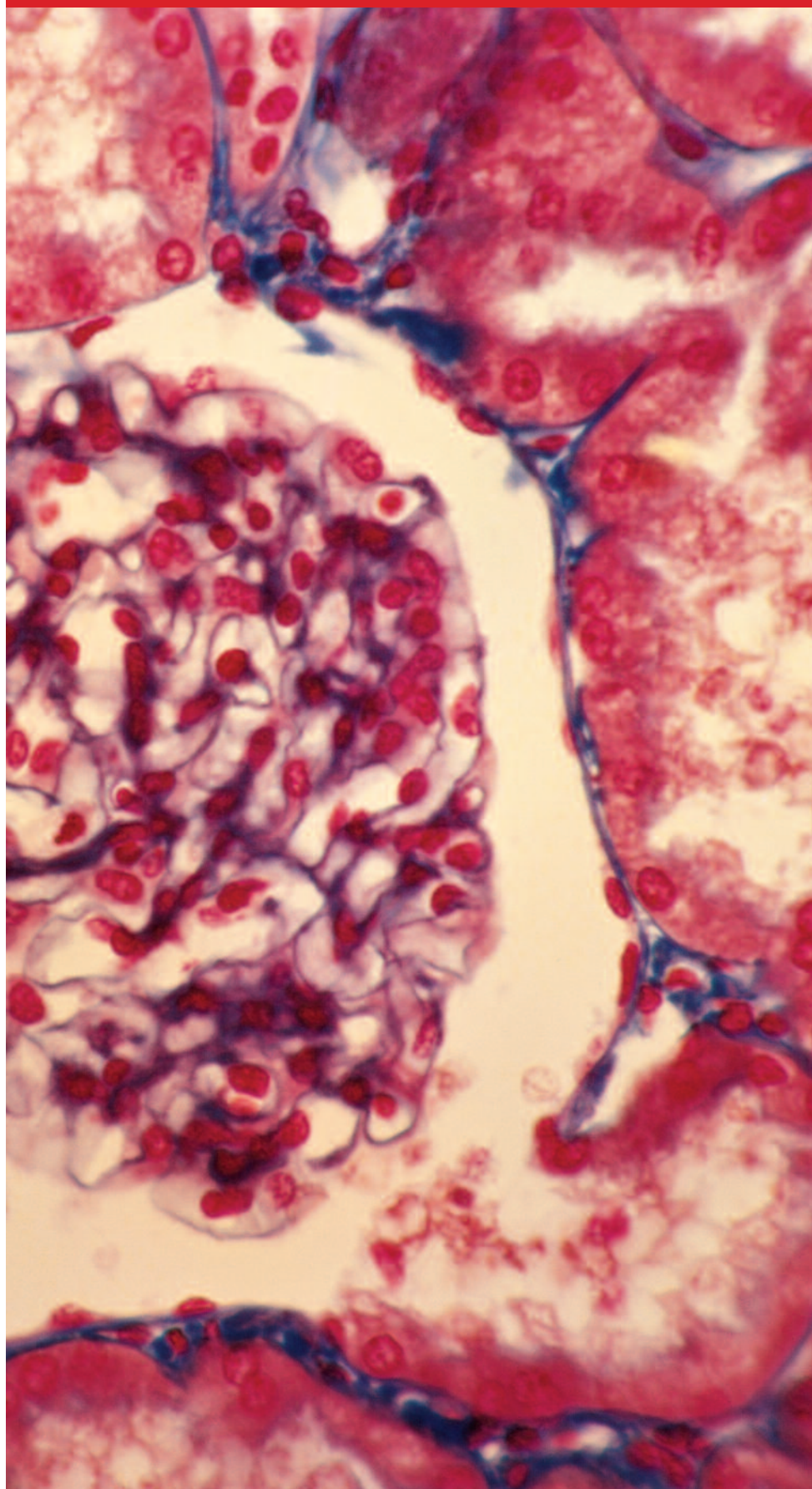
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Planning ahead

“Life expectancy at birth, for infants born in England and Wales between 2010 and 2012, was 79.1 years for males and 82.9 years for females. For men aged 65, life expectancy increased from 17.6 years in 2006–08, to 18.5 years in 2010–12.¹ For females of the same age, life expectancy increased from 20.3 to 21.1 years over the same period. In 2011, 9.2 million people living in England and Wales were aged 65 and over.² This was an increase of almost one million from 2001, when 8.3 million were 65 and above. In 2011, more than half of those aged 65 reported having a long-term health problem or disability, which limited their daily activities.

In 2011, more than half of those aged 65 reported having a long-term health problem or disability

Growing old

The median age of patients starting renal replacement therapy (RRT) in the UK in 2012 was 64.6 years.³ Elderly patients tended to start on haemodialysis (HD). The median age of patients starting HD was 66.9 years, whereas for those starting on peritoneal dialysis (PD), it was 60.5 years and for those receiving a pre-emptive renal transplant, 48.6 years. The median age of all patients receiving RRT in 2012 was 58 years, compared with 54 years in 2000.^{4,5} Over the same time period, the percentage of patients receiving RRT who were aged over 70 years increased from 19.2% to 24.9%.

Inactivity

Most elderly dialysis patients are dependent on others. Cook and Jassal found that only 5% of HD patients aged over 65 were fully independent, with no functional impairment in any activity.⁶ Just over half were dependent in at least one core activity of daily living, with the most common areas of dependence being housework, shopping, laundry and cooking. Similar levels of dependence have been reported in elderly patients on PD.⁷ Physical functional disability in HD patients is not limited to the elderly, although the proportion of functional disabilities and care needs increases with both age and length of time on dialysis. Across all ages, adult HD patients have been reported to spend, on average, two years living with a moderate disability and 1.3 years living with a severe disability.⁸

Taking care

As the age and dependence of dialysis patients increases, more patients who may benefit from RRT or are already receiving dialysis will be resident in nursing homes, providing new challenges when planning care. Models of delivering PD in a nursing home setting are well established,⁹ but HD provides different challenges for nursing home residents;^{10,11} the need for advance care planning, as highlighted in this issue by Laura Clipsham *et al*, becomes more imperative. Perhaps the most important measures are strategies

to maintain activity, including guidance on exercise, as provided by Alice Smith and James Burton.

John Bradley, Editor

Declaration of interest
None declared

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Correction

The article 'What I tell my patients about the Registry for Rare Kidney Diseases' published in Vol 18 No 4 should have included an acknowledgement of funding for the registry. The author would like to thank the British Kidney Patients Association and Kidney Research UK for their financial support of RaDaR.

■ Advance care planning and discussions regarding end-of-life care are vital before the patient becomes too frail



Planning for the future: developing an advance care plan for patients with end-stage renal disease

Patients with end-stage renal disease (ESRD) have an unpredictable disease trajectory, with a marked increase in symptoms and health related concerns in the last year of life.¹ Typically, a gradual deterioration in functional status occurs, punctuated by periods of ill health and multiple hospital admissions.² The role of end-of-life care discussions and advance care planning (ACP) needs to be considered before a patient becomes too frail or their mental capacity becomes compromised. ACP explores patients' understanding of their illness, considers priorities and wishes for care, facilitates continuity of care and can avoid unwanted and

unnecessary hospital admissions.³ Here, we discuss how a patient-held advance care plan, which can be shared with both primary and secondary care, was developed to improve end-of-life planning.

As the average age of patients developing renal failure rises, it is increasingly recognised that not all will be medically suitable for dialysis. For some, renal replacement therapy (RRT) may not increase survival and will adversely affect quality of life.⁴⁻⁶ In 2012, 21.2% of patients commencing dialysis at the University Hospitals of Leicester NHS Trust were aged 75 years or older.⁷ UK Renal Registry data have shown that prognosis is poor

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in the elderly; patients aged 75 years and over commencing RRT have a median survival of three years, compared with 18 years for patients in their twenties.⁸ Mortality rises steeply above 75 years of age, with 50% of patients over 80 dying within 12 months of commencing dialysis.⁹

ACP is increasingly recognised by the Department of Health as a quality target to evaluate whether patients' wishes at the end of life are being met, irrespective of disease. The National End of Life Care Strategy recommends future care planning in patients considered to be at the end of life,¹⁰ currently defined as those likely to die within 12 months, and includes patients with advanced, incurable illness.¹¹ *The National Service Framework for Renal Services* recommends that such patients have a jointly agreed plan for end-of-life care built around their needs and preferences.¹²

Why develop an advance care plan for patients with ESRD?

Patients are more likely to access social and hospital care in the final months of life.¹³ Awareness of this may assist in planning future care, enabling patients to die in the place of their choice. Therefore, an important principle for patients who do complete ACP is that the document is patient-held and accessible to all care sectors, including emergency services, to enable their wishes to be fulfilled as much as is reasonably possible.

Advantages of advance care planning

Patients may be reluctant to undertake ACP when well and, consequently, their wishes for treatment in the event of a sudden deterioration may not be known. This may lead to unwanted hospital admissions in an emergency, particularly outside normal working hours, with a risk of unwanted or inappropriate interventions. The advantages of ACP are summarised in Box 1.

Considerations involved

A steering committee led by a senior renal community team nurse with an interest in end-of-life care, and comprising a renal consultant, palliative care consultant and specialty registrar, and haemodialysis nurses from main and satellite dialysis units, met on a monthly basis over six months. A community Macmillan nurse, GP and district nursing representative were also invited to meetings.

There were numerous challenges; namely: ensuring suitable patients were identified and approached appropriately (see Box 2), and clarification of whose responsibility initiating ACP discussions would be and the communication

Box 1. Advantages of identifying patients approaching the end of life

- Enables a change of emphasis of care from active prolongation of life to palliation, including symptom relief and attention to holistic care
- Better acceptance of the terminal nature of the disease by patients and carers
- Fewer hospital admissions
- Opportunity to facilitate a 'better death', fulfilling patients' wishes and priorities for care
- Better communication between patients, carers and healthcare professionals
- Improves inter-team communication and continuity of care
- Fewer inappropriate resuscitation attempts

Box 2. Patients likely to benefit from ACP

Those who:

- Are deteriorating despite dialysis
- Are receiving conservative kidney management
- Have a failing transplant and opt not to have further renal replacement therapy
- Are considering discontinuing haemodialysis
- Are experiencing a crisis (eg, stroke, malignancy)
- Wish to discuss end-of-life care

skills required. The practicalities of informing relevant professionals of the presence of the document and its content, including communication within the unit via the renal IT system (Proton), were considered.

Triggers for initiating advance care planning

ACP and end-of-life discussions are vital before the patient becomes too frail and/or becomes unable to make a treatment decision. The presence of one or more of the following triggers would prompt a multidisciplinary discussion as to whether ACP should be broached:

- Patients with Stage 5 chronic kidney disease (CKD) for whom the answer to the 'surprise question' is 'No'. That is, 'Would you be surprised if the patient died in the next six months?'
- Patients wanting to stop dialysis or those receiving palliative dialysis.
- Patients with symptomatic renal failure where the decision has been made to not have dialysis.
- Patients with CKD Stage 5 and symptomatic renal failure despite optimal dialysis.
- Patients with clinical indicators such as: >10% unintentional weight loss over six months,

Patients are more likely to access social and hospital care in the final months of life

symptomatic renal failure, serum albumin <25 g/l, dependence in most activities of daily living, in bed >50% of the time.¹⁴

Development of an advance care plan document and supporting paperwork

The ACP document and supporting patient information leaflet were developed and piloted on six patients. Preliminary feedback was positive, with patients opting to continue using the document.

Contents of the advance care plan

Section one contained general information about the document's purpose and space for next of kin details, and emphasised the document was not legally binding.

Section two was for healthcare professionals to complete. It covered information concerning the patient's diagnosis, history of their renal illness and treatment, and any relevant past medical history.

Section three was for the patient, or a nominated representative, to complete. This provided insight into the patient's understanding of their condition, their recollection of discussions about RRT and other health concerns. Discussions with family and friends were recorded, and patient's preferences for care and preferred place of death documented. Views on future hospital admissions and any other concerns, such as resuscitation status, were also noted here.

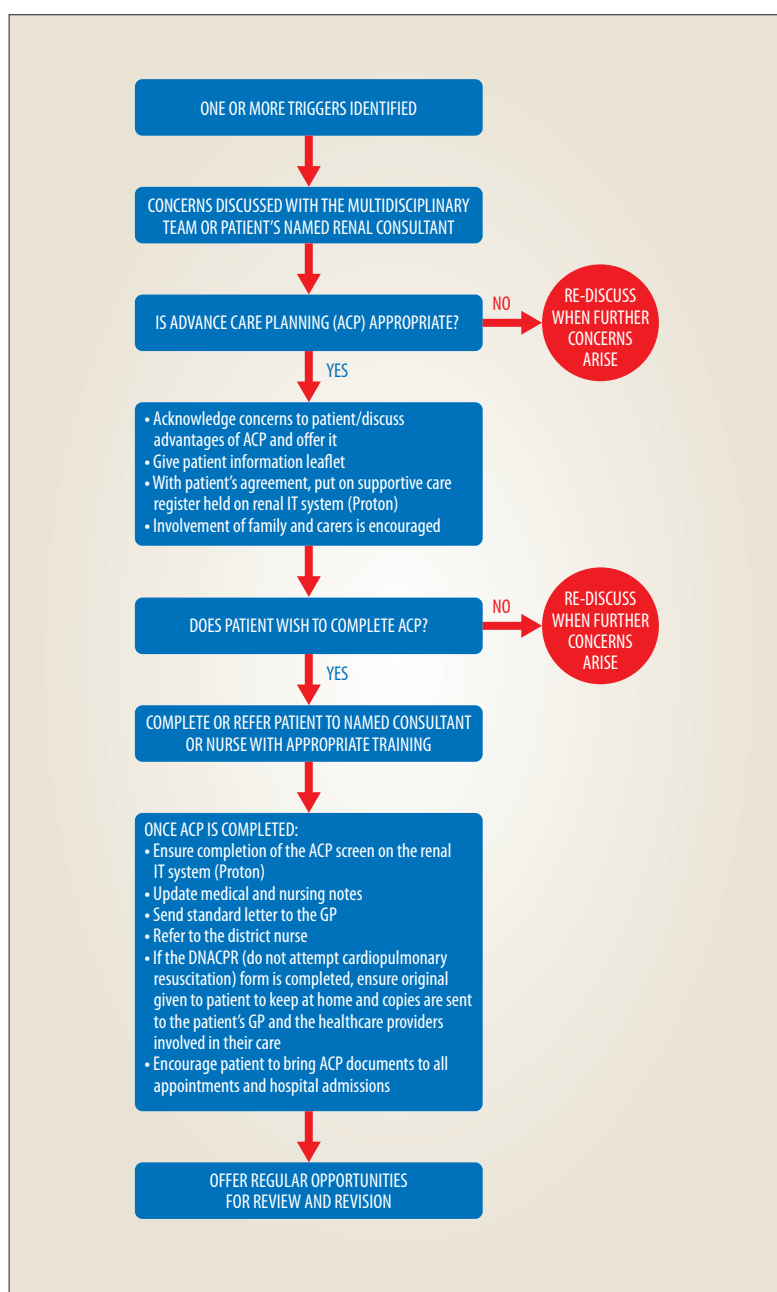
Changes to patient's wishes and preferences for care could be recorded in the final section. Patients were encouraged to take the document to appointments and hospital admissions, enabling timely revisions.

Supporting documents

Supporting documents included:

- Guidelines to support staff in recognising patients who may be approaching the end of life
- A patient information leaflet
- A DNACPR (do not attempt cardiopulmonary resuscitation) form
- A letter to the patient's GP informing them of the presence of the advance care plan, with a summary of end-of-life discussions and decisions, copied to the district nursing team and any other teams involved in the patient's care.

It was agreed that only the patient's consultant and senior members of nursing staff, who had attended appropriate communication skills training, could complete the ACP document. A flow chart summarising the algorithm used to initiate the development of the ACP document is shown in Figure 1.



■ Figure 1. Algorithm for initiating advance care planning

Conclusions and practice implications

Increasing numbers of patients with ESRD are managed conservatively through choice, or as a result of being medically unsuitable for RRT. ACP improves patient-centred care, enables informed choice and assists 'best interest' decision-making should patients later lose capacity. The multidisciplinary team should consider whether patients are eligible for entry on a renal supportive care register to allow identification and prioritisation of their care needs, and offer the option of ACP. Where ACP was trialled with patients, it was well received and such discussions welcomed.

There are many aspects to completing ACP, and consideration should be given to who undertakes

Where advance care planning was trialled with patients, it was well received

this and how this information is shared between professionals. Patients are encouraged to involve family members in their decisions, but these decisions are first and foremost their own and they decide with whom to share them. Patients wishing to complete a legally binding document are advised to complete an advance decision to refuse treatment. ACP can be changed at any time while the patient has capacity and should not be used to replace discussions about care with patients who have capacity. It should be viewed as an ongoing process rather than a one-off event ■

Declaration of interest

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Key points

- Patients with end-stage renal disease have an unpredictable disease trajectory, resulting in an increase in health-related concerns, particularly in the last year of life.
- Considering gradual deterioration of the patient, ill health and multiple hospital admissions, advance care planning (ACP) and end-of-life care discussions are vital before the patient becomes too frail. The plan can be changed at anytime, providing the patient has capacity.
- ACP ensures the patient understands their illness and considers their wishes for future care and hospital admissions.

Resources

British Renal Society

As I write this, UK Kidney Week is imminent and I am looking forward to a programme of fantastic quality that includes areas of interest for the whole team. There are sessions on shared decision-making, pregnancy, obesity, acute kidney injury, patient safety ... you get the picture. Having attended the abstract marking day, I am inspired by the quality of submitted work. I think that is why Kidney Week works so well; it's a great opportunity to learn from one another, wherever we meet, whether that is in formal sessions, in the corridor, at the civic reception or anywhere else you find yourself.

Simon Ball President of the BRS; Consultant Nephrologist, CSL Renal Medicine and Associate Medical Director for Clinical Systems Development, University Hospitals Birmingham

Partnerships

We are now looking to see how the British Renal Society can work with partner organisations to share not only these kinds of experiences and outcomes, but also sustainability in the form of approaches to business planning. I will return to this subject next time.

Kidney Health

I recently attended a meeting of many stakeholders who are now looking to promote the 'Kidney Health: Delivering Excellence' document, a major piece of work from the Kidney Alliance, which I commended to you in my last column; that work will start in earnest during UK Kidney Week. This is clearly an important task for the whole community to become involved, not least so that we can present a consistent set of priorities to our commissioning partners. Please do take the opportunity to feedback to Kidney Health ■

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Statin-induced myopathy, mimicking Guillain-Barré syndrome, in a transplant patient taking doxycycline

A 71-year-old male with a history of autosomal dominant adult polycystic kidney disease, necessitating cadaveric renal transplant in 1991 (cytomegalovirus [CMV] donor negative to recipient positive) and subsequent bilateral open native nephrectomy in 2012, attended the renal clinic with general malaise and weakness. He was normally independent, active and self-caring. Six days before admission, he had been prescribed a one-week course of doxycycline for a lower respiratory tract infection. His drug history included doxycycline 100 mg, bisoprolol 5 mg, Adcal D3® (ProStrakan), domperidone 10 mg, finasteride 5 mg, prednisolone 5 mg, lansoprazole 30 mg, furosemide 40 mg and simvastatin 40 mg, all once-daily, ciclosporin 100 mg twice daily and paracetamol 1 g four times daily. His baseline renal function was stable, with creatinine levels of 130 µmol/l, and his trough ciclosporin level was raised from 150 ng/ml at baseline to 231 ng/ml.

The patient had noticed painless weakness in his lower limbs three days into the doxycycline course and, in the clinic, required two people to transfer him from chair to chair. He was admitted and, over the next 24 hours, demonstrated marked bilateral ascending leg weakness, progressing to the upper limbs and causing difficulty in deep breathing. Objectively, he had bilateral symmetrical upper and lower limb weakness of 4-/5 and was virtually areflexic, with only the right biceps tendon being spared. Spirometry showed a reduced forced vital capacity (FVC) of 1.95 l. Simvastatin was discontinued at this point owing to his muscular weakness. A neurology review the day after admission noted bilateral facial weakness, low monochord voice, complete areflexia and progressive flaccid weakness of all four limbs, which was denser in the proximal muscle groups.

The working diagnosis was Guillain-Barré syndrome and a lumbar puncture was performed. The results were consistent with this diagnosis, with normal cerebrospinal fluid glucose levels of 4 mmol/l, raised protein levels of 0.8 g/l (0.15–0.6),

red and white blood cell counts both <5/mm³, no organisms and a negative herpes simplex polymerase chain reaction (PCR); serum CMV PCR was also negative. IV immunoglobulin was started but, in spite of this, the patient's FVC continued to deteriorate and he developed signs of bulbar palsy. He was transferred to an intensive care unit (ICU) for intubation, ventilation and IV hydrocortisone.

At that time, the patient's inflammatory markers rose, with an associated febrile episode. He was commenced on IV Tazocin® (Wyeth), although no pathogen was identified on blood or urine cultures. Acute kidney injury developed within 24 hours of ICU admission and continuous venovenous haemofiltration was instituted. Creatine kinase levels were >80,000 U/l and the acute kidney injury was attributed to rhabdomyolysis.

Discussion with our tertiary referral centre for neurology suggested myopathy, mimicking Guillain-Barré syndrome, with potential precipitants being the respiratory infection or co-prescription of simvastatin and doxycycline. Unfortunately, neurophysiological assessment is unavailable in our hospital and the patient was too unwell to undertake the 125-mile round trip to the nearest unit to investigate nerve conduction. The clinical presentation, mimicking acute demyelination, delayed recognition of rhabdomyolysis.

Following discontinuation of the statin, the patient's weakness gradually improved. He was discharged from ICU 72 hours later with residual lower limb weakness, which resolved over two months.

Discussion

Statin-induced myopathy is well documented, as is an increased risk of myopathy on a combination of a statin and ciclosporin.¹ Ciclosporin increases plasma concentration of statins through inhibition of the cytochrome P450 3A4 (CYP3A4) metabolic pathway.² Our patient had been taking ciclosporin since his transplant in 1991 and a statin since 2006, with no recent dose alterations.

Statin-induced myopathy has been described in the context of precipitating antibiotics previously:

the macrolides are cleared through the same metabolic pathway (CYP3A4) and interaction potentially precipitates rhabdomyolysis.^{3–6} Fusidic acid has been reported to have triggered rhabdomyolysis in the context of co-prescription with a statin, again due to clearance via CYP3A4.⁷ Interestingly, we found a case series of statin-induced rhabdomyolysis, mimicking Guillain-Barré syndrome, with fusidic acid prescription – resulting, as in our case, in delayed recognition of rhabdomyolysis.⁸

Doxycycline is a primarily bacteriostatic antibiotic, inhibiting protein synthesis. It is not reported to cause muscle weakness in humans, except in those with myasthenia gravis;¹ however, it has been associated with bulbar paralysis, myopathy, elevated creatine kinase, acute renal tubular necrosis and striated muscle necrosis in calves.⁹

Muscle denervation can result in the release of muscle enzymes, and raised creatine kinase levels have been documented in Guillain-Barré syndrome.¹⁰ Unlike in our case, this is reported in the early stages of the syndrome, with modest elevations in creatine kinase – up to seven times the upper limit of normal. Muscle biopsy changes consistent with rhabdomyolysis have, unusually, been documented in the setting of Guillain-Barré syndrome^{10,11} – although this remains contentious as other studies have demonstrated the contrary.¹²

Doxycycline may increase the plasma concentration of ciclosporin^{1,13} and we note the relatively high trough ciclosporin level on admission. We suggest that the mechanism underlying our case was co-prescription of doxycycline, potentiating ciclosporin, which in turn increased plasma statin concentration and precipitated severe myopathy. For patients taking ciclosporin, the Medicines and Healthcare products Regulatory Agency and the US Food and Drug Administration previously recommended a maximum daily dose of simvastatin of 10 mg to reduce the risk of myopathy.^{14,15} Since this case occurred, a further drug safety update was published in August 2012, stating that simvastatin is now contraindicated with ciclosporin and many commonly prescribed antibiotics (see Table 1).¹⁶

To our knowledge, no other case reports have been published directly linking doxycycline to statin-induced rhabdomyolysis, but our experience

Table 1. MHRA drug safety update guidelines on drug interactions with simvastatin

Interacting agents	Prescribing recommendations with simvastatin
Itraconazole, ketoconazole, posaconazole Erythromycin, clarithromycin, telithromycin HIV protease inhibitors Nefazodone Ciclosporin Danazol Gemfibrozil	Contraindicated
Fibrates (except fenofibrate)	Maximum dose 10 mg daily
Amiodarone Amlodipine Verapamil Diltiazem	Maximum dose 20 mg daily
Fusidic acid	Close monitoring required
Grapefruit juice	Avoid grapefruit juice

in this case leads us to recommend that creatine kinase levels are checked at the onset of any significant weakness in those on long-term statins who have been co-prescribed antibiotics. We also advise that simvastatin is discontinued in those taking ciclosporin and that physicians review their patients' prescriptions for possible interactions in light of the new drug safety guidelines. Transplant recipient patients are likely to be exposed to polypharmacy and this case has highlighted the need for vigilance for drug interactions, particularly in the context of unexplained symptoms ■

Declaration of interest

The authors declare that there are no conflicts of interest.

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Key points

- Simvastatin should be discontinued in those taking ciclosporin.
- Physicians should review patients' prescriptions for possible simvastatin interactions in light of new guidelines.
- Creatine kinase levels should be checked in those taking a statin who present with any muscle weakness.

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Vancomycin therapy in patients on high-flux HD: a single-centre experience

Vancomycin is a glycopeptide antibiotic used to treat serious infections with gram-positive bacteria that are resistant to other antibiotics. Patients receiving haemodialysis (HD) via central venous catheters are at an increased risk of gram-positive bacterial infections.¹⁻⁴ Strains of staphylococci and enterococci resistant or only partially sensitive to vancomycin have developed;⁵ therefore, appropriate controlled use of vancomycin is essential.

Intravenous vancomycin is poorly metabolised and is mainly excreted unchanged in urine. It takes 200–250 hours to be cleared in end-stage renal disease (ESRD). Vancomycin has a low volume of distribution (0.61 kg), a low protein-bound fraction (50%) and a low molecular weight

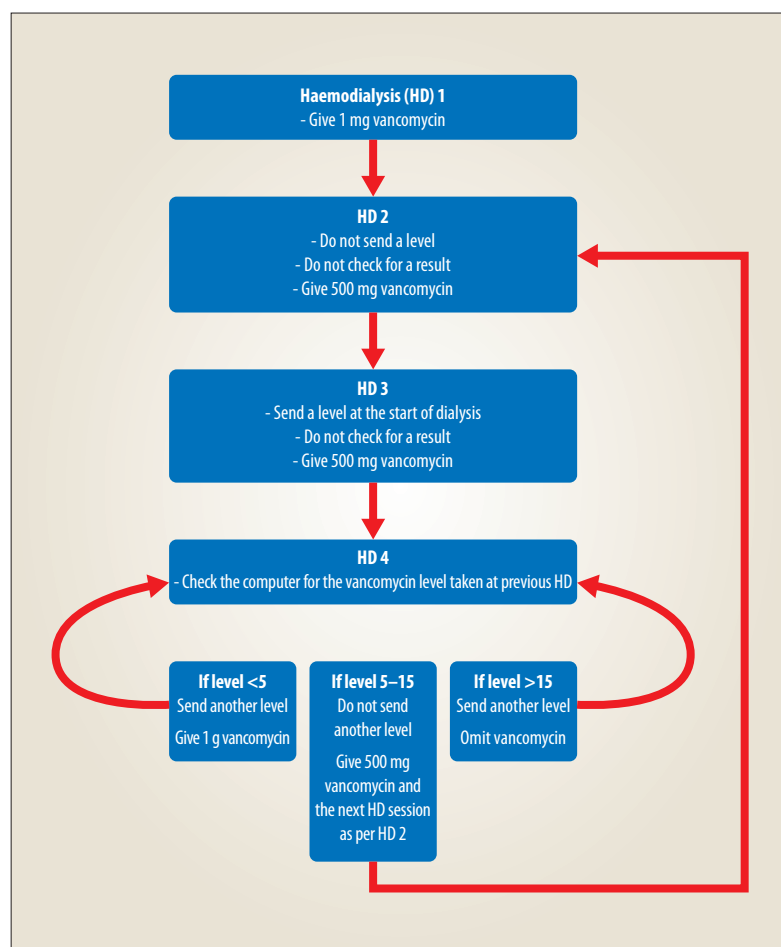
(1449 Da); it can also easily diffuse through high-flux HD membranes.^{6,7}

Vancomycin activity is considered to be time-dependent – that is, antimicrobial activity depends on the time that the serum drug concentration exceeds the minimum inhibitory concentration (MIC) of the target organism. The therapeutic range for trough vancomycin levels in our trust is 5–15 mg/l, guided in part by knowledge regarding the MIC of our local pathogens. Trough vancomycin levels greater than 15 mg/l are associated with more ototoxicity and nephrotoxicity – of im-

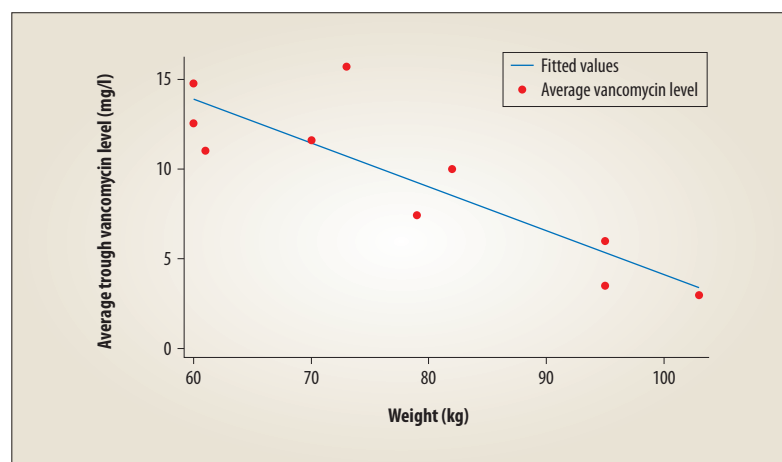
Appropriate controlled use of vancomycin is essential

portance in HD patients with acute kidney injury in whom recovery is predicted and in chronic patients with significant residual urine output.⁸ Trough vancomycin levels should be performed before the HD session.⁹ It is also recommended that the vancomycin dose should be administered as either a postdialytic or intradialytic (during the last hour of dialysis) dose. Intradialytic is preferred, as it is more convenient for the patient and dialysis unit.¹⁰

Previous vancomycin prescribing for HD patients in our trust required stat doses and serial vancomycin levels. Doses, timing (with respect to dialysis) and monitoring of levels were variable. Vancomycin prescribing carried a risk of therapeutic failure, recurrent infections and spread of infection, promotion of resistant strains of bacteria, temporary loss of native renal function and the cost of unnecessary blood tests/samples. We developed a protocol for the use of vancomycin in our high-flux HD population to regulate and standardise its use, and to ensure that MICs were maintained, while avoiding both toxicity and sub-therapeutic concentrations. This study was performed to assess whether the developed protocol was achieving its aims, and to ascertain whether there was variation in trough levels with weight and whether a dose adjustment for weight was required. Pharmacokinetic studies of vancomycin available in ESRD patients are in 'normal'-weight individuals and all studies for weight adjustment are in those with normal renal function. No adequate studies have been



■ **Figure 1.** North Bristol NHS Trust protocol for the use of vancomycin in high-flux haemodialysis patients



■ **Figure 2.** Linear regression: average trough vancomycin level versus weight

performed into weight adjustment in those with ESRD.

Patients and methods

The study was performed with approval from the Quality Improvement and Clinical Audit Department of the Clinical Governance Directorate of North Bristol NHS Trust. The vancomycin protocol shown in Figure 1 is currently used by the North Bristol NHS Trust. Data were collected prospectively over a six-week period between March and May 2012. A daily record of all HD patients receiving vancomycin was kept in the renal unit. A questionnaire was developed, assessing the use of the vancomycin protocol. The vancomycin prescription chart, drug chart, computer-based records and paper notes for each patient were reviewed. The laboratory results for the trough vancomycin assays, microbiology samples and inflammatory markers were recorded. Data were analysed using Stata® 11.

Results

Eleven HD patients were prescribed vancomycin during the six-week period. There was documented evidence of antibiotic success (normalisation of infective and inflammatory markers [C-reactive protein and white cell count] and/or resolution of clinical signs of infection) in seven patients (64%). Of the remaining four patients, two lacked any documentation of resolution and two required a change of antibiotic therapy.

The weight of one patient was not recorded; the mean weight of the remaining ten patients was 77.8 kg. Four patients (36%) had at least one trough vancomycin level of <5 mg/l. The mean weight of these patients was 93 kg. Three patients (27%) had at least one trough vancomycin level of >15 mg/l. The mean weight of these patients was 71.7 kg. Excluding the levels outside the target

range, nine patients (82%) achieved average trough levels of 5–15 mg/l.

Average trough vancomycin level was regressed against weight. The greater the weight, the lower the average trough vancomycin concentration (see Figure 2). Unadjusted linear regression of average trough vancomycin level and weight was performed, showing a significant relationship: the greater the weight, the lower the average trough vancomycin concentration ($R^2=0.75$, regression coefficient -0.243 , $p<0.001$; see Figure 2).

Discussion

This small observational study suggests that use of the protocol developed achieves the target trough vancomycin level in the majority of patients. It also suggests that a weight-adjusted dosing protocol for vancomycin is required in high-flux HD patients. A larger study is required to further assess this ■

Declaration of interest

The author declares that there is no conflict of interest.

Acknowledgements

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Key points

- Vancomycin is a glycopeptide antibiotic used to treat serious infections with gram-positive bacteria that are resistant to other antibiotics.
- Patients receiving haemodialysis (HD) via central venous catheters are at an increased risk of gram-positive bacterial infections, and so appropriate controlled use of vancomycin is essential.
- The renal team at North Bristol NHS Trust developed a protocol to achieve the target trough vancomycin level in high-flux HD patients.
- The protocol helped to achieve the target trough vancomycin level in the majority of HD patients.

■ Light micrograph depicting neutropenia with a single neutrophil surrounded by erythrocytes

Tacrolimus-induced neutropenia following renal transplantation: a case report

Tacrolimus is an effective immunosuppressant used in renal transplantation. It provides excellent graft and patient survival and is associated with a low incidence of acute rejection.^{1,2} It has many side effects, the most common being chronic allograft nephropathy, diabetes mellitus, arterial hypertension and neurotoxicity.³ Haematological side effects seem to be rare and their aetiology is still unclear. However, a causal association between tacrolimus and these haematological side effects is difficult to prove because renal transplant patients are subject to many other treatments to prevent rejection and infections. Here, we report a case of a tacrolimus-induced severe neutropenia in a kidney transplant patient.

Case report

A 28-year old woman with chronic kidney disease (IgA nephropathy) underwent kidney transplantation in March 2012, after receiving haemodialysis for three years. After transplantation, she received tacrolimus, mycophenolate mofetil (MMF), corticosteroids, valaciclovir, sulfamethoxazole and trimethoprim. At the time of transplantation, her peripheral blood count was normal.

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Two months after transplantation, she presented with arthralgia, diarrhoea and mouth ulcers with desquamative gingivitis. A peripheral blood count showed leucopenia (white blood cell count [WBC] 2,720/mm³) with severe neutropenia (neutrophil count 490/mm³). Haemoglobin and platelet count were normal. The renal function was stable (serum creatinine = 70.4 µmol/l).

Therapeutic drug monitoring of tacrolimus and MMF was performed using a CMIA technique (ARCHITECT; Abbott) and a chromatography system (HPLC, Varian), respectively. Trough blood concentration of tacrolimus was 11.6 ng/ml and mycophenolic acid AUC_{0-12hrs} was 53 mg/l.

At first, MMF was suspected as the cause of the neutropenia. The dose of MMF was decreased from 2,000 to 1,500 mg/day on Day 82 after transplantation, but WBC count decreased further to 870/mm³. In view of the oral lesions, tacrolimus was suspected as the causative factor and was replaced by ciclosporin on Day 87 following transplantation. Eleven days later, the WBC count increased to normal (7,000/mm³); the neutrophil count also normalised (2,500/mm³) and the oral lesions disappeared (see Figure 1). Treatment with corticosteroids, valaciclovir, sulfamethoxazole

and trimethoprim was continued throughout this period.

Discussion

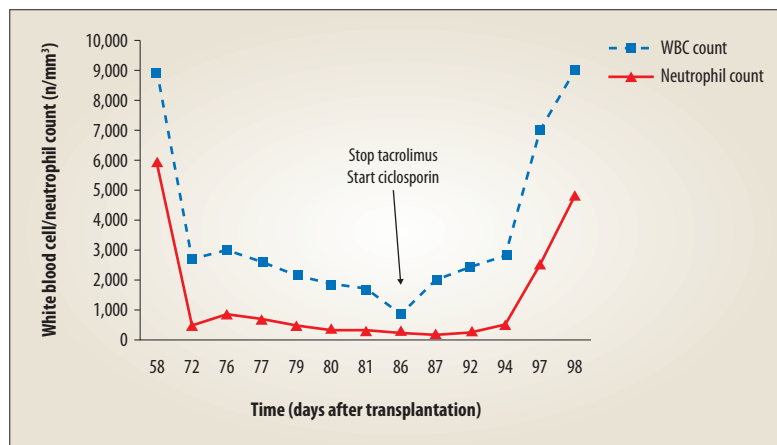
Transplant recipients are known to develop neutropenia frequently, especially in the early post-transplant period, with incidence reported between 4.9% and 37.5%.^{4,5} Neutropenia after renal transplantation may result from several causative factors and is most often related to antiviral and immunosuppressive agents⁶ used to prevent organ rejection and infectious diseases. MMF and valganciclovir are the main drugs responsible for neutropenia.³ Other drugs such as tacrolimus, sirolimus, rituximab and co-trimoxazole are also known to cause neutropenia.

In our case, the patient received MMF, tacrolimus, valganciclovir, sulfamethoxazole and trimethoprim. All these drugs can cause neutropenia. At first, MMF was suspected, and many studies have reported cases of MMF-induced neutropenia in renal transplant patients.⁷

In this report, the WBC count continued to decrease despite the reduction of MMF doses to 1,500 mg/day. With the persistence of neutropenia and with oral lesions suggestive of tacrolimus toxicity, we decided to switch from tacrolimus to ciclosporin. The levels of neutrophils and WBCs started to increase after the second day following the switch. Valganciclovir, sulfamethoxazole and trimethoprim were not suspected because they had never been stopped.

Other cases have been reported³ with a similar pattern to our report. In these cases, neutropenia occurs within three months after renal transplantation. Although the association between tacrolimus and myelosuppression, in particular leucopenia, has been suspected for a long time, the exact mechanism has not been elucidated.⁸ However, a number of hypotheses have been proposed by de Rycke and colleagues:³

- Direct inhibition of myeloid cells. This hypothesis was rejected by *in vitro* experiments. Direct inhibition of myeloid cells is not likely to be the mechanism of action of tacrolimus-induced leucopenia, but *in vivo* effects may be different.
- Effect of tacrolimus on mononuclear accessory cells by production of cytokines by lymphocytes or monocytes inhibiting haematopoiesis and inducing apoptosis. By acting on these mononuclear accessory cells, tacrolimus might indirectly be able to alter the balance between neutrophil death and survival.
- Pharmacokinetic interaction between tacrolimus and mycophenolic acid (MPA): tacrolimus increases MPA bioavailability by inhibiting MPA glucuronidation.



- Formation of autoantibodies against myeloid precursors or mature neutrophils after drug exposure.

■ **Figure 1.** Evolution of white blood cell and neutrophil count after renal transplantation

Conclusion

The difficulty of establishing a causal relationship between tacrolimus and the occurrence of haematological side effects is compounded by the treatment with concomitant agents and the susceptibility of transplant recipients to infections, which can also cause myelosuppression. In our case, the resolution of neutropenia after switching tacrolimus to ciclosporin supports tacrolimus being the cause, although the mechanism has not yet been demonstrated ■

Declaration of interest

The authors declare that there is no conflict of interest.

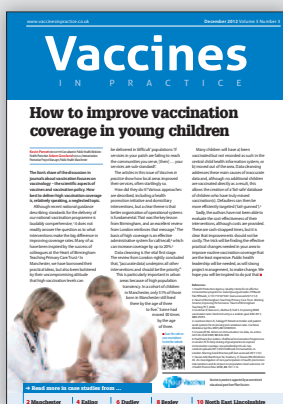
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Key points

- Tacrolimus has become an important agent in the prevention of rejection after renal transplantation.
- Despite its importance, the use of tacrolimus is complicated by its numerous side effects.
- Although haematological side effects are rare, the case of a patient who developed severe neutropenia within two months of renal transplantation is described.
- In this case, tacrolimus was identified as the causative agent following exclusion of other causes.

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What can we do for you?

Exercise includes activities like riding a bike, walking the dog or even climbing the stairs. As long as it keeps you moving and you do it regularly, it will help to get you fitter

What I tell my patients about exercise

Physical inactivity is now recognised as the developed world's biggest health problem, and the prescription of exercise for the treatment of chronic disease is, thankfully, becoming more established.¹ Unfortunately, kidney patients have been rather neglected in this regard compared with some other clinical services, such as those for heart and lung disease. At the moment, very few UK renal units offer any kind of exercise advice or support for their patients. However, recently, there has been quite a lot more research into the role of exercise in the management of kidney disease, and we are beginning to see that it can be very beneficial indeed.² We need to do more studies to find out the best exercise regimes for kidney patients and to discover the best ways of helping people take up an exercise habit and

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stick to it. But, in the meantime, we hope that the following advice will be helpful.

The main thing to remember about exercise is that everyone is different. Each person has their own individual reasons for exercising, their own preferences and dislikes, and their own lifestyle to fit it

into. There is no 'one size fits all' solution, but there is something for everyone. Some people have been active all their lives and are very motivated but, when newly diagnosed with chronic kidney disease, have no idea whether to modify their activity or if they should even exercise at all. They may just need 'permission' and some guidance about 'red flags' to look out for. Others have never been active and have an unpleasant impression of exercise, or are afraid of feeling physically embarrassed or culturally uncomfortable in a gym. These people may need more help to identify reasons to become more active, to find activities that suit them, and to set realistic and meaningful action plans and goals.

Why is exercise so important?

Human beings evolved over thousands of years as nomadic hunter-gatherers, who had to work hard to find food and were active for most of their waking hours. Our bodies are designed for this, and our metabolism is set up to support continuous physical activity. Today's easy lifestyles, where most of us do not have to do much in the way of physical work, do not suit the human body at all. If we do not use our bodies as nature intended, they deteriorate and start to go wrong. We know that being inactive increases the risk of developing long-term health problems, such as heart disease, strokes, diabetes, cancer, dementia, depression and some types of kidney disease. Exercise is also used as part of the treatment of many of these diseases.

What is 'exercise'?

When you hear that word, maybe you think of our Olympic heroes, pushing themselves to the utmost extremes of effort to win a medal? Or do you think of young, fit people working out in the gym, running marathons or doing high-energy aerobics classes? If so, you may be thinking that it is not for you; but what about going for a bike ride with the family, walking the dog, or even climbing the stairs? 'Exercise' is simply physical activity that you do over and above your normal daily tasks, for pleasure or because it's good for you. Therefore, 'exercise' means different

things for different people – but anyone can 'exercise' by increasing whatever amount of physical activity they normally do. For example, if you usually take the lift up to the second floor, you can do some 'exercise' by climbing the stairs instead.

There are two main types of exercise – aerobic and resistance (see Table 1). You need to do a bit of both types, but not necessarily in the same session.

How can exercise help people with kidney disease?

Unfortunately, people with kidney disease can suffer from a variety of symptoms and health problems, and it is not surprising that this can lead to anxiety, depression and a reduced ability to enjoy the pleasures of everyday life. Research has shown that being physically active can have a beneficial effect on many of the health issues associated with kidney problems. Three of the main ways exercise can help are described below.

Exercise helps to protect the heart

You probably know that having kidney disease makes it more likely for an individual to develop heart disease as well. It is particularly important to look after your heart; for example, by giving up smoking and keeping your blood pressure and cholesterol levels under control. In addition, regular exercise really helps to protect your heart and keep it in good shape by lowering blood pressure, controlling cholesterol, preventing diabetes and improving the condition of the blood vessels.

Exercise keeps your muscles strong

People with kidney disease often notice that they feel weaker and more tired than they used to, and that their muscles tend to shrink and waste away. This happens to everyone if they do not use their muscles and keep them strong, but it can be worse if your kidneys do not work properly because of the extra toxins in the blood. Muscles are really important for everyone – not only weightlifters and gym enthusiasts, but anyone who just wants to be able to move around, climb the stairs or get up out of a chair.

Table 1. Types of exercise

Aerobic or cardiovascular	The type that makes you feel warm and out of breath, like walking, running, swimming or cycling. Aerobic exercise strengthens the heart, blood vessels and lungs
Resistance or strength training	Uses weights (or your own bodyweight) to build up and strengthen the muscles. Stronger muscles makes aerobic exercise easier!
Warming up	Every exercise session should start with ten minutes or so of gentle warm-up activity to loosen your muscles and joints and get your heart and lungs working gradually
Cooling down	At the end of your exercise, you should gradually cool down with gentle activity until your heartbeat and breathing are back to normal. Do not suddenly stop – let your body adjust to the changes. It is also useful to gently stretch the muscles that you have been using

Table 2. Exercise guidelines**Aerobic exercise**

What?	Anything you enjoy! Walking, swimming, cycling, dancing, using gym equipment or aerobic classes – it is up to you, and you can use a mixture of different activities if you want to
How often?	3–4 times a week (every other day)
How long?	Aim for 30 minutes of continuous exercise. However, if you cannot manage this to begin with, it does not matter – just do what you can and try to increase the time a little bit each time. You can do two 15-minute sessions in a day instead of one 30-minute session if that works better for you
How hard?	Find a level of effort where you are slightly out of breath but not gasping. Your breathing level must allow you to talk to someone while you are exercising, but only in short sentences before you need to catch your breath. If you are chattering away too easily, you need to work a bit harder!
A suggestion	Aerobic exercise can be as simple as going for a walk. If this is what you choose, you could try using a pedometer. This small device clips on to your clothing and counts the number of steps you take. It is a great way of measuring your progress – write down how many steps you take each time you go out, and try to do a few more each week. A pedometer should cost less than £5 and they are widely available in sports shops or online

Resistance exercise

What?	To build strong and healthy muscles, you need to challenge your muscles with weights. If you go to the gym you can use the machines and equipment there – ask the staff to show you how. But you can do resistance training at home too, using simple things like tins of beans. For some exercises you can use your own bodyweight (see suggestion below).
How often?	2–3 times a week
How hard?	Choose a weight that you can lift 10–12 times before you need to rest – you may need lighter or heavier weights for different exercises. Always lift weights slowly, using very controlled movements, and keep going until your muscles tire – this will tell them that they need to get stronger. Keep breathing normally, do not hold your breath, and avoid lifting weights above your head
A suggestion	Concentrate on the large muscles in your lower body (legs) as these are the ones that will help you most in your everyday activities. Here is a simple resistance exercise you can do at home. Sit on an upright chair like a dining chair, with your feet flat on the floor. Slowly stand up and then slowly sit down again. Repeat this as many times as you can, then have a rest and try to do a few more. Try not to use your hands to help – keep your arms crossed in front of you, if you can. If you do this regularly, you will find that it gets easier and you are able to stand up and sit down more times before you have to rest. Your muscles have become stronger!

Muscles are also important for general health, because they control the way the body uses blood sugar and fat. Having good muscles and using them regularly really helps to prevent diabetes and keep the heart healthy.

Exercise helps you to live a better life

We all know that the likes of Mo Farah and Usain Bolt are going to have to keep up their training if they want to win gold again at the 2016 Rio Olympics. If they stop exercising now, they won't stand a chance because their physical fitness will decline. The same principle applies to everyone else. You may not be aiming to win the 5,000 metres or run a record-breaking 100 metres, but you will certainly be able to think of some physical activity that is important to you – be it playing a round of golf, taking your grandchildren to the park, walking round the shops on a Saturday afternoon, or being able to climb the stairs and look after yourself in your own home. If you do not keep yourself active, your fitness will decline in just the same way as that of an athlete and there will come a time when you will not be able to do many of those things any more.

Everyone has the capacity to improve their physical condition and get stronger, no matter where they start. In fact, the least active people tend to notice the biggest improvements when they take up exercise.

Are there any precautions before I start?

Moderate regular exercise is good for nearly everyone, but there are some people who need to be extra careful and may need special advice and help with their exercise programme. Please ask your doctor or healthcare professional, especially:

- If you have more advanced kidney disease or kidney failure
- If you have other health problems in addition to kidney disease, such as heart or liver conditions, or difficulties with blood pressure control
- If you have problems that affect your mobility or balance
- If you are diabetic. Exercise can help diabetes but you should ask about controlling your blood sugar levels – and please look after your feet.

Once you have decided to do some exercise, you should remember the following simple guidelines:

- Do not exercise if you are feeling unwell.
- During exercise, STOP if you feel unusually weak or breathless, if you feel dizzy or nauseous, or if you feel pain.

Where and how can I exercise?

A few kidney units in the UK offer exercise help and advice to their patients. Ask whether yours is one of them – and if not, ask why. If the doctors or other healthcare staff need more information about exercise for kidney patients, they can contact the authors of this article or the British Renal Society Rehab Network.³

At some haemodialysis units, patients can exercise during dialysis sessions using specially-adapted exercise bikes. This is a great way to get your exercise in a supported environment, so if you are offered the chance to try it out – go for it! Many patients find that it really helps them to build up their physical condition and become more active in their home lives as well. It also helps to pass the time while dialysing.

Some GPs can arrange for patients to see a specialist fitness instructor or take part in exercise classes. Ask at your surgery to find out if you are eligible for this type of support.

You can also try out your local gym or leisure centre yourself. Maybe you are worried that it will be full of muscular young people in Lycra, and that you will not fit in there? Go and have a look – many gyms and leisure centres are actually full of ‘normal’ people just like you, especially in the daytime. Some have special times of day for older people or for ladies only, and offer the chance to enjoy the facilities and make new ‘fitness friends’.

Best of all, do it yourself! Think of something you really enjoy and make it a priority in your life. It might be walking, swimming, dancing, cycling, or a mixture of different activities – as long as it keeps you moving and you do it regularly, it will help to get you fitter.

How much exercise should I do? This varies from person to person depending on their condition and what they are hoping to achieve. See Table 2 for some general guidelines. Always start gently and build up gradually – just try it out and see how you go. A small increase in activity is better than none at all, so do not be put off by thinking that you have to achieve the impossible.

The main thing about exercise is to do it regularly. There is no point in doing one or two sessions and then giving up – it will only do you good if you keep it up.

I am still not sure I can do it! Exercise does not mean that you have to run a marathon. Everyone is

different, so do not be worried that it will be too hard for you. Just do what you can manage. Start gently and build up gradually, and do not expect too much of yourself too soon. The key is to push yourself just a little bit, and to keep doing it regularly. Write down the reasons you have decided to take up exercise, and what you hope you will gain from it. Set yourself some goals and write them down too. Do not be too ambitious – start with very modest goals that you are pretty sure you can achieve quite soon, and then set new ones every few weeks.

You may have to adjust your lifestyle and routine to fit in your new exercise habit, but make it a priority – you will be the one who benefits and it will be worth the effort. It is a good idea to keep an exercise diary where you write down what you have done, how long you did it for, how hard you worked, and how it felt. That way you can track your progress, and you will be able to see what works best for you.

Another great idea is to get other people to exercise with you, to make it an enjoyable social experience and to keep each other going. This could be friends, your spouse, other relatives, your children or your grandchildren. Exercise is good for everyone, and getting the younger generation into the exercise habit is a wonderful gift to them for a healthy future ■

Declaration of interest

The authors declare there is no conflict of interest.

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Key points

- Recent research shows that exercise plays a very beneficial role in the management of kidney disease.
- Exercise includes activities like riding a bike, walking the dog or even climbing the stairs.
- Your kidney unit or GP may be able to offer advice or help with classes, but you can also just join a gym or leisure centre yourself.
- It is always best to start exercise gently and build up gradually. It should also be done on a regular basis and involve a mix of aerobic and resistance training.

■ *What I tell my patients about ...* is a patient information service specifically designed for renal units to use with their patients. You can now view this, and all of the previous *What I tell my patients about ...* articles, online and download them free of charge via www.bjrm.co.uk/patient-information

How seven-day working will affect kidney services

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Sir David Nicholson, former Chief Executive of NHS England, is often quoted as saying that changes to our health system, and particularly the need to save over £20 billion, are 'so massive that you could see them from Mars'. The reforms have certainly been a seismic organisational shift for the Department of Health, Public Health England and the Care Quality Commission. However, the public, our patients and frontline staff have been more concerned about quality failures, sustaining services and cuts in local authority social care budgets. Now that the new structures are bedding in, we are going to see these agendas converge to drive large-scale changes that will affect us all. The headlines often mention reconfiguration – where things are done and which hospital services will close – but equally important is how things are done and how they will be done differently in the future; both are changing. Sir Bruce Keogh, Medical Director of NHS England, said that specialist services should be brought together as much as possible, be provided across no more than 15–30 sites in England and that the shift to seven-day services is well under way. So, what will this mean for kidney units and kidney care?

To gain the advantages of seven-day working (easier access, earlier diagnosis, reduction in admissions, improved weekend mortality and shorter lengths of stay), all parts of the health and social systems need to operate every day of the week; this does not mean that all services necessarily need to work in the same way at the weekend as they do during the week. Many argue that GP practices should be open on Saturday morning and Sunday afternoon but only for urgent appointments. The working, taxpaying public may, however, prefer to have their routine blood pressure or diabetes care at the weekend, rather than taking time off work. A few transplant clinics now operate outside of routine hours to accommodate our working transplant recipients; these clinics score very highly on patient experience and satisfaction. Perhaps we should consider similar clinic hours for young people, those of working age and the elderly, whose working children may wish to attend. Our maintenance dialysis services have been running six days a week since inception, and there is no need to consider changing this purely to tick a seven-day working box; if evidence for the benefit of frequent

haemodialysis continues to grow, we may have to work out how we accommodate this to provide better quality and outcomes. Kidney transplantation has always been a 24/7 commitment, so will see no major changes. Seven-day working means we will have easier access to diagnostics, discharge planning and other services for our patients at the weekend. It will also mean that our inpatients and their relatives will expect senior medical, nursing and multiprofessional input every day of the week. We will expect social care and GP colleagues to support weekend discharges and, in return, they will expect advice and the right to request a review. People with acute kidney injury should be recognised earlier, whatever ward they happen to be on, and we will be expected to respond and transfer without undue delay. The result should be better patient care.

If this is what seven-day working might look like, how will we get there? What are the first steps? Do we have enough people? Can we afford it? These questions bring the phrase 'the future is already here – it's just unevenly distributed' to mind. Different patterns of working in emergency and urgent acute care are happening but might be constrained in the short term by the numbers of trained staff available. The initial worry was that we were training too many doctors; however, the rate-limiting shortages may be in nursing and the wider multiprofessional team. Daily senior medical presence on our kidney wards is now the norm and is becoming increasingly common in other specialties; service and system standards will make this a requirement. Ten new clinical standards, which were published in December last year, are to be implemented over the next three years, describing the standard of urgent and emergency care all patients should expect seven days a week.

In respect of finance and cost, the Healthcare Financial Management Association has looked into the financial implications of introducing seven-day services for urgent and emergency care and supporting diagnostics in the NHS. The report concluded that the move to seven-day services does appear achievable, but it may be unsustainable for all existing hospitals to move all their current range of services to a seven-day basis. This brings us back to the push to consolidate services on fewer sites and to reduce specialist centres to between 15 and 30 across the country. These are changes that we are all going to feel ■

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Update: Renal Association Patient Safety Project



Patient safety is an obligatory priority for all renal unit healthcare professionals. The Renal Association Patient Safety Project has been running for over six years and is now developing into a multiprofessional project in collaboration with the British Renal Society (BRS) and the Association of Renal Technologists (ART).

Incident reporting

Incident and risk issues have been reported to the Renal Association Patient Safety Project from: renal units; the National Patient Safety Agency (NPSA); the Medicines and Healthcare products Regulatory Agency (MHRA); and NHS England.

- All incidents should be reported through the hospital incident reporting system. Incidents are downloaded to the National Learning and Reporting System (NLRS), which has been taken over by NHS England from the NPSA. NHS England will continue to analyse trends of incidents and issue alerts as indicated.
- Review and analysis of patient safety issues should be an integral part of clinical governance within all renal units, involving all renal healthcare workers and a process of regular audit.

Medical device failure

The term 'medical device' covers equipment, disposables and software necessary for the use of devices. Around two-thirds of incidents relate to failure of medical devices. In the case of dialysis disposables, incidents may be related to manufacturing faults or to a change in the composition of plastics, either being too brittle or too flexible.

- Device-related incidents should be reported to the MHRA, which has the statutory authority to investigate device-related incidents, take action and issue alerts as appropriate.

User error and technique failure

Approximately one-third of incidents reported by renal units are related to healthcare workers failing to use equipment or devices correctly, or incorrect practice of clinical techniques.

- These issues emphasise the importance of training and supervision.
- Care should be taken when renal healthcare workers are using equipment of a type that they are unfamiliar with, where techniques may need to be retaught.

Blood loss

The number of blood loss related incidents continues to rise, which has resulted in a small number of fatalities; the most common is venous needle dislodgement.

- Recommendations to avoid venous needle dislodgement have been circulated by the European Dialysis and Transplant Nurse Association/European Renal Care Association.
- Blood loss detectors, either as stand-alone devices or integrated with dialysis machines, are commercially available and should be considered for use in high-risk patients. Blood loss, with potential fatal outcomes, can occur if dialysers and dialysis lines are inadequately tightened or washback procedures are incorrectly carried out. Serious bleeding can occur from fistula needling sites, from elective removal of femoral dialysis lines, and also from where femoral dialysis lines have been pulled out or have become detached from fixation wings.
- Attention should always be paid to the manufacturers' instructions on the usage and fixation of dialysis lines, particularly avoiding alcohol-based cleaning fluids, which can soften plastic.

Vascular access

It is well recognised that healthcare-associated infections are a cause of increased morbidity and mortality of patients, particularly related to dialysis catheter infections. Renal units should continue to review their processes in regard to achieving Renal Association standards for arterio-venous fistula rates. All units should review their training, catheter care bundle implementation, bacterial surveillance and policies of line removal.

Haemolysis associated with haemodialysis

Incidents of haemolysis associated with haemodialysis have been attributed to the use of hydrogen peroxide or chloramine for sterilising hospital or renal unit water systems. However, haemolysis not related to these causes has been observed, possibly related to kinking of dialysis lines, but other incidents have no proven explanation.

- Water supplies to renal unit water plants should come directly off the mains supply.
- Units should ensure adequate communication with estates departments, particularly to the timing of water supply sterilisation.

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- Guidelines regarding water supply to renal units are available via the Renal Association website.

Prescribing

There are continuing incidents relating to prescribing errors, in particular: reduced renal excretion of drugs not being considered; renal toxicity of drugs; susceptibility to infection from immunosuppression; inadequate treatment of hyperkalaemia; and generic prescribing errors.

- The training of junior doctors, in regard to prescribing in renal patients and liaison with renal pharmacists, is essential.
- Renal units should consider introducing systems for close monitoring of immunosuppressive drugs and of prophylaxis against infection.

Risks for acutely ill patients

Renal inpatients are commonly elderly, have additional co-morbidities and are susceptible to rapid deterioration. Early identification of such patients, through the use of early warning scores, is essential to enable prompt management. Wherever possible, renal inpatients should not be managed on non-specialist wards.

Human factors

There is increasing awareness of the part human factors play in putting patients at risk. This covers continuity of care, handover, communication, and failure of interprofessional working. Careful handover of ill patients between shifts is essential. Some hospitals now have instituted both theoretical training sessions and practical experience, with the use of simulation wards.

Future development of the patient safety project

The Renal Association Patient Safety Project now operates under the umbrella of the Renal Association Clinical Services Committee, and has developed into a collaborative process with the BRS and ART. We continue to work closely with the MHRA, NHS England and the Royal College of Physicians and are looking to be more proactive in terms of identifying risks as well as incidents.

The project would welcome suggestions from renal units for priorities in patient safety. Improvements in patient safety will also be facilitated by a review of clinical standards data from the UK Renal Registry, where all units are benchmarked ■

Acknowledgments

The author would like to thank all renal units who have contributed to this project, and Dr Graham Lipkin and Dr Alastair Hutchison for their support in the development of this project.

Declaration of interest

The author declares that there is no conflict of interest.

Further reading

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When the 'National Kidney Patients Helpline' was launched 15 years ago, it was simply perceived as a telephone number that any kidney patient or carer could dial, Monday to Friday, during the National Kidney Federation (NKF) office hours to get help and advice – what a complete underestimation of need this proved to be!

Immediately, the NKF became aware that even though the line was charged at a local rate, many patients could not afford a prolonged call – the first change was to make the calls free of cost.

The second stemmed from the volume of calls – we thought one desk and one helpline manager would suffice; this rapidly expanded to two full-time operators, a purpose built confidential office space, and dedicated specialist communication and printing equipment. The helpline now takes up to 200 calls a week.

The third change was to the means of communication – patients don't just want to reach us by telephone, they want to write to us, email us, contact us via the NKF website, via Facebook, Twitter and via the three NKF social networking online communities that we established.

The NKF never gives medical advice, we simply point patients in the right direction; we do this verbally and we do it by supplying them with one or more of 150 different titles of renal leaflets that have been created by the NKF medical advisers (the same leaflets we supply to renal units). Originally, the leaflets were about end-stage renal disease – but nowadays, there is just as much demand for early-stage advice to those newly diagnosed.

Many calls reveal patients in real trouble, patients who need support, help, or even hand-holding, which cannot be done via telephone calls and leaflets – they frequently need someone to stand up for them in their battles with the huge machine that is the NHS.

And, so, the NKF Advocacy Service was born, now consisting of eight NKF employees, spread throughout England, Scotland, Wales and Northern Ireland; a service, partly funded by the BKPA (British Kidney Patient Association), providing essential, on-the-ground help as and when needed by any kidney patient or carer.

All of this only works if patients and carers are aware of the services available to them. Help can be found at 0845 601 02 09 ■

Timothy Statham OBE,
Chief Executive

Fistula refusal: a qualitative study exploring decisions against fistula access

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Haemodialysis (HD) requires the individual to have well-functioning vascular access (VA); an arterio-venous fistula (AVF) is considered the best and most reliable access for HD.¹ It is the preferred method because it provides the best long-term VA with the fewest complications.¹⁻⁴ When an individual is medically unsuitable for an AVF, an arteriovenous graft (AVG) may be used.¹ Alternatively, if an individual begins emergency HD or there is insufficient time to establish mature VA (AVF/AVG), a line (central venous catheter [CVC]) may be used.¹ Lines are considered the least desirable VA, due to their associations with increased morbidity and mortality compared with a fistula or graft.^{5,6}

The preference for fistula use is recognised internationally,^{1,7-9} although this does not always translate in practice.¹⁰ It has been highlighted that the UK has fewer patients with a fistula compared with other European countries such as Italy, Germany, France and Spain;¹ recent research indicates the situation is still the same.¹⁰ The UK recommendations for fistula prevalence were at 80% in 2006¹¹ and, more recently, the UK Renal Association¹² has advocated that 85% of prevalent patients should be receiving HD via a functioning fistula. Despite various drives and interventions to increase the uptake of fistulas,¹³⁻¹⁵ research indicates a recent decline both in the UK and internationally.¹⁰ Provided patients are deemed medically suitable, ultimately the decision lies with them as to whether or not to proceed with the fistula.

Little research has been conducted into the reasons for this decline; in terms of patient choice and experience, more work is needed in this area to identify and address factors affecting patients' decisions.¹⁵ One qualitative, ethnographic study was conducted in the USA, exploring the experience of patients who already had a fistula or were awaiting surgery,¹⁶ but this did not explore perceptions of individuals who refused a fistula. To the

researchers' knowledge, only one previous study by Xi *et al*¹⁷ has focused on decision-making in individuals who have declined a fistula. This study was conducted in Canada in a dialysis unit that had a high prevalence of line use, so its relevance to the UK context is unclear.

The aim of the current study was to explore qualitatively patients' reasons for fistula refusal, investigating perceived disadvantages of AVF/AVG and perceived benefits of their existing line as VA for HD. Utilising grounded theory,^{18,19} the research sought to create a model depicting the key categories identified to inform service delivery, with the possibility that targeted interventions could be designed to improve experiences for future HD patients.

More work is needed in this area to identify and address factors affecting patients' decisions

Method

Ethical approval was granted by the Edgbaston Research Ethics Committee, (reference: 11/WM/0241). The researchers employed an abbreviated version of grounded theory.²⁰

Participants

Participants were recruited in October/November 2011 from four HD sites in Wolverhampton. HD patients meeting the eligibility criteria, as presented in Box 1, were identified by the service lead for VA and invited to participate.

In line with grounded theory recommendations,^{19,21,22} the sample size required for the study was achieved following 'theoretical saturation' (that is, when no new or relevant data emerged from identified categories).¹⁹ In this study, the researchers identified that theoretical saturation was achieved following an interview with the 15th participant.

Twenty-six eligible patients were invited to participate; eight declined, one died prior to interview and two patients' interviews were put on hold due to poor health. Participant characteristics are outlined in Table 1.

Box 1. Participant eligibility criteria**Inclusion criteria:**

- Haemodialysis (HD) patients who have refused arteriovenous fistula (AVF) access but are medically suitable
- HD patients who have had a failed fistula in the past and are refusing a new fistula site for vascular access, but are deemed medically suitable
- Non-English speaking patients for whom a translation service is readily available

Exclusion criteria:

- Non-HD patients or HD patients dialysing with a fistula or arteriovenous graft (AVG)
- Patients who do not have capacity to provide informed consent to participate

Note: 'Medically suitable' refers to individuals who have been approved for AVF/AVG access without contraindications to health

Materials

A semi-structured interview schedule was used, comprising open questions and prompts, as shown in Box 2. An initial pilot interview was conducted to check the interview schedule and timings; as no significant changes were identified, the pilot was incorporated into the analysis.

Data collection and analysis

Data collection and analysis are parallel processes in grounded theory.¹⁹ Interviews were conducted by the first author (a 26-year-old, female, trainee health psychologist) at a time/place convenient for the participant (either during HD sessions in private areas or in their own homes). Interviews were audio-recorded (Olympus digital voice recorder: WF-311m) and transcribed verbatim. Once transcribed, the interviewer shared the transcripts with participants, to ensure accuracy. Transcripts included both participant and interview-facilitator's speech; pauses were indicated using round brackets including the number of seconds or (.) to represent a pause of <1 second. Participant anonymity was maintained with pseudonyms.

Transcripts were analysed using the phased procedures of grounded theory.¹⁹ This can be seen in Table 2. To ensure reliability of coding, the three authors coded and analysed transcripts for categories, properties and dimensions. Following independent coding, a collaborative process of face-to-face and online discussion ensued to reach consensus and validate categories.

Results

Following analysis, a model of seven interlinked categories was determined (see Figure 1). The core category 'Better the devil you know' encapsulates

Table 1. Participant characteristics

	Number	%*
Mean age (years)	61.4	15.2 (SD)
Gender		
Male	7	46.7
Female	8	53.3
Renal characteristics		
Time on dialysis, mean (months)	68.3	43.07 (SD)
Previous transplant	1	6.7
Previous use of peritoneal dialysis	3	20
Central venous catheter line use only	7	46.7
Prior AVF use	8	53.3
Prior AVG use [§]	3	20
Cause of renal failure – identified by participant		
Blood disorder	1	6.7
Diabetes	3	20
Hypertension	2	13.3
Kidney syndrome (named)	3	20
Septicaemia	1	6.7
Unsure	5	33.3

* Indicated as % unless stated as standard deviation (SD)

[§] Individuals with prior AVG also had prior AVF use (ie AVF/AVG access, n=8)

Box 2. Examples of semi-structured interview questions (Note: this is not an exhaustive list)

Tell me about what happened when the renal team first discussed having a fistula for haemodialysis with you ...

Question: What was involved in reaching your decision to not have a fistula?

Prompts: How did you approach it? What were you thinking? What were you feeling? Did you think of any positive reasons for having one? What were the things that worried you? Did you discuss it with anyone? What do you see as the disadvantages/advantages of a fistula? What are the disadvantages/advantages of a line?

General prompts: What were you thinking/feeling then? Can you tell me a little more about that?

Table 2. Grounded theory phases^{19,20,23}

1. Open coding	Initial line-by-line coding to break down and examine the data collected; to identify initial categories/properties/dimensions
2. Axial coding	Intermediate procedure of constant comparative analysis to identify patterns, relationships and comparisons within and between these
3. Selective coding	Identification of a core category that encapsulates the categories illustrated and validates the relationships within and between these

all the categories.^{19,23,24} Quotes have been selected to demonstrate these interlinked categories of the model.

Better the devil you know

This core category is central to the other six categories and shows the importance of what is known about fistulas, based on patient experience, whether first-hand or vicarious. Individuals' perceptions of the disadvantages or benefits of the

VA options were due to their own prior experience of failed fistulas or the observed experiences of fellow patients.

Failed fistulas

For individuals who had previously had a fistula, after some several attempts in some cases, the thought of trying again was just too much.

Antonia: *'I'm butchered up enough, you know what I mean? ... It, it's too much cutting and slashing for me. I've done everything that they recommended, three times, three times failed, after four, I don't want it to keep failing.'*

Vicarious experience

Witnessed experiences of failed or problem fistulas provided other patients with a deterrent to go through the procedure themselves.

Mary: *'I've seen so many occasions in this place where the fistulas go wrong, they don't work and they're repeated and they still don't work.'*

For some, a combination of their own failures and observing the experiences of others provided a position of hindsight that reaffirmed their decision.

Marcus: *'The fact that I did everything that I, according to the instructions that I was given (.) and that it still failed. I've also now, obviously, had the benefit of seeing the problems that other people who are dialysing here with me, experience from time to time.'*

Trust

Directly linked to the core category, patients' trust in their VA, information source and their own faith were consistent reasons for keeping their lines.

In VA option

The concept of the line being something they could trust, a known quantity, in comparison with the fistula, was evident for all individuals. Patients could see no reason for change while their current VA was working well.

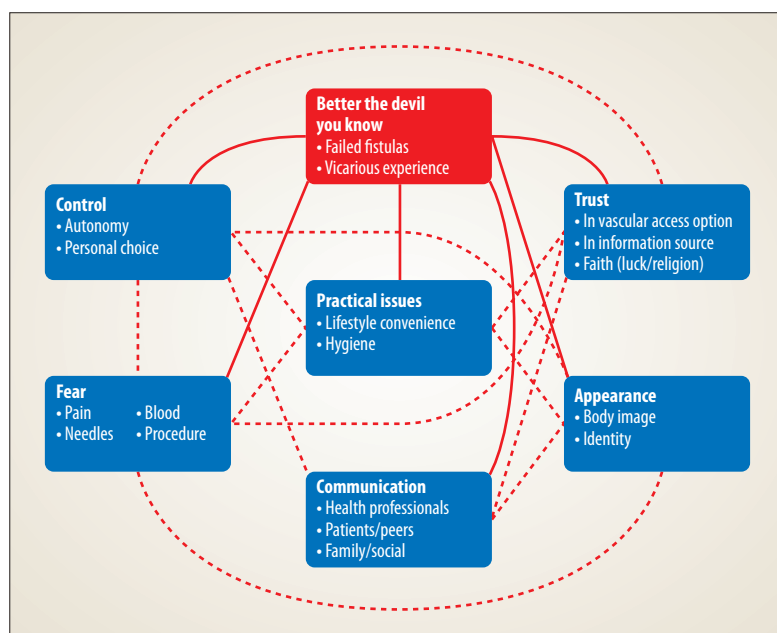
Marcus: *'I've had not a single infection over three years (.). Very little problems with it ... Yeah, so ... (.) if it ain't broke, don't fix it! [Laughs] ... as they say!'*

Patients demonstrated a lack of trust, and fear of the alternative.

Winnie: *'Well as I've just said, why change something that is working adequately for something that may not work. I could bleed badly, I could do all sorts of things ... I mean it's like changing your car in a way...if your car that you've got is working adequately and you're pleased with it and you're happy with it, why change it?'*

In information source

Linked also with communication, patients' trust in the source of information was another reason for maintaining their lines.



Mary: *'I didn't warm to him (.) I think you've got to have confidence in people who are treating you.'*

Antonia: *'If they knew that at the beginning (.), maybe it wouldn't have failed the first time. But, we're never going to know that are we? This is the problem.'*

Faith (luck/religion)

Despite the known risks of infection, there was a common feeling of trust in luck or a deity of sorts, being on their side.

Taeera: *'I've been told that with the line I may have some kind of infections, but until now, I haven't had any infections at all. So I'm thankful to God that at the moment everything is going well and I hope that everything will stay like that.'*

For others, their trust in faith outweighed any decision to consider a fistula.

Joan: *'I reached this age when, where I wouldn't be bothered in nothing else. If my time comes and I have to go, then I go ... When death comes and they say you have to go, you have to go. The Bible tell me that you don't feel no pain when you're dead, all your memories disappear you know.'*

Control

Linked closely with the core category and with trust, patients saw the decision as being in their control; establishing their personal choice or freedom in making such decisions.

Autonomy/freedom

By exerting control and having the freedom in decision-making, patients also felt a sense of freedom with the line.

Personal choice

Tina: *'It's my life at the end of the day I've got to think of. (.) Cos, I've been through enough surgery, so that's it.'*

■ **Figure 1.** Fistula refusal: core category, categories and properties of vascular access choice. Note: dashed lines indicate links between categories

Winnie: *'[My] doctor ... erm (.) started asking why I didn't have a fistula. And then I sort of rebelled against it, well I thought why, why (.) no necessity ... I feel free-er from, well, I don't feel I'm going to knock my arm and make it bleed or anything like that.'*

Fear

Tied in with their own or vicarious experiences, fear influenced patients' decisions; fear of the unknown, fear of pain and anxiety regarding needles and blood.

Pain

Some patients perceived fistulas as more painful than their lines.

Joan: *'I can see the face they make, and so, god it hurts and ... so I'm not going to, oh god, I'm not having it.'*

Needles

Grace: *'Because I'm afraid of blood and needles (.) Definitely, definitely afraid. And as time gone by (.), sometimes nobody could even mention the word needle to me.'*

Blood

Mary: *'I'm not ignoring medical opinion, but I think it could be quite dangerous, because I bleed very easily ... And when they take you off the machine, it's still bleeding. Well with warfarin, you're going to bleed even more.'*

Procedure

Mat: *'I'm very scared. I've never had an operation before in my life, you know. I'm very scared.'*

Appearance

Directly linked to the core category, the line was perceived to be a lesser evil than the fistula, in terms of its appearance. Many used the words 'ugly', 'unsightly', 'lumps', 'diabolical', 'bruising', 'swelling' and 'vanity'.

Body image

Patients were concerned with the appearance of others' fistulas.

Douglas: *'The lumps they produce. I don't want that (.), not at my age. No. I think they look ugly. It does look ugly ... And there's a guy here, his arm, well, it's absolutely diabolical (.) It's full of lumps. I don't want to end up like that.'*

Linked with control, patients with failed fistula sites wished to avoid further scars.

Antonia: *'You see, they can't touch these now [previous fistula sites], so now they've got to go into brand new virgin skin ... And they're so unsightly, the scars are (.), for a lady in particular, I think. I'm not going to*

do it again.'

The discrete appearance of the lines, compared with fistulas, was mentioned favourably, inter-linking with lifestyle convenience.

Marcus: *'You wouldn't want to be walking around with a half-sleeve shirt on for instance ... I still like to do exactly what I did when I wasn't on dialysis. I mean (.) all I've got is a discrete line there and I tend not to obviously go out (.) bare-chested in the summer, but you know! ... Nobody can see it, no one knows it's there'(.), unless I tell them.'*

Identity

Aside from the physical appearance, individuals felt their identity would be altered with a fistula, affecting their lifestyle and their relationships with others.

Skyblue: *'Because I (.), I don't know it make me feel, not strong (.), you know, to pick small thing and do work like that. I just want to lift something and make sure, you're hard, your body is hard enough to do it ...'*

Skyblue: *'I don't want people talking and talking and talking to the next people ... now I look like I am ... (.) I look like I am, person, sick person.'*

Practical issues

Associated with the core category, patients regarded the lines as more convenient and practical for their lifestyle; some perceived the hygiene and care of the line as less arduous than the fistula.

Lifestyle convenience

Individuals made clear distinctions between the convenience of the line compared with a fistula.

Douglas: *'Oh, God, well to me there's ... (2) the advantages, you come in here, you get hooked up, took off, there's no hanging around. The disadvantages [of fistula], er ... (.) when you're took off, you've got to sit there for however long to wait for it to clot or whatever, there's some people sitting there for half an hour, three quarters of an hour (.) and it's still oozing out.'*

Connected with fear and trust, there were worries that a fistula would be harder to care for.

Charlotte: *'I think it would be the care of it ... you've got to take care not to knock it or harm it or injure it and I lead a pretty active life, and I'm thinking oh, no!'*

Hygiene

Connected to the categories of trust/faith and control, some patients believed that their hygiene routines would reduce infection risk.

Marcus: *'People say, yes, you're far more prone to infection ... well, that's for people who mess about. My line never gets touched at all (.), other than here in sterile conditions. I go in the shower, if it gets wet (.), it just dries naturally. I never touch my line ever ... I keep it spotlessly clean. It's cleansed every week here (.),*

dressing changed (.), don't touch it ... I think people probably fiddle and turn and things ... well you just shouldn't do it, end of story.'

Communication

Communication ties in with the core category, where individuals would make sense of interactions based on their own or vicarious experiences. Communication was evident within several sources: healthcare professionals, patients and family/friends.

Healthcare professionals

Patients' decisions to maintain their line were accompanied with perceived support from healthcare professionals.

Douglas: *'Yeah, yeah I discussed it with the nurses here and (.) there's one or two that say, I don't blame you, you know. So ...'*

Some patients evidenced mixed messages from healthcare professionals; linked to trust and control, patients reflected on interactions that endorsed their decision.

Winnie: *'I've seen the consultants here (.)... who is fairly keen that (.) I have a fistula. I said no I didn't want any, fistula (.) because I couldn't see the point of changing something which is working adequately ... So they've sent me back to ... talk to another consultant, who looked at my lines and he said erm, there was no reason to change them, in his opinion I don't think.'*

For some, a lack of communication and information in the early stages was evidenced as a reason for maintaining their line.

Joan: *'Well, they said this [the line] is the first thing that started with (.), put it in because, I didn't know that I was to change it.'*

Others describe a lack of empathy from healthcare professionals when they tried to explain their reasons for refusing a fistula.

Tina: *'I say no (3), but they don't realise, you know, what I mean, what I had to go through.'*

Patients/peers

Beyond observing others' experiences, patients cited being actively deterred from fistulas, following distressing conversations with fellow patients:

Douglas: *'Er (.), there's one or two who have said, "I'll never do this again, never again." If they turn around and tell me it's either a fistula or you're going to die, I'll die.'*

Family/social

Patients' autonomy and anxieties were supported by family input.

Grace: *'Oh yeah my family know all about it. Yeah ... Well they agree with me. I'm the one who's going to feel the pain, not them. They agree with me yeah.'*

Similarly, families reinforced patient views about the appearance of fistulas.

Douglas: *'The wife doesn't want me to have one (.). No way ... Cos of the looks.'*

Discussion

This study qualitatively explored patients' reasons for fistula refusal, highlighting the perceived disadvantages and benefits of VA types for HD and resulting in the development of a theory and model (see Figure 1). The core category, after the proverb in full,²⁵ 'Better the devil you know ... than the devil you don't know', encapsulated the themes within all the model categories and underpinned patients' decisions for fistula refusal. Patients felt that it was better to deal with the line, in spite of its drawbacks, than risk the fistula. This came from patients' first-hand fistula failure or from vicarious observations of their fellow patients and integrated the other six categories of trust, control, fear, appearance, practical issues and communication, illustrated in the model in Figure 1.

The concept of refusing fistulas, based on personal or vicarious experience, supports recent research.^{17,26-28} It has been suggested that patients 'fall in love' with their lines.¹⁵ This study would question whether this is really love of the line or merely avoidance of the perceived alternatives. This position was echoed in recent investigations of VA, where patients' acceptance of the status quo was revealed.¹⁷

Supporting previous research,^{16,17,29} trust was a key theme. Patients demonstrated: trust in their line access; a mistrust in sources of information that were inconsistent with their line preference; broken trust following fistula failure; and faith that despite the risks of infection, patients' lines worked 'just fine' for them, although this may reflect a trust in their own ability to maintain hygiene, evidenced in the link with practical issues. Contrasting with trust, yet interwoven with the concept, patients exerted a sense of control in their choice and autonomy of their right to refuse fistula access. While choice and control are a cornerstone within the NHS,³⁰ deciding on VA is suggested to be autonomous only when individuals have all the information.³¹ As fistula uptake is associated with increased dialysis knowledge,³² interventions could look to increase knowledge using methods that endorse patient choice and control. The concept of control was evident relating to practical issues of VA; patients felt the line offered more control and predictability in terms of lifestyle convenience. Yet in a health setting, patients are actually less empowered to engage in

Patients felt the line offered more control and predictability

self-management while dialysing with a line,³³ contrary to patients' perceived view of control. This study also identified patients' perceptions of the enhanced quality of lifestyle the line offers, opposing research in actual quality of life indicators among the VA modalities.³⁴ Therefore, lifestyle improvements, increased self-management and independence could be angles to consider when communicating the benefits of fistulas.

This study revealed communication as important for patient decision-making, where mixed messages from healthcare professionals added weight to patient beliefs; this is a new finding and adds to the importance of communication and trust already identified.^{16,17} It offers an opportunity to intervene by highlighting staff-training issues; as research suggests, everyone needs to be in accord to ensure credibility for advocating 'fistulas first, lines last'.¹⁴

Patients demonstrated fear and anxiety related to the pain of cannulation, needles, blood and the procedure to create a fistula as disincentives, supporting previous findings.^{15,17,26,27,29} Anxieties about repeated procedures failing are consistent with previous research.²⁸ Opportunities to intervene in future may lie with improving pre-operative techniques to reduce failure,^{7,35} improving the cannulation experience of current patients,²⁹ thereby reducing the vicarious learning involved in anxiety development where possible. Additionally, psychological service collaboration for anxiety, combined with education on needling techniques available to reduce pain³⁶ and appearance-related issues (swelling/bruising)^{37,38} may be beneficial. The concept of anxiety and fistula appearance impacting patients' body image and identity supports previous research.¹⁵⁻¹⁷ It is important to distinguish between the perceived impact of fistulas upon physical body image and on one's identity; Richard and Engebretson¹⁶ refer to

'triple stigma' of VA, based on what patients feel about their own VA, others' VA and how others react to their VA. These earlier findings of internal and external stigma¹⁶ support the appearance category and properties of the model. Previous researchers have questioned whether gender influences the importance of appearance in renal patients;³⁹ this study suggests that body image and appearance matter to both males and females; however, further investigation into the specifics of each category property is warranted.

Conclusions

This study has achieved its aims of exploring line-prevalent patients' reasons for fistula refusal and, in doing so, has created a model which may be applied to patients currently refusing fistula access. It is known that patients with long-term line use are less likely to convert their VA,²⁶ and addressing the issues highlighted in the current study may go some way to reducing the perceived disadvantages

and increasing the incentives for fistula use.

Now the foundations of a model are in place, further research could be conducted to ascertain greater depth and breadth

of the identified categories. Indeed, each category could warrant separate research in its own right. The specific selection of line-prevalent patients refusing fistula access could be viewed as a limitation of the study design. However, further research examining other patient views (that is, new patients refusing fistula access or patients with working fistulas) could be conducted to see how these fit with the identified categories and may be used to augment the model developed here.

Anecdotally, the researchers witnessed the importance of patients feeling able to explain and articulate their motivations for maintaining their lines and refusing fistula access. While this may in part be explained by the interviewer's non-clinical role within the renal service; recognition of patients' individual reasons may increase empathy and help identify potential barriers or facilitators that may engage patients to reconsider their VA options ■

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Declaration of interest

The authors declare no conflicts of interest. The results presented in this paper have not been published previously in whole or part, except in abstract form.

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Key points

- Although an arteriovenous fistula (AVF) offers the most reliable vascular access for haemodialysis (HD), many patients refuse fistula access in preference for a central venous catheter.
- This study interviewed 15 HD patients about their experiences related to their decision to maintain their lines and refuse AVF.
- A model was developed from the six categories identified upon analysing patients' decisions to maintain their line: trust, control, fear, appearance, practical issues and communication.
- By addressing the issues identified, practitioners may be able to reduce perceived disadvantages.

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Book review

Landmark Papers in Nephrology

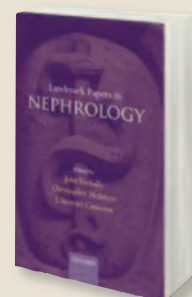
Edited by John Feehally, Christopher McIntyre, J Stewart Cameron. Oxford: Oxford University Press, 2013: 464 pages, £63.00

Owning a copy of this magisterial book is indeed a worthwhile investment. This volume covers 200 abstracts of the seminal papers that have shaped the evolution of nephrology. The accompanying succinct, informative commentaries from leaders in the field critically reflect the impact of each publication. The content ensures a thorough examination of the depth and breadth of nephrology. It succeeds in marrying the background of nephrology with current day understanding and practice with ease.

Divided into 20 chapters, early chapters focus upon the anatomy and physiology of the nephron. This is followed by the investigation of renal disease and the genetic mechanisms that underpin renal pathophysiology. Subsequent chapters investigate the impact of the 1827 observations of Richard Bright on our understanding of glomerular disease. The landmark introduction of the renal biopsy in the 1950s paved the way for the revolution of clinic-pathological diagnosis, classification and treatment of kidney disease. Exploration of infection and diabetes is followed by the clinical classification of acute kidney injury, chronic kidney disease, dialysis and transplantation. The co-morbidities and complications of renal disease are covered in chapters relating to cardiovascular disease, renal anaemia and bone disease. Clinical epidemiology and patient quality of life reflects upon the populations that are affected by renal disease and, conversely, the impact renal disease has upon the life of an individual.

The fluid narration establishes a rapport with the reader from the outset. The crisp, engaging reviews are compelling and the pages turn from cover to cover. The distinguished editorial team has done a superb job. Upon completing the book, one is left with a sense of excitement and two obvious lingering questions – which top ten papers would you choose and why? It opens dialogue for the readers' own selections, and so, the lively debate continues.

Should you buy this book – yes. It shall become a well-thumbed member of your library or a very useful departmental reference. Its comprehensive dissection of nephrology and selected reference papers would well serve as the starting point for journal clubs, presentations, vivas, thesis introductions or grant proposals. Alternatively, with its sleek purple exterior, elegant fonts and delightful prose, it would serve as a noteworthy gift for all nephrology enthusiasts ■



Upon completing the book, one is left with a sense of excitement

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Why are patients disappearing from dietetic services?

'It's like dietitians only see people disappearing on them,' declared a service user during a recent dietetic renal service evaluation, funded by the National Institute of Health Research (NIHR). To clarify, they offered an explanation as to why they feel people do not engage with us healthcare professionals: the delivery of essential dietary information may not be very useful. Describing their experience of receiving advice, one patient proclaimed, 'Have I suddenly become a child, a naughty child? I'm an adult, I make free choices, and I'll deal with them.' This perspective is potentially the tip of an iceberg; each year, non-attendance costs the NHS £360 million¹ and of this, it is not known how much can be attributed to patients' negative perceptions of healthcare professionals.

Evaluating the work of dietitians

Dietitians provide evidence-based services² in an NHS system which seeks to deliver optimum care,³ but also is a system that has been reported as failing to meet patients' and families' healthcare needs.⁴ The Francis report found that healthcare delivery which is not service user-led can lead to catastrophic events, and therefore recommended that future changes to service delivery should be informed by the experiences of service users and their families. But how do dietitians produce an evaluation to improve service quality that is meaningful to patients within the current health service structure?

As a postgraduate student on the NIHR Clinical Academic Training Programme and as a renal dietitian, I have had the opportunity to explore this area and undertake a project in which enlightening responses about the dietetic service have been obtained from service users and their families. This research has helped to develop critical skills of investigation and interpretation, with the aim of solving these issues.

These critical skills have facilitated insights into the service users' world, and thus, have allowed my practice to shift from a biomedical focus towards a more patient-oriented service. This may

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seem challenging, since renal dietetics is driven by biochemistry; it is the nature of this speciality. As healthcare professionals, we know the consequences of uncontrolled potassium levels and have a duty of care to act on our interpretations of results by giving the appropriate dietary advice.⁵ But this biochemical conflict, as experienced by patients, does not need to be difficult to negotiate. Biochemistry still plays an essential part in our practice, but is not the main focus for many individuals. This is reflected in another service user's perspective of receiving advice: *'I don't want to hear about potassium, I don't want to hear about phosphate, I don't want to hear about boiling potatoes twice or thrice and turn[ing] them into pure mush.'*

Hearing and understanding that the service users' agenda was different to the dietetics' biochemical perspective, I have developed my practice to reflect the patient-centred model more prominently. This involves taking the time to investigate and discuss emotions around the practicalities of following a renal diet; for example, taking into consideration a patient's partner's apprehension in preparing the first meal for their spouse upon returning home from hospital, and the perceived difficulties of entertaining guests. Acknowledging and paying attention to these less obvious agendas has helped improve emotional support through the use of empathy and sharing of other patients' experiences. Practically, improvements have also been made by individualising the renal diet for specific occasions and people; for example, grandchildren, close friends and acquaintances. Furthermore, this patient-centred approach has provided personal and professional satisfaction.

How can we change current dietetic services?

The research I undertook highlighted that evaluating a service in order to change practice may be impossible without seeking alternatives. Upon reflection, the standard quantitative service evaluation form may not have fully uncovered the range of experiences these service users were having. Through the employment of qualitative methods, service users and families revealed that they may not engage with the current service because the therapeutic relationship may not be genuinely effective. This has presented a new area for clinical practice investigation to better understand service user engagement. This understanding may lead to more professional accountability as we get a clearer picture of what is important to the people who engage with our services. Encouraging increased reflexivity on current practice will inform evaluations as to whether practice delivers acceptable outcomes to patients. This would consequently present an opportunity to introduce evidence-based changes into practice so it can more accurately reflect service users' values.

But how can you get this in-depth feedback in daily clinical practice? It is certainly challenging. Quantitative Likert-based scales are used as they are easy to administer and are an ethical use of service users' time; they are convenient, satisfy clinical governance and, ultimately, provide timely evidence for commissioners.⁵ However, these therapist-friendly tools do not allow people to express their own experiences of a dietetic service in their own words.

However evaluation is achieved, it is only by deep engagement with both the dietetic and the service users' worlds, and by truly understanding individuals' needs, that services can be both biochemically evidence-based and patient-centred. Maybe then we will see fewer patients potentially disappearing from services to which we devote time and money to develop. More importantly, services have the potential to be enhanced in a way that is deemed accessible and acceptable to patients, thereby increasing our ability to promote better health and well-being ■

Declaration of interest

The author declares that there is no conflict of interest.

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Scottish Government funds Kidney Research UK project

South Asian communities in the west of Scotland are the focus of a new project managed by Kidney Research UK and funded by the Scottish Government. The project is designed to increase the number of potential South Asian organ donors.

The two-year project will help raise awareness and challenge beliefs which act as a barrier to organ donation. In Scotland, less than one per cent of people on the NHS Organ Donor Register are known to be from these communities.

The project will see a network of up to 20 trained outreach workers from South Asian backgrounds, called 'peer educators', speaking to different faith and cultural groups about organ donation in communities across the Greater Glasgow and Clyde area.

The need for organ transplants in South Asian communities is more than three times higher than that of the general public, due to diabetes, kidney disease and cardiovascular disease being more prevalent.

The shortage of donors results in people with a South Asian background waiting much longer for transplants – in the case of kidney transplants, up to twice as long as the rest of the population.

The peer education model, which has been used by Kidney Research UK within similar communities across the UK, has successfully encouraged almost 1,500 people from these groups to join the NHS Organ Donor Register.

Neerja Jain, Project Manager at Kidney Research UK, said:

'We are thrilled to be working with the Scottish Government to raise awareness of organ donation. Kidney failure affects the Asian community up to five times as much as the Caucasian community. A kidney from someone of the same ethnic group is likely to lead to a better matched organ sooner, which is why it's so important to raise awareness of the need for organ donation among these communities.'

Pam Niven, Programme Manager for Organ Donation and Transplantation at the Scottish Government, added:

'Organ donation is often a taboo subject within Black, Asian and Ethnic Minority communities, largely due to misconceptions surrounding the issue. There's a real shortage of compatible donors, but this can be turned around through education and projects like this, which is why I'm urging people from South Asian backgrounds to speak to their peers about organ donation.'

For further information, please contact Neerja Jain at: neerjajain@kidneyresearchuk.org

Details on organ donation and transplantation for Black, Asian and Minority Ethnic (BAME) groups is available at www.organdonationscotland.org



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