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Educating acute dialysis patients – can we do better? $\stackrel{\text{\tiny{$\infty$}}}{=}$

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Introduction

Worldwide, dialysis remains the most widely used form of kidney replacement therapy for chronic kidney disease (CKD) patients. The initiation of chronic dialysis via a planned fashion with organised preparation is viewed as the most beneficial for CKD patients' clinical outcomes.¹⁻⁶ Despite initiatives to ensure this is the case, it is well known that, worldwide, not an unsubstantial number of these CKD patients will need to start dialysis acutely. This is normally referred to as 'crash-landing' on to dialysis or starting in an unplanned fashion. A patient is referred to as having a crash-lander dialysis start when they are referred late to a nephrologist and hence have minimal or no nephrology care prior to starting dialysis.⁷ An unplanned start is when a patient does not start dialysis using their chosen modality, starts dialysis during a hospitalisation or, starts dialysis with a central venous catheter (CVC) as opposed to a permanent access (arteriovenous fistula (AVF), arteriovenous graft (AVG), or peritoneal dialysis catheter).⁸ In the UK, late presentation (dialysis initiation within 90 days of seeing a Nephrologist) occurred in 16.3% of the dialysis starts in 2019-2020 but this varied between 6.1% and 32.8% depending on the dialysis centre in question.⁹ Reasons to crash land to dialysis or start in an unplanned fashion are manifold, and include lack of appropriate identification, timely referral to Nephology from primary care, acute and unforeseeable renal decline amongst other factors.10,11

Most of these patients will be initiated on, and remain on intermittent in-centre or satellite haemodialysis for speed of access, ease of modality and convenience. The timely placement of an alternative access or modality is often not planned during the in-patient admission; with the result that these patients are discharged home to dialyse in the community with tunnelled dialysis CVC as vascular access.^{8,9} This increases the risk of infections and is associated with worse patient survival.¹² Data supports that the introduction of an education programme may allow more of this cohort chose an independent form of renal replacement therapy (RRT) similar to those in the planned dialysis start population.^{13,14}

Literature on education provision in acute dialysis demonstrates that comprehensive and tailored education delivery is possible but not widespread in use.^{13,14} The literature in this area is lacking, due to a combination of there being no guidelines, associated with the limitations on time and resources. Patients' are often unwell during this period, which means that the priority is to medically stabilise and an on-going plan for education and empowerment is often overlooked.

We wished to review our acute start population to look the dialysis modality education provision after starting dialysis, long term modality choice and outcomes and compare these with a group who started on dialysis in a planned manner in the same time period to assess for significant differences in outcome and to identify areas for improvement.

Methods

We conducted a comprehensive retrospective observational study at our busy secondary care centre in the UK, covering a substantial 64month period from January 2016 to April 2021. The study aimed to compare two groups of patients: those who initiated acute start dialysis during their hospital admission, including patients previously known to the Advanced Kidney Care (AKC) service but not initially planned for dialysis, and those who initiated dialysis after receiving modality choice education within the same time frame.

Data for the study was sourced from various sources, including an electronic patient database called PROTONTM, hospital discharge summaries and clinic letters. We gathered essential information related to patient education, the chosen on-going dialysis modality, renal recovery and mortality outcomes for a period of 12 months following dialysis initiation. Patient depravation was calculated from their registered address post code according to the English indices of deprivation data 2019. This was analysed with an unpaired t-test to compare the acute start group (ASG) and planned start group (PSG). The 'index of multiple deprivation' encompasses a combination of income, employment, education, health, living environment, barriers to housing and services and crime measurements. Decile 1 represents the most deprived 10% of areas nationally.¹⁵

We employed Microsoft Excel for data collection and analysis. By utilising a retrospective approach and accessing comprehensive patient

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records from multiple sources, we aimed to gain a comprehensive understanding of the two patient groups and assessed the outcomes associated with different dialysis initiation strategies. Statistical analysis between the outcomes of the ASG and PSG were carried out using a chi-square test, with *p* values less or equal to 0.05 considered statistically significant. The inclusion of patients known to the AKC service but initially not planned for dialysis allowed us to examine the impact of early dialysis initiation on patient outcomes, comparing it with the outcomes of patients who received modality choice education before starting dialysis.

The extensive time span covered by our study provides a robust basis for analysis, taking into account variations in treatment practices and advancements in medical care over the 64-month period. This study's findings could potentially shed light on the effectiveness of different dialysis initiation approaches and contribute valuable insights to kidney care practices and patient outcomes.

Results

556 patients required acute dialysis in the study period, median age 70 (range 16–96). These patients were referred from the GP or through the hospital pathway after presentation to accident and emergency. 102 (18%) continued to require dialysis on discharge. All of the 102 patients were started on HD, 5 using a pre-existing arteriovenous fistula (AVF) and the remaining *via* a central venous catheter (CVC). 2 patients were

awaiting fistula formation and 1 had a fistula awaiting maturation. 7 patients had previously opted for peritoneal dialysis (PD) but had no PD access and 1 patient had previously opted for conservative management. 12 (12%) patients had a PD catheter inserted during their admission, 11 of those continued on PD, 1 did not tolerate this and was discharged with a tunnelled haemodialysis line.

Of the 102 who acutely started and remained dialysis dependant, 16 (16%) were previously known to AKC. 30 (29%) patients were known to our renal department but did not have immediate plans for renal replacement therapy. 33 (32%) were not known to us but had pre-existing kidney disease. 23 (23%) were not known to us and were not documented to have pre-existing kidney disease.

The documentation regarding dialysis modality education was unclear based on the information available to us. We estimated that a third of patients who remained dialysis dependant did not have any form of formal education by one year post dialysis initiation.

In the same 64-month period, 485 patients were initiated on dialysis following formal education in a planned outpatient fashion. The median age of this group was 64 (range 18–93). Of those, 266 (55%) were started on in-centre haemodialysis (ICHD) and the remaining 219 (45%) on PD.

Patient demographic data, underlying renal disease, along with their modality at initiation, 90 days and 1 year are shown on Table 1 and Fig. 1. There was no statistical significant difference between the ASG

Table 1

Patient demographics and renal replacement modality and mortality at initiation, 90 days and 1 year.

| | | Acute starts (%) n=102 | Planned starts (%) n=485 | Hazard ratio (95% confidence interval) |
|--------------------------|-------------------------------|------------------------|--------------------------|--|
| Age | Median | 70 | 64 | 1.06 (1.05–1.07) |
| | Range | 16–96 | 18–93 | |
| Ethnicity | Afro Caribbean | 8 (8%) | 59 (12%) | 0.49 (0.29-0.84) |
| | European | 71 (70%) | 273 (56%) | Reference |
| | South Asian | 23 (23%) | 144 (30%) | 0.74 (0.52-1.06) |
| | East Asian | 0 | 9 (2%) | 1.13 (0.22-5.76) |
| Deprivation decile | Index of Multiple Deprivation | 2.5 | 3.5 | 0.88 (0.66-1.17) |
| | Employment | 2.5 | 3.5 | 0.91 (0.73-1.12) |
| | Education and Skills | 2.5 | 4 | 1.00 (0.87-1.14) |
| | Health and Disability | 3 | 3.5 | 1.12 (0.95–1.31) |
| Underlying renal disease | Diabetic nephropathy | 17 (17%) | 169 (35%) | |
| | Hypertensive disease | 7 (7%) | 48 (10%) | |
| | Obstructive | 3 (3%) | 27 (6%) | |
| | Tubulointerstitial nephritis | 0 | 4 (1%) | |
| | Myeloma kidney | 3 (3%) | 3 (1%) | |
| | Adult polycystic kidney | 2 (2%) | 14 (3%) | |
| | disease | | | |
| | Renal artery stenosis | 0 | 8 (2%) | |
| | Cardiorenal syndrome | 2 (2%) | 4 (1%) | |
| | IgA nephropathy | 8 (8%) | 17 (4%) | |
| | Other glomerulonephritides | 14 (14%) | 43 (9%) | |
| | Other diagnosis | 8 (8%) | 29 (6%) | |
| | No documented diagnosis | 40 (39%) | 120 (25%) | |
| Day 1 | ICHD via temporary line | 97 (95%) | 0 | |
| | ICHD via tunnelled line | 0 | 92 (19%) | |
| | ICHD via AVF or graft | 5 (5%) | 172 (35%) | |
| | HHD | 0 | 2 (<1%) | |
| | PD | 0 | 219 (45%) | |
| Day 90 | ICHD via tunnelled line | 58 (55%) | 76 (16%) | |
| | ICHD via AVF or graft | 14 (14%) | 187 (39%) | |
| | HHD | 1 (1%) | 0 | |
| | PD | 18 (18%) | 216 (45%) | |
| | Died | 8 (8%) | 2 (<1%) | |
| | Recovered | 3 (3%) | 0 | |
| | Lost to follow up | 0 | 4 (1%) | |
| | Transplanted | 0 | 0 | |
| 1 year | ICHD via tunnelled line | 13 (13%) | 36 (7%) | |
| | ICHD via AVF or graft | 44 (43%) | 191 (40%) | |
| | HHD | 1 (1%) | 8 (2%) | |
| | PD | 12 (12%) | 159 (33%) | |
| | Died | 24 (24%) | 60 (12%) | |
| | Recovered | 7 (7%) | 2 (<1%) | |
| | Lost to follow up | 1 (1%) | 18 (4%) | |
| | Transplanted | 0 | 11 (2%) | |
| | ransplaitteu | 0 | 11 (270) | |

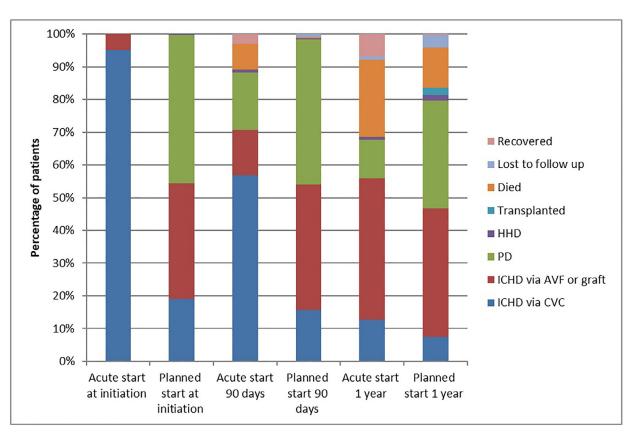


Fig. 1. Dialysis modality at initiation, 90 days and 1 year.

and PSG for any measurements of deprivation, with p = 0.36 for index of multiple deprivation.

There is a statistically significantly higher number of patients initiated on home dialysis modalities (home haemodialysis (HHD) and PD) in the PSG when compared to the ASG, both at 90 days and 1 year (both p < 0.001). There is also a significantly higher number of deaths in the ASG at 90 days and 1 year (p < 0.001 and p = 0.007, respectively).

Out of the total 587 patient initiated on chronic dialysis, 219 (37%) were initiated on PD and the remainder on ICHD. The outcome of all patients at one year by modality of dialysis at initiation is displayed in Fig. 2. The Kaplan–Meier survival curve demonstrates the mortality between the ASG and PSG is shown in Fig. 3.

Discussion

Our study population has a higher number of Asian and Afro-Caribbean patients as compared to the rest of England (73% White, 14.9% Asian and 8.5% Black).⁹ The median age of our population is comparable with the national average (65 vs. 64 years).

Similar to other studies, our acute start on dialysis population received limited education on dialysis modality, even up to one year post initiation of dialysis.⁶ There are many reasons for this which includes a lack of insight as to when someone will need dialysis, lack of financial and staffing resources. The acute start patients are also at a stressful and vulnerable point in their kidney failure journey, many often critically unwell, limiting their capacity and understanding of the situation and making dialysis education more challenging.

100% of our acute start patients started ICHD, as opposed to 54% starting ICHD in the planned start population within the same time period. The acute start patients continued to represent a high number of ICHD at 90 days and one year, with lower rates of HHD, PD and transplantation. These results are on par with other studies worldwide, where 86 to 100% of acute start dialysis patients start on and remain with

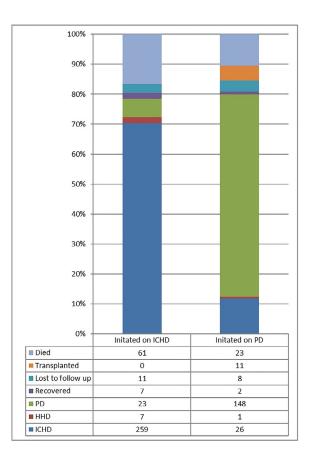


Fig. 2. Outcomes of maintenance dialysis population at one year divided by modality at initiation.

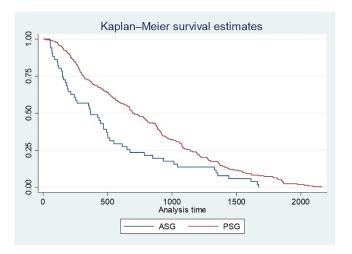


Fig. 3. Kaplan-Meier survival curve between ASG and PSG.

ICHD.^{13,16,17} This is a significantly higher figure when compared to 71.6% starting ICHD out of all the all dialysis start patients for 2020 in the UK.⁹

Studies have demonstrated a significant decrease in the use of ICHD following the initiation of education programme for this patient population. $^{13,16-18}$ Following formal education, 21–58% of acute start dialysis patients chose PD, 10% –24% home HD, 33–58% ICHD. Patients were 4 times more likely to switch to an independent RRT modality as a result. 13,14,17,19,20

There is also an increased use of tunnelled line access in the acute starts population, both at initiation but also at 90 days and one year. Our results are comparable with the national survey where 87.4% of late-presenters were initiated on renal replacement therapy *via* a line, compared to 41.5% in the planned start population.⁹

The mortality rate at one year in the acute start dialysis population was 24%, which was statistically significantly higher than the 12% in the planned starts population.

Due to this being a retrospective observational study, it has a higher risk of bias and confounding variables. The cause for the increased mortality in the ASG is likely multifactorial, contributed to, no doubt by the increase in dialysis line use, reduced number of transplants in this population and compounded by the general frailty and older age of the acute dialysis start group.

Another limitation of this study is that the data is collected from electronic records, which were inputted by clinicians at the time of the event. As the data collection is retrospective, the results of this paper rely on the accuracy and reliability of the previously recorded information. Data particularly regarding dialysis education may not be inputted or inputted incorrectly hence creating a falsely low result.

There are few comparable decisions in the treatment of chronic diseases that have such a profound and lasting impact on patients' everyday lives as the choice of dialysis modality. Providing education for the acute dialysis starts is feasible and crucial in promoting patient autonomy. Research on the utilisation of formal education for acute dialysis starts have described a holistic education pathway with multimedia provision of information and interactive experiences. Motivational interviewing techniques and individual counselling skills are used to explore patient's

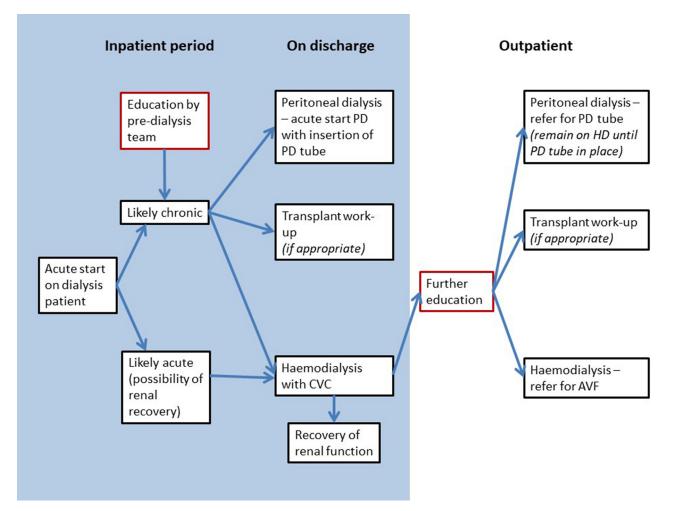


Fig. 4. Education pathway for acute start patients.

priorities and wishes. Decision aids such as the Ottawa decision support tool are useful to support patients' decision making. Family and a support network are of utmost importance and should be involved early in the education process.^{13,17} The education material should include booklets, flipcharts, manuals, videos and photographs.^{7,16,19,20} Demonstration of dialysis modalities and physical tours of the facilities have also been shown to be helpful.^{19,20} Some centres have organised for patients to meet up with those established on various dialysis modalities, as well as group sessions for peer support.^{13,18} All published studies in this area have involved the one or a group of trained specialist nurses as the lead educators. They provided information over a period of usually three to five sessions; with one study having a median education time was 5.6 h (IQR 1.5–9.2 h) over the median of 8 visits per patient.^{13,18,20}

Following the review of our service for educating patients acutely started on dialysis, we plan to form an agreed pathway for education provision to ensure all patients receive standardised information in a timely manner. Education for the inpatients have previously been responsible solely by the AKC team, however due to the increased workload for these specialised nurses, the responsibility of education on the wards would be delegated to the ward doctors and nurses. This will also improve communication as there would be established understanding and rapport between the staff with the patient and their families during the admission.

Standardised inpatient education provision requires a multidisciplinary team approach, with support from the vascular access team to facilitate early access formation such as inpatient peritoneal dialysis catheter insertion and referral for fistula or graft formation for those choosing HD. Fig. 4 highlights the importance of patient education at all stages and the need for early consideration of PD, definitive access and referral for transplantation.

All clinical staff need to be aware of the importance of education and clear documentation of information provided. An important issue highlighted by this research is the lack of clear documentation of education provision for the acute start dialysis patients. Review of the coding for education outcomes will help us to better identify those needing further support and education follow up.

Conclusion

In conclusion, our study highlights the importance of education provision for acute dialysis patients and the impact it can have on their modality choice and outcomes. Acute dialysis initiation, often referred to as 'crash-landing,' remains a significant issue despite efforts to promote planned dialysis starts with organised preparation. Lack of timely identification, referral to nephrology and unforeseeable renal decline contribute to the need for acute dialysis initiation.

Our findings show that the majority of acute start patients were initiated on ICHD and continued with this modality at 90 days and one year, with lower rates of HHD, PD and transplantation. In contrast, the PSG had a higher proportion of patients choosing home dialysis modalities (HHD and PD) at 90 days and one year. Furthermore, acute start patients had a significantly higher mortality rate at one year compared to the planned start group.

Education plays a pivotal role in promoting patient autonomy and empowering them to make informed decisions about their dialysis modality. Our study highlights the need for comprehensive and tailored education delivery for acute dialysis patients. While the literature in this area is lacking, evidence from other studies demonstrates that a formal education program can lead to a higher percentage of acute start patients choosing independent RRT modalities.

To address the educational needs of acute dialysis patients, we propose the implementation of a standardised education pathway involving a multidisciplinary team approach. Clear documentation of education provision is crucial to identify patients needing further support and follow-up. The involvement of specialised nurses, vascular access teams, and other clinical staff will ensure timely access formation and improve communication with patients and their families during the admission period. Overall, our study underscores the significance of education in improving outcomes for acute dialysis patients and highlights the necessity for establishing comprehensive education programs as a standard practice. By providing patients with the necessary knowledge and support, we can enhance their ability to make well-informed decisions about their dialysis modality, leading to better long-term outcomes and quality of life.

Summary box

What is known

The initiation of chronic dialysis *via* a planned fashion with organised preparation is viewed as the most beneficial for patients' clinical outcomes. In the UK, late presentation occurred in 16.3% of the dialysis starts in 2019–2020, with significant variation between centres. Most patients will be initiated and remain on intermittent in-centre or satellite haemodialysis (ICHD) *via* a central venous catheter (CVC) for speed of access, ease and convenience. This increases the risk of infections and is associated with worse patient survival.

Comprehensive and tailored education delivery in this population is possible, but often not available. The introduction of an education programme has been shown to increase the number of patients on an independent dialysis modality to those similar in the planned dialysis start population.

What is the question

To review our acute start population to look at dialysis modality education provision after starting dialysis, long term modality choice and outcomes. Compare the results with those who started on dialysis in a planned manner to assess for significant differences in outcome and to identify areas for improvement.

What was found

102 acute start dialysis patients identified in this time period, all were initially started on haemodialysis (HD). Documentation and records keeping was poor for dialysis education. We estimated that a third of patients who remained dialysis dependant did not have any form of formal education.

During the same time period, 485 patients were initiated on dialysis following education in a planned outpatient basis. There was a statistically significantly higher number of patients initiated on home haemodialysis and PD in the PSG when compared to the ASG, both at 90 days and 1 year (p < 0.001). There is a higher number of deaths in the ASG at 90 days and 1 year (p < 0.001 and p = 0.007, respectively).

What is the implication for practice now

There are only a few comparable decisions in the treatment of chronic diseases that have such a profound impact on patients' everyday lives as the choice of dialysis modality. We plan to introduce structured education pathway for our acute dialysis starts by utilising the multidisciplinary team to aid information provision, vascular access nurses to support inpatient PD catheter insertion and early referral for arteriovenous fistula or graft formation. We have raised awareness regarding the importance of education and clear documentation with our clinical staff. We aim of empowerment and enhancement of patient choice towards a home dialysis modality.

Declaration of competing interest

No funding was required for this research.

CRediT authorship contribution statement

Yimeng Zhang: Data curation, Formal analysis, Writing – original draft. **Jyoti Baharani:** Supervision, Writing – review & editing.

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