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What are the factors that determine treatment choices in patients with kidney failure: a retrospective cohort study using data linkage of routinely collected data in Wales

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ABSTRACT

Objectives To identify the factors that determine treatment choices following pre-dialysis education.

Design Retrospective cohort study using data linkage with univariate and multivariate analyses using linked data.

Setting Secondary care National Health Service Wales healthcare system.

Participants All people in Wales over 18 years diagnosed with established kidney disease, who received pre-dialysis education between 1 January 2016 and 12 December 2018.

Main outcome measures Patient choice of dialysis modality and any kidney replacement therapy started.

Results Mean age was 67 years; n=1207 (60%) were male, n=878 (53%) had ≥3 comorbidities, n=805 (66%) had mobility problems, n=700 (57%) had pain symptoms, n=641 (52%) had anxiety or were depressed, n=1052 (61.6%) lived less than 30 min from their treatment centre, n=619 (50%) were on a spectrum of frail to extremely vulnerable. n=424 (25%) chose home dialysis, n=552 (32%) chose hospital-based dialysis, n=109 (6%) chose transplantation, n=231 (14%) chose maximum conservative management and n=391 (23%) were 'undecided'. Main reasons for not choosing home dialysis were lack of motivation/low confidence in capacity to self-administer treatment, lack of home support and unsuitable housing. Patients who choose home dialysis were younger, had lower comorbidities, lower frailty and higher quality of life scores. Multivariate analysis found that age and frailty were predictors of choice, but we did not find any other demographic associations. Of patients who initially chose home dialysis, only n=150 (54%) started on home dialysis.

Conclusion There is room for improvement in current pre-dialysis treatment pathways. Many patients remain undecided about dialysis choice, and others who may have chosen home dialysis are still likely to start on unit haemodialysis.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ National evaluation using routinely collected renal patient electronic record that is unique to Wales.
⇒ Anonymised data linkage enabled analysis of factors that determine treatment choices.
⇒ Outcomes are contextualised with evidence from the qualitative and economic components of a national evaluation of the factors that create barriers to home dialysis from the multiple perspectives including patients, professionals and health system.
⇒ Outcomes may not be applicable to substantially different healthcare systems.
⇒ Wales has a predominately white population, and a lack of ethnic minority perspectives is a noted gap.

INTRODUCTION

Chronic kidney disease (CKD) is common, thought to affect up to 3 million people in the UK.[1] Patients with CKD or reaching the stage of kidney failure must choose between a number of different treatments including dialysis, transplant or a more palliative approach termed maximum conservative management (MCM). Two forms of dialysis are currently offered to patients, haemodialysis (HD) and peritoneal dialysis (PD).

During HD, the patient's blood is pumped through a dialysis filter which removes toxins and excess fluid. While most patients attend an outpatient dialysis centre for unit HD (UHD), some patients undertake home HD (HHD). PD is another form of dialysis that patients undertake at home. During PD, dialysis fluid is instilled into the abdomen via a plastic tube and is left to dwell for 4–6 hours. During this time, toxins diffuse into the dialysis fluid which is drained, discarded and replaced by fresh fluid in a continuous process. As compared with home dialysis (HHD, PD), UHD is associated with the lowest quality of life, the highest mortality and the highest cost of treatment.[2–9]

Kidney centres across Wales have introduced multidisciplinary pre-dialysis education

programmes to engage patients in shared decision-making about the type of treatment based on Elwyn *et al*'s three-talk model of choice, option and decisions.[10] Although pre-dialysis education has undoubtedly improved the shared decision-making process, UHD remains the most common start modality for patients. This is surprising when we consider that for many patients, home dialysis may be more appropriate in terms of outcomes.

There are several clinical and sociodemographic factors which may influence choice of treatment. Aside from individual patient values and preferences, these factors are likely to include comorbid disease burden, frailty, socioeconomic deprivation and distance from the dialysis units. Thus far, there is a paucity of data in 'pre-dialysis' patients, exploring how these factors are linked to treatment choice. The aim of the current study was to develop a better understanding of how clinical and sociodemographic factors determine which treatments are discussed and subsequently chosen across Wales. Taken together with a qualitative study examining patient preferences and values,[11] this quantitative analysis will inform future service redesign, so that patients are better supported to choose the therapy that best matches their preferences and values.

METHODS

Study design

We used a retrospective cohort design created through linkage of routine clinical data collected at the time of pre-dialysis education linked with datasets held in the Secure Anonymised Information Linkage (SAIL) databank in Swansea University.[12]

Setting

Adult patients residing in Wales who have progressive kidney impairment routinely undergo nurse-led pre-dialysis education. The types of education materials provided and usual processes in each of the participating centres have been reported elsewhere.[13] The available treatments are listed in box 1.

Box 1 Summary list of available kidney replacement therapies in Wales*

1. Unit haemodialysis (this can either be based in a hospital or a standalone unit operated by a third-party dialysis unit provider that may be physically located on or off a hospital site)
2. Home-based dialysis
   - Peritoneal dialysis
   - Home haemodialysis
3. Maximum conservative management
4. Kidney transplant
   - Pre-emptive transplant (transplant procedure undertaken prior to dialysis being required)
   - Transplant preceded by dialysis while awaiting donor kidney (dialysis can be unit or home based)

*Depending on clinical suitability, not all options will be available to every patient.

Data sources

Our study included structured clinical data that are collected in a standardised form held in the renal electronic patient record (Vitaldata, Vitalpulse UK) used for patients with progressive kidney disease or requiring kidney replacement therapy (KRT) which covers 97.5% of dialysis for an adult population of 2.5 million.[14] We did not include the small number of patients who are residents in Wales and attend National Health Service (NHS) England renal units. Example of screenshots of a typical pre-dialysis education session as recorded in the electronic patient record can be found in online supplemental figures 1 and 2.

An extract of the data from the renal electronic patient record, with free text removed to prevent re-identification of the patient, was sent to the NHS Wales Informatics Service who pseudo-anonymised the data allowing linkage within SAIL.

The SAIL databank holds a range of anonymised person-based datasets for the population of Wales. These are linked to the kidney patient data using a pseudo-anonymised linkage field. SAIL uses a combination of deterministic and probabilistic matching. Records are first matched on a deterministic basis using NHS number followed by name, surname, date of birth, sex and finally postcode. Any unmatched records are subject to probabilistic matching.[15–17]

Linkage was not possible either where a demographic match could not be obtained, or data coverage was not available. Data coverage was not available for patients who lived or who may have moved outside of Wales during follow-up, or whose general practitioner was not a participant in the SAIL database. Datasets include PEDW (Patient Episode Database for Wales), a dataset that holds administrative data describing hospitalisation episodes in NHS Wales along with ICD-10 (International Classification of Diseases 10th Revision)[18] codes classifying the episodes. The primary care dataset contains Read[19] coding of patient diagnoses, observations and medications for participating general practices in Wales. A comorbidity score was derived, without limiting the duration of lookback period, from these data using established methods.[20 21] The Welsh Demographic Service records details of patient demographics including the date of death.

Study cohort

All adults who underwent pre-dialysis education under the care of the adult renal units of NHS Wales between 1 January 2016 and 12 December 2018. The time frame was chosen to maximise good coverage of linked data. Where patients underwent more than one episode of education, we only considered the first session.

Variables

We calculated patient age on the day of pre-dialysis education. We extracted height and weight from either

the primary care record or the renal electronic patient record choosing the value immediately prior to the pre-dialysis education date. Where possible, we calculated body mass index (BMI).

We recorded if home dialysis modalities and MCM care were discussed with the patient, and if not, why not. We assumed that in all patients, UHD had been discussed. We recorded if a patient had reached a decision regarding choice of dialysis modality or opting for MCM. As patients may choose a mode of dialysis and a simultaneous desire for a kidney transplant, we only recorded the primary choice as transplant if a patient had a living donor with an expectation of successful transplant before reaching established kidney failure or if the patient would only accept a transplant as the form of KRT.

We calculated the estimated glomerular filtration from serum creatinine values stored in the electronic patient record using the Modification of Diet in Renal Disease study formula[22] including variables for age, sex and ethnicity. We chose the value prior to the pre-dialysis education date as baseline. We did not calculate estimated glomerular filtration rate (eGFR) if a patient was on KRT at the time of pre-dialysis education. We classified CKD severity into stages where 1 is least severe and stage 5 is most severe.[23]

We calculated a comorbidity score by linkage to the PEDW database. We selected episodes occurring at any time prior to the pre-dialysis education date. We searched for associated ICD-10 codes that would map to each component of the Charlson Comorbidity Index,[24] counting at most one diagnosis within each category. A score of 0 would suggest there were no comorbidities in addition to CKD.

We calculated the number of whole days a patient had been an inpatient in the year prior to the pre-dialysis education using the PEDW dataset.

Patient-reported outcome measures were recorded at the time of pre-dialysis education using the EQ-5D-5L questionnaire and Visual Analogue Scale (VAS) of self-rated health administered by the renal specialist nurse. We used a crosswalk value set using published methods[25–27] and a UK-specific reference set to obtain an index value of between 1 suggesting perfect health and −0.594 suggesting poorest possible health. The VAS score ranged from 100 being 'the best health you can imagine' to 0 'the worst health you can imagine'. The EQ-5D-5L set was used under licence number 36706.

A Clinical Frailty Score was collected using the Rockwood score[28] which uses an ordinal scale ranging between very fit (1) and terminally ill (9).

The travelling time to the nearest tertiary renal centre was calculated by estimating the driving time in a car using a typical route allowing for traffic conditions between the postcode of the patient's home and the closest renal unit using the Google Maps API.[29] This was based on a journey commencing on a nominal date of 13 July 2020 at 07:30 from the patient's home.

The Welsh Index of Multiple Deprivation (WIMD)[30] is the official measure of deprivation of the Welsh Government. The population of Wales is divided into lower-layer super output areas each representing around 1500 people. We linked to this database using the 2014 release (the current release for the cohort studied) and the patient home address at the time of the pre-dialysis education. A value of 1 is most deprived and 1909 least deprived.

Follow-up and outcomes

The primary outcomes were patient survival at 1 year and overall, and kidney disease progression. Kidney disease progression was considered a composite of either requiring KRT or reaching an eGFR of under 8 mL/min. We followed patients up until a set date determined by coverage by linked data; this resulted in a median follow-up of 1144 days (IQR 882–1380) for each patient from the date of their first pre-dialysis education session.

Statistical methods

Analysis was performed using IBM SPSS Statistics V.26 using the SAIL data safe remote access software. We calculated summary statistics such as mean and measures of dispersion such as SD.

To simplify statistical analysis, we transformed or simplified a number of variables for the purposes of statistical analysis or ease of interpretation for calculated ORs. We transformed age to decade of life and BMI per 5 units. We dichotomised quality of life score around the median. We also dichotomised the variables for frailty score, comorbidity score and degree of hospitalisation into two groups. We encountered some missing data, and only analysed on the basis of a complete case analysis. We explored association between candidate predictors using univariate regression. If no correlation was present at p value significance of <0.05 threshold, we did not enter the value into a multiple regression analysis. We used logistic regression to determine ORs. We took a p value of <0.05 to be statistically significant. We used likelihood ratios to evaluate models of multiple regression using a forward selection process.

To prevent re-identification of pseudo-anonymised patients, in line with the SAIL agreement,[12] if a cell in a table contains data on less than five individuals, the value is obfuscated by changing the value from its absolute value to the value of <5.

Patient survival was calculated at 1 year following pre-dialysis education as the proportion of patients still alive. No correction was made for age or comorbidity.

Patient and public involvement

The study presented in this paper is derived from a workstream that was part of a national evaluation to investigate the factors influencing patient choice. Additional workstreams included a qualitative study with patients and healthcare professionals[31] and health economic evaluation of costs. [32] The overall evaluation and workstreams

were designed as a co-productive study. We report on the specific elements of the co-production elsewhere[13] and describe the co-productive methods including patient and public involvement in the published protocol.[11] In this retrospective analysis of routinely collected linked data, patients and the public were involved in setting and refining the research questions, interpreting the results to specific contexts, dissemination of outcomes to multiple audiences and reviewing drafts of the paper.

We worked with both the commissioners of kidney services in Wales, the Welsh Renal Clinical Network, third-sector charity partners which currently support patients in Wales and patients living with kidney disease who have made decisions about treatment options and who have experience all of the options available for KRT in Wales.

RESULTS

The total number of patients was 1707 and the mean number of education sessions was 1.13 (SD 0.40) per patient.

We linked the data to the PEDW and the primary care dataset for 96% and 89% of patients, respectively.

Patient characteristics

Details of the patient characteristics at the time of the pre-dialysis education can be found in online supplemental table 1. The majority of patients were at CKD stage 4 or severe reduction in kidney function. 60% of patients were male and the mean age was 67 years; these values are consistent with values described in the UK national registry data for patients who start KRT.[33]

A higher proportion of patients were living in areas of more deprivation, with 21.8% living in the most deprived quintile compared with 16.6% living in the least deprived. Only 7.9% of patients had no additional comorbid condition, in addition to CKD, with 14.4% having five or more additional comorbidities.

Patients reported problems with quality of life, in particular 65.6% of patients reporting problems with mobility, 35% reporting problems with self-care, 62% of patients reporting problems with their usual activities (eg, work, study, housework, family or leisure activities), 57% of patients reporting problems with pain or discomfort, and 52% of patients reporting problems with anxiety or depression.

Patient choice

The majority of patients (552 of 1707 (32%)) chose UHD, followed by PD (356 of 1707 (21%)), MCM (231 of 1707 (14%)) and HHD (68 of 1707 (4%)). 23% of patients were undecided at the first pre-dialysis education session, of which 17% went on to have a further dialysis education session.

Patients who chose MCM tended to be older (82.8 years), have a higher median frailty score (4) and have more days of hospitalisation than patients who chose home dialysis or transplantation.

Patients who chose UHD tended to be older, have more comorbid disease and hospitalisation rates than patients who opted for home dialysis or transplantation.

Patient discussion

Online supplemental table 2 shows which modalities were discussed at the time of pre-dialysis education and values of the factors associated with the patient groups where this was recorded. HHD was discussed with 945 of 1441 (66%) of patients, PD with 1078 of 1454 (74%), transplant 588 of 1454 (41%) and MCM 735 of 1462 (50%) patients. Patients who had a discussion that involved HHD, PD or transplant had a lower mean age than patients who did not include these treatments in the discussion. The patient group who had a discussion that involved MCM were older than patients who did not have this modality discussed with them. The likelihood that the various options were discussed did not appear to be influenced by patient gender, travelling time to the unit, deprivation, BMI or eGFR. There appeared to be more chance that MCM was discussed, or home dialysis options not discussed where the EQ-5D or VAS score was lower or there were more comorbidities or inpatient hospitalisation days.

Details of discussion for patients who did not opt for PD

To explore detail of patient treatment choice, we investigated the 1351 patients who did not choose PD. In this group, we explored details of the discussion in 1134 (84%) of patients where a coded record of the discussion had been made with detail to be found in table 1.

The main reason patients did not choose PD was lack of motivation (12%) and the main reason clinicians did not discuss it was a perception that the patient would not be physically able to do it (32%). Of the 371 patients who did not choose PD, but thought PD was a viable option, 58 of 371 (16%) chose transplant, 35 of 371 (9%) chose UHD, 15 (4%) HHD, 7 (2%) MCM and the majority (256 (69%)) were undecided.

Details of discussion for patients who did not opt for HHD

1639 patients who did not opt for HHD had a coded record of the pre-dialysis education discussion on 1382 (84%) occasions. Details of the reasons clinicians did not discuss home dialysis or patients did not choose home dialysis can be found in table 1.

The main reason patients did not choose HHD was again lack of motivation (8%) and the main reason clinicians did not discuss it was that the patient was deemed medically unsuitable (37%). Of the 451 patients who thought HHD was viable, but did not choose it, 151 (38%) chose PD, 80 (18%) UHD, <50 (<11%) transplant, <5 (<1%) MCM and the majority (170 (38%)) were undecided.

Multivariate analysis of predictors of discussion

A multivariate analysis was undertaken and is summarised in table 2. This suggested patients who were older were 28% less likely (per decade) to have a discussion that included HHD, 33% less likely to discuss PD or 70% less

Table 1 Details of discussions in the group of patients who did not choose home dialysis with details of reason for patient choice where discussed or reason for non-discussion by clinician during pre-dialysis education

For patients who did not choose PD with a coded reason record, n=1134	
Did discuss PD, n=760 (67%) **Patient reasons for not choosing PD**	**Did not discuss PD, n=374 (33%)** **Clinician reasons for not discussing**
Lack of motivation to self-care 12% Lack of carer 4% Concerns over body image 3% Lack of confidence 2% High BMI 2% Adverse experiences self/family/friends 1% Other reasons 28%	Not physically able 32% Previous abdominal surgery 25% High BMI 14% Other reasons 29%
For patients who did not choose HHD with a coded reason record, n=1382	
Did discuss HHD, 886/1382 (64%) **Patient reasons for not choosing HHD**	**Did not discuss HHD, 496/1382 (36%)** **Clinician reasons for not discussing**
Lack of motivation to self-care 8% Lack of confidence 4% Adverse experiences self/family/friends <1% Other reasons 36%	Medically unsuitable 37% Lack of carer 18% Unsuitable accommodation 14% Not physically able <6% Problematic vascular access <1% Other reasons 26%

Some percentages are marked <x% where the information governance agreement prevented us from reporting small values.
BMI, body mass index; HHD, home haemodialysis; PD, peritoneal dialysis.

likely to have transplantation discussed with them. Older patients were 119% more likely to have MCM discussed by their clinical team for each decade increase in age.

Patients with higher BMI (per 5 units) were less likely to have PD (17%) or MCM (19%) discussed. Patients with a higher comorbidity score were 52% less likely to have transplantation discussed (when comparing patients with ≥3vs 0–2 comorbidities). Patients with more episodes of hospitalisation were 54% less likely to have transplantation discussed but 52% more likely to have received a discussion including MCM. Patients with EQ-5D quality of life score greater than median were 62% more likely to have PD discussed. Patients with higher grades of frailty were 44% less likely to have PD, 49% less likely to have a discussion of HHD or 63% less likely to have transplant discussed but more than 164% more likely to have MCM discussed.

Table 2 Multivariate analysis of factors associated with chance that dialysis modality discussed with patient during pre-dialysis education

	Was HHD discussed? n=638	**Was PD discussed? n=646**	**Was transplant discussed? n=750**	**Was MCM discussed? n=639**
Variables (reference category)	**OR**	**OR**	**OR**	**OR**
Age (per decade)	0.72 (0.64 to 0.81) p<0.001	0.67 (0.57 to 0.78) p<0.001	0.30 (0.25 to 0.37) p<0.001	2.19 (1.86 to 2.57) p<0.001
Body mass index, mean (per 5 units)		0.83 (0.73 to 0.95) p=0.008		0.81 (0.71 to 0.94) p=0.004
Number of comorbidities (≥3 vs 0–2)			0.48 (0.31 to 0.73) p<0.001	
Inpatient hospitalisation days in year prior to pre-dialysis choice (≥8 vs 0–7 days)			0.46 (0.30 to 0.70) p<0.001	1.52 (1.04 to 2.23) p=0.032
EQ-5D score (above vs below median)		1.62 (1.03 to 2.54) p=0.038		
Frailty score high vs low (vulnerable and above vs lower group of very fit to managing well)	0.56 (0.39 to 0.80) p=0.002	0.51 (0.31 to 0.83) p=0.007	0.37 (0.24 to 0.56) p<0.001	2.64 (1.79 to 3.89) p<0.001

Multivariate logistic regression using forward stepwise model. Values are ORs (95% CI) both to two decimal places. P values given to three decimal places.
HHD, home haemodialysis; MCM, maximum conservative management; PD, peritoneal dialysis.

Table 3 Characteristics of patients who underwent pre-dialysis education tabulated by patient's choice of home dialysis and significant univariate correlations and multivariate analysis

Variables	Chose home dialysis (HHD, PD)?		Univariate correlation	Multivariate OR n=1154
	Yes	No		
Count, n (%)	424 (31)	943 (69)		
Age, mean	62	69	−0.201, p<0.001	0.79 (0.73 to 0.87), p<0.001
Gender female, %	40	39		
Body mass index, mean	29.45	30.47		
eGFR, mL/min, mean	16	17		
Number of comorbidities, median	2	3	−0.10, p<0.001	
Inpatient hospitalisation days in year prior to pre-dialysis choice, median	0	1		
Deprivation—WIMD, median	874	788		
Travelling time, minutes, median	26.62	24.4		
EQ-5D score, median	0.77	0.68	0.16, p<0.001	
Self-rated health VAS, median	73	64		
Frailty score, median	2	3	−0.24, p<0.001	0.38 (0.28 to 0.51), p<0.001

Univariate correlation calculated with: Spearman's r where yes=1.
Multivariate correlation logistic multiple regression using stepwise forward technique using likelihood ratios to determine model. Multivariate model uses simplified predictor variables (EQ-5D score dichotomised about median), frailty low (vulnerable and above vs lower group of very fit to managing well), age per decade of years.
Excluded patients who chose transplant or MCM.
Values to two decimal places or three decimal places for p values.
eGFR, estimated glomerular filtration rate; HHD, home haemodialysis; MCM, maximum conservative management; PD, peritoneal dialysis; VAS, Visual Analogue Scale; WIMD, Welsh Index of Multiple Deprivation 2014.

Factors influencing patient choice for a home dialysis modality

Online supplemental table 3 showed the values of baseline characteristics of patients tabulated by their chosen KRT modality at the time of pre-dialysis education. Patients who chose MCM tended to be older, have more episodes of hospitalisation and increased levels of frailty.

There is a significant correlation of choice of home dialysis with increasing quality of life score (EQ-5D) and significant negative correlation with increasing age, increasing comorbidity burden and frailty. There was no association with gender, hospitalisation, deprivation, travelling time or self-rated health by VAS.

We also performed a multivariate analysis, which can be found in table 3. This showed the presence of an association between patient choice of a home dialysis modality and patient age (age per decade OR 0.79; 95% CI 0.73 to 0.87, p<0.001) and frailty (above median 0.379; 95% CI 0.28 to 0.51).

Patient outcomes

Overall, 821 of 1707 (48%) patients progressed to requiring KRT up until the date of data extraction, with 1103 of 1697 (65%) progressing to requiring KRT or reached an eGFR of under 8 mL/min. The proportion of patients who progressed to meet the endpoint of requiring KRT or eGFR <8 varied between groups and can be found in table 4. Survival was best at 1 year in the group who opted for transplantation at 99% and lowest in the group who chose MCM at 62%.

Table 4 Summary of patient outcomes, tabulated by patient choice at time of pre-dialysis education

Variables	HHD	PD	UHD	Transplant	MCM	Undecided
Count, n (%)	68 (4)	356 (20.9)	552 (32.3)	109 (6.4)	231 (13.5)	390 (22.8)
Died, n (%)	15 (22.1)	82(23)	230 (41.7)	7 (6.4)	168 (72.7)	140 (35.8)
1-year survival, %	91.2	93.5	82.2	99.1	62.3	86.2
Ever have KRT?, n (%)	47 (69.1)	231 (64.9)	294 (53.3)	79 (72.5)	<5 (<3)	165 (42.2)

Count values less than 5 are marked as less than 5 to prevent re-identification of patients.
Values to one decimal place.
HHD, home haemodialysis; KRT, kidney replacement therapy; MCM, maximum conservative management; PD, peritoneal dialysis; UHD, unit haemodialysis.

Table 5 Outcomes for subgroup of patients who reached eGFR <8 or received kidney replacement therapy (KRT), tabulated by patient choice at time of pre-dialysis education

Variables	HHD	PD	UHD	Transplant	MCM	Undecided
Count of patients reaching eGFR <8 or started KRT, n (%)	54 (80.6)	255 (71.8)	396 (72)	89 (81.7)	81 (35.7)	228 (58.6)
Ever have HHD, n (%)	<10 (<10)	9 (3.5)	5 (1.3)	5 (5.6)	<5	9 (3.9)
Ever have PD, n (%)	<5 (<5)	135 (52.9)	11 (2.8)	22 (24.7)	<5	41 (18)
Ever have transplant, n (%)	12 (22.2)	55 (34.6)	21 (5.3)	45 (50.6)	<5	26 (11.4)
Ever have UHD, n (%)	38 (70.4)	137 (53.7)	280 (70.7)	33 (37.1)	<5	134 (58.8)
Ever have any KRT, n (%)	47 (87)	231 (90.6)	294 (74.2)	79 (88.8)	<5	165 (72.4)

eGFR or KRT status data were available for 1697 of 1707 patients in the original cohort.
Count values less than 5 are marked as less than 5 to prevent re-identification of patients.
Patients may have more than one type of KRT during follow-up.
Values to one decimal place.
eGFR, estimated glomerular filtration rate; HHD, home haemodialysis; MCM, maximum conservative management; PD, peritoneal dialysis; UHD, unit haemodialysis.

We examined the outcomes in the subgroup of patients who either reached an eGFR of <8 mL/min or required KRT during the study. These data can be seen in table 5. The MCM group had the lowest rate of progression at 36% followed by the undecided group at 59%. These rates and the proportions of patients who attained their chosen therapy can be found in table 5. This shows only 13% of patients who chose HHD, 53% PD, 71% UHD and 51% transplant achieved their chosen modality during the follow-up time.

Of the subgroup of patients who chose HHD or PD and required KRT, only 150 of 278 (54%) achieved a home dialysis modality. The proportion of patients achieving their aim of a home dialysis therapy was explored in more detail on a univariate basis. No statistically significant associations were found to predict achieving outcome, including age, gender, deprivation, hospitalisation, distance from renal unit or quality of life measures.

DISCUSSION

This is the first national cohort study to examine factors influencing KRT choices using data linkage. Wales has a high prevalence of home dialysis compared with other nations within the UK,[33] and despite this and potential benefits of home dialysis, it was not always discussed or chosen by patients with established kidney failure in the current health system. Patients lacked confidence and motivation, and some lacked home support or had preconceptions of what they wanted. Apart from a small number of patients citing home adaptions as a problem for HHD, the barriers for PD and HHD were the same. Indecision was a common outcome. 23% (390 of 1707) of all patients did not reach a clear decision following their pre-dialysis education. Of these patients, 42% (165 of 390) started KRT during the study and 59% (134 of 228) went on UHD. Patients choosing MCM were less likely to progress to more severe CKD (36% reaching a eGFR <8) presumably due to comorbid disease and lower survival. As expected, under 3% of patients choosing MCM received KRT. What patients initially chose and why was not necessarily a good marker of where patients started KRT. Only 150 of 278 (54%) patients who choose HHD or PD and progressed to KRT went on to home dialysis. Many of the factors most often cited as barriers to home dialysis for those patients who are considered eligible (motivation, confidence, home adaptions) are potentially modifiable.

Our study has some methodological limitations worth noting. While data linkage in this pseudo-anonymised dataset allowed us to access a broader range of datasets including comorbidity and hospitalisation without the need for individual patient consent, it led to loss of information which was present in the free text/narrative portion of the pre-dialysis education session. This information may have informed reasons behind patient choices which were otherwise not captured by the coded reasons. Our study had both good rates of data linkage and follow-up, but it is possible that the cohort was subject to selection bias. For example, patients who were never suitable for dialysis did not undergo education, or perhaps patients who were thought to be excellent candidates for kidney transplantation missed out education and went straight to transplantation. Our methodology, to keep the study simple and avoid use of repeated measures, only took the first education session into account. It is possible that different results could have been obtained if the latest education session had been used rather than the first. More men were awaiting pre-dialysis education than women (60%) in the time frame of this study, and although this is consistent with global demographics—men are over-represented in patients awaiting and on KRT—we see this as a limitation and potential gender bias.

Although previous studies have shown potential links between factors such as deprivation and travel time to units as a predictor of choice,[2 34 35] our multivariate analysis did not show this. However, we did see very clear (and

predictable) indicators of discussions towards MCM and transplant, for example, discussions of MCM increased with age and frailty. We interpret this with caution and suggest that care needs to be taken that these patients are not simply being presented with MCM or UHD as their only options from the outset. It is possible that the use of WIMD as a measure of deprivation did not have sufficient granularity to accurately describe the true extent of deprivation experienced by patients at a household level. Consideration should be given to collected data on patient-level markers of deprivation such as income and employment.

In the context of barriers to home dialysis, our analysis of routinely collected data did not show any significant relationship between patient demographics and why they did not choose home dialysis. This may be attributed to the geographical locality of analysis being too wide to be meaningful. However, 'other' and 'non-coded reasons' were frequently found in the electronic patient record in place of a predefined reason selected from a drop-down list to explain what was discussed, chosen and why.

Recent studies have provided a number of explanations as to why patients who were eligible did not opt for or achieve a home-based treatment option. The care pathway for a home treatment option is more complex, resource intensive, with more stages than a unit-based option, making the unit an easier default for patients and clinicians. Current shared decision-making interventions are not providing patients with sufficient confidence to manage the treatment independently. Options are often presented as a general list which can be confusing and overwhelming. Patients may be subject to social deprivation including a lack of adequate housing.[11] Patients, carers and clinicians also remain unaware of the relative benefits and harms of each option or the costs. For instance, PD was less likely to be discussed with the elderly or those with higher BMI, but studies have shown superior outcomes in patients with higher BMI[36] and age has not been shown to impact on technique survival.[37]

System issues include a lack of visibility of home-based therapies and a system designed almost exclusively around UHD as substantive barriers to patients choosing home dialysis.[13 31] This study also emphasises the influence of these wider systemic issues; even if 100% of suitable patients choose home dialysis, the majority of these would not achieve home dialysis in the current system. The reasons are multifaceted and include, for example, patient death, rapid decline in quality of life, received a transplant, training was too long or never finished, patients change their mind, lack of health service resources or change in patient family/social circumstances.[11]

In an increasingly stretched healthcare system with an overworked and understaffed workforce, more opportunities need to be created and adapted to make it easier for healthcare professionals while at the same time increasing the support for patients to get home. In Wales, eligibility for live donor transplant is identified very early. Patients are then nurtured throughout with tailored support to get their chosen option. These principles could potentially be adopted for home therapies. Patients would benefit from seeing and experiencing more realistic home-based settings at an earlier stage of their journey. Shared learning from other disciplines, such as rehabilitation, could be adopted such as setting up a simulated home-based training suite in a unit setting. Home-based options also need to accommodate or replicate the social networks and safety nets (it is easier for professionals to monitor patients on UHD) provided by the units. Involving the third-sector and wider social care services as well as updating and adapting remote monitoring platforms could help reconfigure the function of dialysis units more towards what they were intended to do.

Although this study was not powered to look into any specific cultural barriers to home dialysis, we would recommend future research addresses minority perspectives—including health inequalities—and their influences on barriers to home dialysis as well as interventions (adapted and novel) to address them. This study has provided a model to link data to examine multilayer outcomes in an exceptionally complex healthcare pathway. The National Institute for Health and Care Excellence currently recommends starting discussions at least 1 year before needing KRT,[38] but we need to know more about how best to individually tailor the best approach for each patient. Ongoing research is needed to monitor the impacts of these multiple interventions overtime and more integrated service models developed to adapt and more quickly address the outcomes.

CONCLUSIONS

Policies aspire to increase the number of patients on home therapies as outcomes are better for patients. This study sheds new light on the numbers of patients eligible for home dialysis who end up with another treatment option and the reasons for this.

Further continuous service improvements are required to privilege and promote home dialysis for eligible patients, better use of audit data to monitor treatment decisions and map changes over time to see if service improvements are bringing about changes in patients opting for and receiving a home therapy, accompanied by better pre-dialysis patient education and ongoing support.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval The study was approved by an Information Governance Review Panel (Agreement 0881), which assessed whether the proposal met strict information governance arrangements set out across the multiple data access agreements. This ensured patient anonymity and did not require referral to the National Research Ethics Service. The overall evaluation that included additional workstreams was approved by the Research Ethics Committee Wales (REC) 5 (reference number: 19/WA/0020). Further detail is available in the published protocol.[11]

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Data availability statement No data are available. Data are not publicly available. Electronic health records are, by definition, considered sensitive data in the UK by the Data Protection Act and cannot be shared via public deposition because of information governance restriction in place to protect patient confidentiality. SAIL data are available by application to the Secure Anonymised Information Linkage databank (https://saildatabank.com/).

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Appendix

Screenshots of the renal electronic patient record showing a fictious patient dialysis education session record.

Figure 1: Shared Decision Making Screen

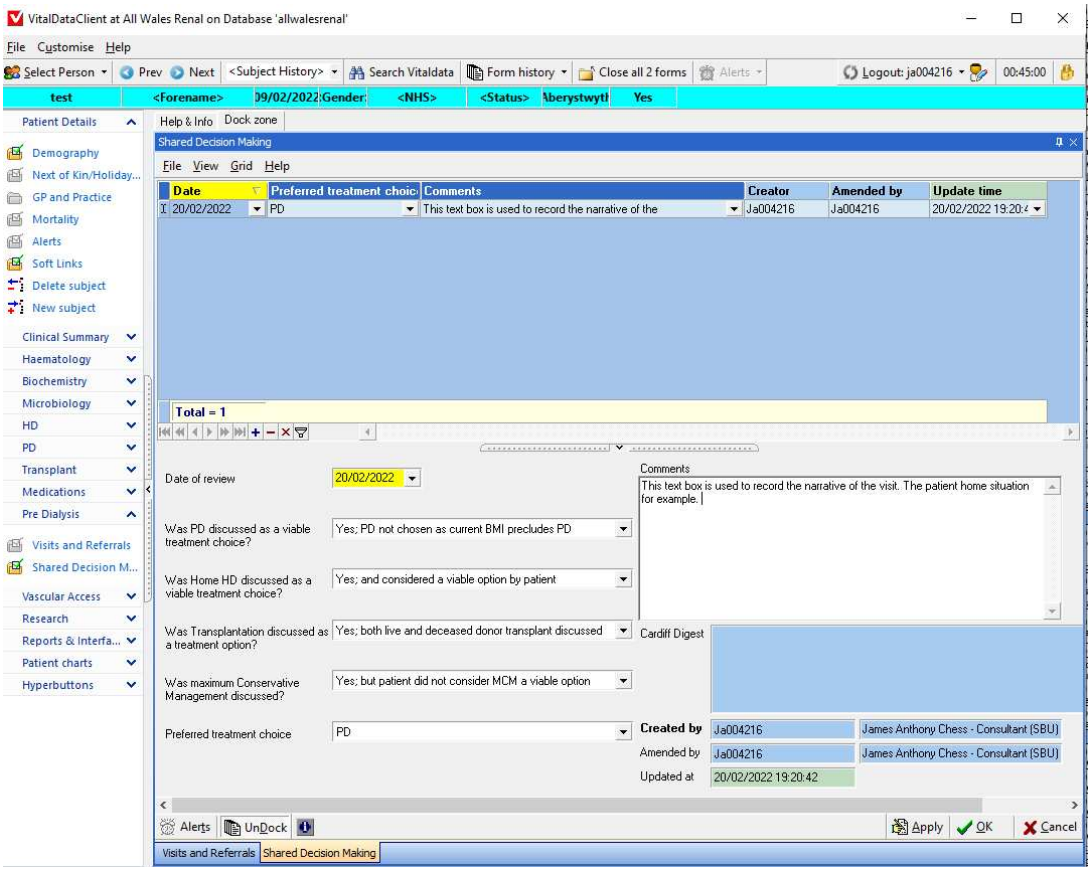
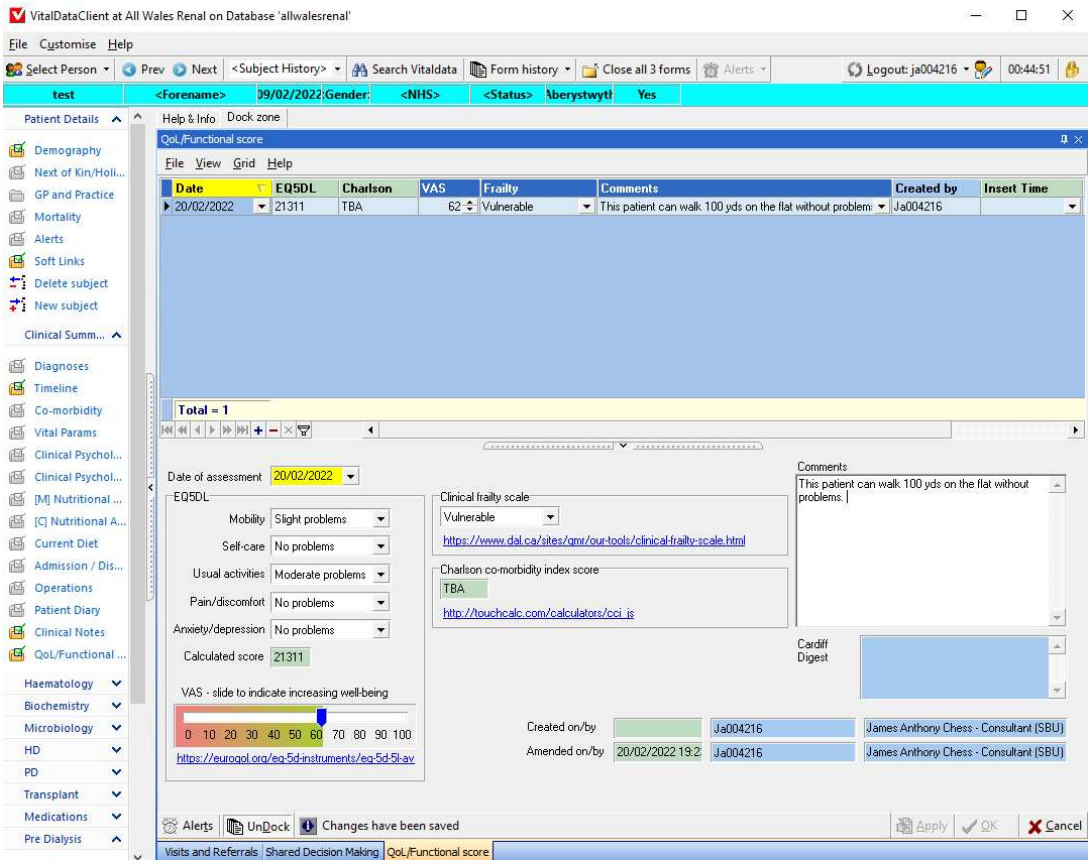


Figure 2:Quality of Life/Functional score screen



Appendix Table 1: Baseline demographics and characteristics of 1707 patients who underwent pre-dialysis education between 2016 and 2018		
Variable	Category	Descriptive Statistics
Age in years, mean (SD)		67.7 (15.8)
Age group, n (%)	18-64	595 (34.9)
	65-74	432 (25.3)
	75-84	464 (27.2)
	>=85	216 (12.7)
Gender, n (%)	Female	680 (39.8)
	Male	1027 (60.2)
Deprivation - WIMD Quintile, n (%) n=1622	Quintile 1 (Most deprived)	354 (21.8)
	Quintile 2	382 (23.6)
	Quintile 3	334 (20.6)
	Quintile 4	283 (17.4)
	Quintile 5 (Least deprived)	269 (16.6)
Body mass index, n (%) n=1413	Underweight (<18.5)	30 (2.1)
	Normal (18.5-25)	360 (25.5)
	Overweight (25-30)	454 (32.1)
	Obese (>30)	569 (40.3)
eGFR mls/min, mean (sd) n=1590		16.9 (6.3)
eGFR Stage, n (%) n=1676	2 or 3	45 (2.7)
	4	856 (51.1)
	5	689 (41.1)
	On KRT at time of education	86 (5.1)
Number of comorbidities (in addition to CKD), n=1643 (%)	0 (CKD Only)	129 (7.9)
	1-2	636 (38.7)
	3-4	640 (39)
	5 or more	238 (14.4)
Quality of life domains (with any reported problems), n (%) n=1220	Mobility problems	805 (65.6)
	Self-care problems	429 (35.0)
	Usual activity problems	764 (62.3)
	Pain/discomfort	700 (57.1)
	Anxiety/depression	641 (52.0)
Self-rated health VAS, mean (sd) n=1010		65.02 (21.1)
Frailty score, n (%) n=1230	Very fit to Managing well	611 (49.7)
	Vulnerable to Moderately Frail	565 (45.9)
	Severely Frail to Terminally Ill	54 (4.4)
Travelling time to nearest renal centre, n (%)	Up to 30 minutes	1052 (61.6)
	30 to 60 minutes	522 (30.6)
	Greater 60 minutes	133 (7.8)
Inpatient hospitalisation days in year prior to pre-dialysis choice, n (%) n=1690	None	831(49.2)
	1-7	315(18.6)
	8-14	146(8.6)
	>14	398(23.6)

Unless otherwise stated n=1707.
SD, Standard Deviation; WIMD, Welsh Index of Multiple Deprivation 2014; eGFR, Estimated Glomerular Filtration rate; VAS, Visual analogue scale. Summary statistics to 1 decimal place.

Appendix Table 2: Values of factors associated with patient discussion tabulated by whether modality discussed

Variables	Was HHD discussed? n=1441		Was PD discussed? n=1454		Was Transplant discussed? n=1454		Was MCM discussed? n=1462	
	Yes	No	Yes	No	Yes	No	Yes	No
Count,n (%)	945 (65.6)	496 (34.4)	1078 (74.1)	376 (25.9)	588 (40.5)	865 (59.5)	735 (50.3)	727 (49.7)
Age in years, mean	60.0	75.4	65.4	74.1	55.7	75.6	75.4	60.0
Gender female, %	37.9	42.3	38.7	41.8	37.9	40.8	41.4	37.7
Body mass index, mean	30.1	29.0	29.4	30.8	29.8	29.1	28.9	30.4
eGFR mls/min, mean	16.3	17.4	16.4	17.6	16.69	17.0	16.1	17.4
Number of comorbidities (in addition to CKD), median	3	3	2	3	2	3	3	2
Inpatient hospitalisation days in year prior to pre-dialysis choice, median	0	3	0	4	0	2	1	0
Deprivation – WIMD, median	852	798	838	840	859	840	889	787
Travelling time mins, median	25.3	24.3	23.6	26.6	23.6	25.2	25.9	23.7
EQ-5D score, median	0.7	0.6	0.7	0.6	0.8	0.7	0.7	0.8
Self-rated health VAS, median	70	62	69	62	70	61	64	70
Frailty score, median	2	3	2	4	2	3	3	2

WIMD, Welsh Index of Multiple Deprivation 2014 ; eGFR, Estimated Glomerular Filtration rate; VAS, Visual analogue scale.
Percentages and summary statistics to 1 decimal place.

Appendix Table 3: Baseline characteristics of patients who underwent pre-dialysis education tabulated by patient's choice at first assessment

Variable, statistic	HHD	PD	UHD	Transplant	MCM	Undecided
Count, n (%)	68 (4)	356 (20.9)	552 (32.3)	109 (6.4)	231 (13.5)	391 (22.8)
Age in years, mean	59.8	62.4	68.5	48.6	82.8	69.2
Gender female, %	40	40	39	35	46	38
Body mass index, mean	30.6	29.2	31.2	28.8	27.1	29.5
eGFR mls/min, mean	17.4	17.2	16.3	18.3	18.5	16.6
Number of comorbidities (in addition to CKD), median	3	2	3	2	3	3
Inpatient hospitalisation days in year prior to pre-dialysis choice, median	0	0	3	0	4	0
Deprivation – WIMD, median	674	803	745	544	799	743
Travelling time to nearest renal centre, median	25.0	27.2	24.6	18	25.3	29.1
EQ-5D score, median	0.7	0.7	0.6	0.7	0.6	0.7
Self-rated health VAS, median	65	69	60	70	62	61
Frailty score, median	2	2	3	1	4	3

WIMD, Welsh Index of Multiple Deprivation 2014; eGFR, Estimated Glomerular Filtration rate; VAS, Visual analogue scale.
Percentages and summary statistics to 1 decimal place.