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Exploration of Workload, Patient Capacity and Treatment Burden during transition onto Kidney Replacement Therapy

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Submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy (PhD)

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Abstract

Background and aims: Advances in dialysis and kidney transplantation over the last 70 years have transformed the clinical prognosis in kidney failure from that of certain death to a manageable chronic condition where patients can live for many years on kidney replacement therapy. These innovations have transformed the lives of patients, but have also resulted in considerable treatment burden. Treatment burden is the impact of the workload of chronic illness on functioning and wellbeing. It is the product of the interaction between healthcare workload and patient capacity, where patients become overburdened if their healthcare workload exceeds their capacity to meet it, leading to worse outcomes. The aim of this thesis was to explore healthcare workload, patient capacity, and treatment burden during transition onto kidney replacement therapy (KRT).

Methods: There were four phases of research. The first phase was a systematic review of qualitative literature exploring healthcare workload, patient capacity, and treatment burden during transition onto kidney replacement therapy. The second phase was a quantitative analysis of workload, involving a retrospective cohort study of the healthcare workload experienced by 1,022 patients during transition onto kidney replacement therapy. Average time per month spent on healthcare workload was calculated for each participant from six months prior to KRT start to thirty-six months after, and negative binomial regression was used to determine which variables were associated with higher workload. The third phase was a longitudinal qualitative study, involving serial interviews with 30 individuals conducted over the first year of kidney replacement therapy exploring experiences of treatment burden and its evolution over time. This was analysed with a framework analysis informed by Normalisation Process Theory, Theory of Patient Capacity, and Burden of Treatment Theory. The fourth phase constituted an integration of the findings in order to conceptually model treatment burden during transition onto kidney replacement therapy.

Results: Phase 1) A taxonomy of healthcare workload and a taxonomy of patient capacity were created. Four broad categories of workload were described: making sense of KRT; working out what to do and how to do it; meeting the challenges of KRT; and reflecting on work done. Patient capacity influenced the experience of all types of workload and the treatment burden generated by the work. Phase 2) Median healthcare workload peaked

around KRT initiation and was highest in haemodialysis patients. Kidney transplantation was associated with markedly lower workload post initiation (IRR 0.04, CI 0.03-0.05). Increased workload was associated with female sex (IRR 1.17, CI 1.05-1.31), polypharmacy (>15 medications) (IRR 1.35, CI 1.15-1.59), late referral (IRR 1.39, CI 1.18-1.65), older age (IRR 1.27, CI 1.04-1.27), modality change (IRR 1.44, CI 1.08-1.94), and failed transplant (IRR 2.30, CI 1.61-3.41). Phase 3) Five themes affecting treatment burden during KRT transition arose: engaging personal and social resources to navigate KRT transition, being able to meet the challenges of KRT transition, preparing to enact the healthcare workload of KRT transition, undertaking KRT transition related workload and the evolution of burden over time. Phase 4) Two conceptual models of treatment burden during KRT transition were created. The first conceptual model describes how healthcare workload, patient capacity, and healthcare system factors interact in the generation of treatment burden during KRT transition. The second conceptual model conceptualises how these factors interact to influence the evolution of treatment burden over time during the first 12 months of KRT.

Conclusions: Patients transitioning onto kidney replacement therapy experience considerable treatment burden. This thesis provides a detailed exploration of the factors that contribute to the generation of treatment burden and how different factors interact to influence the evolution of treatment burden over time. Four key target areas for interventions to reduce treatment burden during KRT transition were identified: 1) improving the processes and function of the healthcare system; 2) supporting caregivers; 3) enhancing the social network; 4) improving access to kidney transplantation. A potential avenue for further research would be the development of an evidence-based structured service evaluation measure to assess how system processes contribute to generating treatment burden during KRT transition and facilitate the identification of targets for intervention.

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Author's Declaration

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Qualitative Systematic Review

The preliminary search strategy was developed following discussion with my supervisory team. Dr Paul Cannon, Information Scientist at the University of Glasgow Library, assisted in developing the formal final search strategy.

I acted as first reviewer during all stages of the review including title and abstract screening, full text screening, data extraction, quality appraisal, and data coding. The following colleagues acted as second reviewers: Dr Ross Cairns, Dr Heather Walker, Dr Silje Welsh, Dr Benjamin Edgar, Miss Karen Stevenson and Dr Katie Gallacher. I carried out all higher levels of data analysis, and Dr Katie Gallacher double coded 6 papers.

Quantitative Study

The data analysis plan was decided between myself and the supervisory team. The data extraction from SERPR was conducted by Dr Peter Thomson and I cleaned the data and performed all statistical analysis myself with guidance from Dr Bhautesh Jani. Mr Benjamin Edgar assisted with the coding for calculating travel time. Mr Steve Knight and Prof David Kingsmore read the first draft of the manuscript and suggested improvements.

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professionally by 1st Class Secretarial Service. I carried out all data analyses, and Dr Katie Gallacher reviewed the coding of 20% of the transcripts during regular coding clinics.

Thesis writing

I am the sole author of the thesis and this is my original work. My supervisors read and provided feedback on earlier drafts of the chapters. Generative AI (ChatGPT 5) was used for assistance in background reading and in proof reading some elements of the work. Mendeley was used as a referencing software and a combination of manual searching and ChatGPT was used to correct the final reference list.

Publications and Presentations

Publications arising from this research

1. **Jones C**, Cairns R, Walker H, Welsh S, Edgar B, Stevenson K, Jani BD, Mark PB, Kingsmore D, Gallacher KI. Exploration of treatment burden through examination of workload and patient capacity during transition onto kidney replacement therapy: a systematic review of qualitative research. *BMC Med.* 2025;23:61.
2. **Jones CH**, Edgar B, Thomson PC, Gallacher KI, Knight S, Kingsmore D, Mark PB, Stevenson K, Jani B. Healthcare workload associated with transition onto kidney replacement therapy: a retrospective cohort study. *BMC Nephrol.*2026;27:73. doi:10.1186/s12882-025-04693-0.
3. **Jones C**, Edgar B, Stevenson K, Jani B, Mark P, Gallacher K. Exploration of treatment burden during transition onto kidney replacement therapy: a longitudinal qualitative study. *PLOS One.* In press.

Publications related to this research

1. Walker H, Day S, Grant CH, **Jones C**, Ker R, Sullivan MK, Jani BD, Gallacher K, Mark PB. Representation of multimorbidity and frailty in the development and validation of kidney failure prognostic prediction models: a systematic review. BMC Med. 2024;22(1):452.

2. Edgar B, **Jones C**, Aitken E, Stevenson K, Jackson A, Gaianu L, Thomson P, Kasthuri R, Stove C, Kingsmore DB. What are the reported procedural costs of vascular access surgery? J Vasc Access. 2025;26(5):1510–1519.

3. Edgar B, **Jones C**, Aitken E, Stevenson K, Jackson A, Gaianu L, Thomson P, Kasthuri R, Stove C, Kingsmore D. What are the observed procedural costs of vascular access surgery? Protocol for a systematic review. BMJ Open. 2024;14(1)

4. Stevenson K, Meiklem R, Bouamrane MM, Thomson P, Dunlop M, Martin L, **Jones C**, Kingsmore D. Information needs in vascular access decision-making: A qualitative study of patient and clinical stakeholder perspectives. J Vasc Access. 2025 26(6):1979–1989.

5. Edgar, B., **Jones, C**., Martin, L. *et al.* Treatment burden and health literacy among patients referred to a vascular access clinic: a cross-sectional study. *BMC Nephrol*. 2025;26:667

Presentations related to this research

Oral

1. *Exploring the evolution of treatment burden associated with live donor kidney transplantation: a longitudinal qualitative study.* ASGBI International Surgical Congress, Edinburgh, May 2025
2. *Use of a validated vascular access specific quality of life measure (VASQoL) in a prevalent haemodialysis population.* Charing Cross International Symposium, London, April 2023
3. *Vascular access related healthcare workload during transition onto kidney replacement therapy.* VASBI Annual Scientific Meeting, Bournemouth, September 2025.
4. *The Burden of Vascular Access Treatment during transition onto Kidney Replacement Therapy: A Longitudinal Qualitative Study.* VASBI Annual Scientific Meeting, Bournemouth, September 2025.
5. *Treatment Burden, Patient Capacity and Kidney Transplant.* East meets West Pan Scotland Transplant Educational Day, September 2025
6. *Healthcare Workload, Patient Capacity and Treatment Burden during Transition onto Kidney Replacement Therapy*. CSO/ NRS Renal and Diabetes Research Day, Perth, May 2025
7. *Healthcare workload, patient capacity and treatment burden in live donor transplantation.* Live Donor Transplant Network Scotland Research Day, Stirling, December 2024.
8. *The Impact of Vascular Access Workload on Treatment Burden during Transition onto Kidney Replacement Therapy: A Systematic Review of Qualitative Literature*. VASBI Annual Scientific Meeting, Cardiff, September 2024.
9. *Patient Capacity and Treatment Burden in Kidney Transplant.* Midlands Transplant Network Meeting, Birmingham, December 2025.

Poster

1. *Exploration of Treatment Burden Associated with Live Donor Renal Transplantation: A Longitudinal Qualitative Study.* World Transplant Congress, San Francisco, July 2025
2. *Exploring treatment burdens experienced by patients aiming for live donor kidney transplantation.* ESOT Congress London June 2025
3. *Burden of Treatment Associated with Live Donor Transplantation: A Conceptual Model.* British Transplantation Society Annual Congress, Llandudno, March 2026
4. *Exploration of healthcare workload, patient capacity and treatment burden during transition onto kidney replacement therapy: a longitudinal qualitative study*. UK Kidney Week, Bournemouth, June 2025
5. *Understanding the treatment burdens experienced by patient aiming for pre-emptive live donor kidney transplantation: a qualitative study.* British Transplant Society Annual Congress, Brighton March 2025

Abbreviations

AMR	Antibody mediated rejection
APD	Automated Peritoneal Dialysis
ATTOM	Access to Transplantation and Transplant Outcome Measures
AVF	Arteriovenous fistula
AVG	Arteriovenous graft
BBF	Brachio-basilic fistula
BCF	Brachio-cephalic fistula
BoTT	Burden of Treatment Theory
CAMELOT	Cochrane Qualitative Methodological Limitations Tool
CAPD	Continuous Ambulatory Peritoneal Dialysis
CASP	Critical Appraisal Skills Programme
CAT	Cognitive Authority Theory
CCM	Comprehensive Conservative Management
CKD	Chronic Kidney Disease
COREQ	Consolidated Criteria for Reporting Qualitative Research
CuCoM	Cumulative Complexity Model
CVC	Central Venous Catheter
DDTx	Deceased donor transplant
eGFR	Estimated Glomerular Filtration Rate
ENTREQ	Enhancing Transparency in the Reporting the Synthesis of Qualitative Research
EPPI	Evidence for Policy and Practice
EPR	Electronic Patient Record
ESKD	End-stage kidney disease
ESRF	End-stage Renal Failure
H-DCE	Home Dialysis Care Experience
HARQ	Haemodialysis Access- Related Quality of Life Questionnaire
HCTD	Health Care Task Difficulty
HD	Haemodialysis
HHD	Home Haemodialysis
HLQ	Health Literacy Questionnaire

HPRT	Health Power Resource Theory
HRQoL	Health Related Quality of Life
HSS	Hemodialysis Stressor Score
ICHD	In Centre Haemodialysis
IIRS	Illness Intrusiveness Ratings Scale
IPA	Interpretative Phenomenological Analysis
IRR	Incidence Rate Ratios
JBI	Joanna Briggs Institute
KDIGO	Kidney Disease: Improving Global Outcomes
KDOQI	Kidney Disease Outcome Quality Initiative
KDQOL-36	Kidney Disease Quality of Life-36
KFRT	Kidney Failure requiring Replacement Therapy
KRT	Kidney Replacement Therapy
KTQ	Kidney Transplant Questionnaire
KTQoL	Kidney Transplant Quality of Life
KTx	Kidney Transplant
LCC	Low Clearance Clinics
LDTx	Living Donor Transplant
MDM	Minimally Disruptive Medicine
MDT	Multidisciplinary Team
MTBQ	Multimorbidity Treatment Burden Questionnaire
NHS	National Health Service
NHS GGC	NHS Greater Glasgow and Clyde
NHSBT	NHS Blood and Transplant
NICE	National Institute of Clinical Excellence
NKSS	National Kidney Sharing Scheme
NPREM	Needling Patient Reported Experience Measure
NPT	Normalization Process Theory
ntCVC	Non-tunnelled central venous catheter
PAM	Patient Activation Measure
PD	Peritoneal Dialysis
PETS	Patient Experience with Treatment and Self-management

PETS-KT	Patient Experience with Treatment and Self-management-Kidney Transplantation
PPIE	Patient and Public Involvement and Engagement
PRD	Primary Renal Disease
PREM	Patient Reported Experience Measure
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
PRM	Patient Reported Measure
PRM	Patient Reported Measure
PROM	Patient Reported Outcome Measure
QALY	Quality Adjusted Life Years
QEUH	Queen Elizabeth University Hospital
RCF	Radio-cephalic fistula
RCT	Randomised Controlled Trial
RDQOL	Renal-Dependent Quality of Life
ReTransQoL	Renal Transplant Quality of Life
RTSQ	Renal Treatment Satisfaction Questionnaire
SERPR	Strathclyde Electronic Renal Patient Record
SILS	Single Item Literacy Score
SIMD	Scottish Index of Multiple Deprivation
SONG	Standardised Outcomes in Nephrology
TBQ	Treatment Burden Questionnaire
TCVC	Tunnelled central venous catheter
TPC	Theory of Patient Capacity
UX	User experience
VASQOL	Vascular Access Specific Quality of Life Score

Chapter 1 Introduction

1.1 Aims of this chapter

The aims of this chapter are to introduce the concept of treatment burden; define kidney failure requiring replacement therapy and outline the different options and considerations in its management; explain the aims and objectives of this thesis; and provide an overview of the upcoming chapters.

1.2 Background: The concept of treatment burden

In this thesis I explore how people experiencing kidney failure requiring replacement therapy and transitioning onto kidney replacement therapy can be burdened by the demands placed upon them by their treatment, how healthcare workload differs between patients and changes over time, and how the balance between healthcare workload and capacity to manage that workload evolves over the first year of kidney replacement therapy.

Patients can be impacted by physical symptoms, psychological distress, and the resulting limitations on the ability to perform their usual role in society. Alongside this 'burden of illness' there is also the 'burden of treatment', defined as the workload of healthcare when managing long-term conditions and the resultant impact on wellbeing. Healthcare workload includes demands made upon the patient to organize and co-ordinate their own care, comply with complex treatment and self-monitoring regimes, and to meet numerous expectations of personal motivation, expertise, and self-care[1]. Healthcare workload can be examined objectively by looking at measures such as number and length of hospital or clinic visits and number of medications, however burden of treatment is a subjective experience influenced by factors such as age, gender, education, cultural expectations, level of complexity and socioeconomic considerations and it can vary over time for an individual[2]. Eton et al showed that there are distinct patterns of treatment burden in people with multimorbidity over an extended period, with three main groups: those with a consistently high workload; a consistently low workload; and those with an increasing workload. These groups had different demographic, health-related and psycho-

social profiles. Those with lower health literacy, lower self-efficacy, and higher negative social interactions had higher treatment burdens[3].

Patient capacity is a term often used alongside treatment burden, defined as the personal, physical, emotional, social, environmental, and financial resources and abilities that the patient can mobilise to meet the demands of their illness, treatment and of life[4,5]. Patient capacity is not fixed, but a dynamic entity that can be augmented or diminished depending on the resources the patient has available to them[6].

The Cumulative Complexity Model (CuCoM) defines workload as the demands made upon the patient by illness, treatment, and life; and capacity as their ability to meet those demands. As the clinical, social, and personal complexity increases these factors interact in feedback loops simultaneously increasing the workload whilst reducing the patient's capacity to meet that workload. When the workload exceeds the patient's capacity to meet it, this can lead to a patient becoming overburdened resulting in worse adherence, engagement, quality of life, and health outcomes[7].

1.3 Background: Kidney failure requiring replacement therapy and its management

1.3.1 Kidney Failure Requiring Replacement Therapy

Kidney failure requiring replacement therapy (KFRT) is defined as the stage of chronic kidney disease (CKD) where kidney replacement therapy (KRT) is necessary[8]. It is a more patient-centred replacement for older terms such as end-stage kidney failure. KRT is a life-long therapeutic intervention that requires considerable adaptation to daily life, regular contact with healthcare including accommodation of dialysis schedules, diligent adherence to diet, fluid, and medication regimes, and careful monitoring[9].

There is some international variation in practice around the disease progression point where KRT is deemed necessary, however consensus exists that KRT should be offered as part of a shared decision-making process for patients with signs and symptoms of uraemia, refractory hyperkalaemia, or refractory fluid overload related to their advanced kidney disease[10].

KFRT is better considered as not a singular disease entity, but as a final common pathway of varied disease processes where the kidneys can no longer sustain homeostasis[11]. In Scotland, the most common underlying primary renal disease (PRD) in patients transitioning onto KRT is diabetes mellitus (30.0% of patients), followed by glomerular disease (20.5%), hypertension or renovascular disease (12.7%), miscellaneous renal disorders (12.7%), familial nephropathies (10.7%), tubulointerstitial disease (9.4%) and other (4.1%)[12]. The incidence of KRT in Scotland has remained stable at 11.7 per 100,000 population for the last 10 years, but the prevalence of KRT continues to rise as survival improves[12]. KFRT can happen at any age, but the incidence is much higher in older age groups, with KRT incidence of 0.65 per 100,000 aged 0-19[13], 5 per 100,000 for those aged 20-44, 17 for 100,000 for those aged 45-64, 30 per 100,000 for those aged 65-74, and 21 per 100,000 for those aged >75[12]. The higher rate in those aged between 65-74 compared to those aged above 75 may be because of a greater uptake of conservative care in older people or because those exposed to systemic disease processes severe enough to cause kidney failure are generally less likely to survive to their late seventies and eighties[14].

Several factors are associated with a higher risk of requiring KRT. The Scottish Renal Registry reports that the incidence of KRT is almost twice as high in the most deprived Scottish Index of Multiple Deprivation (SIMD) quintile compared to the least deprived[12]. Multi-morbidity is also common in Scottish KRT patients, with 54.6% having a co-existing vascular disease. Sex, ethnicity, education, finances, health literacy, freedoms, social support, geography, culture, beliefs and wider societal inequalities and inequities can all influence the incidence, prevalence, and patient experiences of KFRT[15].

1.3.2 Management of KFRT

There are four main ways of managing KFRT: haemodialysis (HD), peritoneal dialysis (PD), kidney transplantation (KTx) and comprehensive conservative management (CCM). The suitability and eligibility of different modalities vary.

1.3.2.1 Haemodialysis

Haemodialysis is a form of KRT in which blood is passed through an extracorporeal circuit including a semi-permeable artificial membrane which facilitates the removal of excess water, solute, and toxins[16]. First developed in the early 1940s[17], and introduced as

management of chronic as well as acute renal failure in the UK in the early 1960s[18], haemodialysis is the most common starting modality for KRT in Scotland with 78% of incident KRT patients starting on HD[12].

Haemodialysis is most commonly performed three times a week for 4-5 hours a time at an in-centre dialysis units, termed in-centre haemodialysis (ICHD). Some patients undertake incremental dialysis initially, where they dialyse less frequently while they still retain sufficient native renal function to be able to tolerate longer gaps between sessions[19]. Some patients elect for home haemodialysis (HHD), where they perform HD in their home. This can facilitate longer and more frequent sessions, which is associated with better blood pressure and phosphate control, and improvements in both left ventricular hypertrophy and quality of life[20]. HHD has been shown to be associated with higher survival and better control of anaemia, nutritional status, bicarbonate and phosphate status, and systemic inflammatory markers[21]. However, HHD requires the desire and ability to take on a complex task in the home, including having a suitable area in the home to place the equipment, social or familial support, and the ability to learn how to perform HD independently and maintain safe practices[22]. Therefore, despite its superior outcomes, it is not an option chosen by many. Indeed, in Scotland in 2023 only 47 patients on maintenance HD dialysed at home compared to 1994 who dialysed in-centre[12].

Haemodialysis requires reliable vascular access that is durable, comfortable, safe and can support adequate extracorporeal blood flow through the dialysis circuit[23]. Emergency or short term in-hospital dialysis can be performed through temporary non-tunnelled double lumen central venous catheters (ntCVC), however these pose an unacceptably high infection, dislodgement, and thrombosis risk for long term use[24]. There are three main types of long-term vascular access for dialysis: tunnelled central venous catheters (TCVC), arteriovenous fistulae (AVF), and arteriovenous grafts (AVGs). TCVC are long term dual lumen central venous catheters that are inserted under fluoroscopy and tunnelled under the skin so that the skin exit site is separate from the central vein entry site, thus reducing the risk of infection and accidental dislodgement. The main benefits of TCVCs are that they can be inserted under local anaesthesia and used immediately without the need for an operation or period of maturation, do not require needling, and can be used as a short-term bridge to another KRT modality such as PD or transplant without using arteries and veins in the arms that may be needed for access later in life[25,26]. However, TCVCs are

associated with much higher infection, thrombosis, and central venous stenosis rates than other means of access[27], which has led to efforts to limit their long-term use[28].

AVF is a surgically created connection between an artery and a vein using a patient's autologous vessels[29]. Over time, the vein remodels in response to high pressure blood from the artery through a process known as maturation[30]. This in turn can be cannulated to perform haemodialysis. The most common AVFs are radiocephalic fistulae (RCF) at the wrist and brachiocephalic (BCF) or brachiobasilic fistulae (BBF) at the elbow[31]. The main benefits of AVFs are lower bacteraemia rates[32], better access durability, and better patency. They are generally considered to be the preferred access type in suitable patients[23]. However, not all patients have vessels suitable for consideration of AVF formation[33] and of the AVFs created only around 60-80% successfully mature to a functioning usable vascular access[34,35]. Older age and female sex[36], obesity[37,38], diabetes mellitus[39] , heart disease[40] and peripheral vascular disease[41] are all associated with a higher risk of functional failure. Over time, functioning fistulas can develop stenoses due to intimal hyperplasia and subsequent complications from bleeding and thrombosis, which require more hospital visits and treatment[34].

AVFs have been associated with better patient survival than AVGs or TCVCs[42], however concerns have been raised that this is a finding from observational data that was highly vulnerable to selection bias and lacked plausible mechanisms to support causality[23].

AVGs are synthetic grafts tunnelled under the skin that have an arterial inflow and a venous outflow that can be cannulated to facilitate dialysis. They are most commonly placed as a loop in the forearm or upper arm using the brachial artery or proximal radial artery as the inflow and either the cephalic, basilic, brachial or axillary vein as outflow, but can be placed in a straight configuration or in the thigh between the femoral artery and vein[43]. Their main advantages are that although they are reliant on sufficient autologous arterial inflow and venous outflow, they do not require an autologous vein conduit and therefore can be used in patients that do not have suitable veins for an AVF. Modern grafts can be cannulated as early as the same day which negates the lengthy maturation time required for AVFs and facilitates 'just-in-time' access creation where dialysis access can be created at the point where there is an established imminent need for HD. This avoids the physiological strain and potential morbidity of running an AVF for many months

before it is required and avoids the need for a TCVC for urgent starts[44]. Grafts also have a significantly lower primary failure rates compared to AVFs[44]. However, there are some significant disadvantages for AVGs over AVFs. Infective and thrombotic complications are higher[45]. Although they are more likely to work initially, AVGs are less durable, are more likely to develop complications and require interventions to remain functional, and are more likely to fail in the longer term compared to successfully matured AVFs[46].

The philosophy underpinning best practice in vascular access has evolved from a more rigid 'fistula first' approach to 'right access, right patient, right time'[43]. This is in recognition that there is no universally superior access type, and that best practice prioritises patient-centred care with shared decision making tailored to the patient's individual circumstances and patient choice[23].

1.3.2.2 Peritoneal Dialysis

Peritoneal dialysis is a home-based kidney replacement therapy that utilises exchanges of dialysate in the peritoneal cavity to achieve dialysis. During the exchanges small solutes such as urea, potassium, and creatinine diffuse from the blood into the dialysate and are removed from the body when the effluent is drained. It can be performed either manually (Continuous Ambulatory Peritoneal Dialysis (CAPD)) where manual exchanges are performed throughout the day or using a machine (Automated Peritoneal Dialysis (APD)) where a machine performs exchanges throughout the night[47]. Peritoneal dialysis requires the placement of a silicone catheter with its tip in the pelvis, which is the most dependent area in the abdominal cavity, and tunnelled to an exit site on the abdominal wall [48]. A two-week window between catheter placement and PD initiation is usually mandated, however PD can sometimes be initiated earlier through a modified regimen if a more urgent start is required[48]. Patients and their caregivers are trained to perform PD in the home, and are monitored by regular appointments in the nephrology clinic. PD gives patients considerably greater autonomy and freedom compared to ICHD, and this is highly valued by PD patients. However, conducting PD involves the transfer of work and responsibility from clinicians and the hospital to the patient and their home environment, and this can be the cause of burden and distress[49].

During 2024 in Scotland, 12.5% of incident KRT patients started on PD, and 3% of the prevalent KRT population were on PD [12]. The greatest advantage of PD is that it is the

simplest form of home-based dialysis which provides patients with greater flexibility and freedom than ICHD. The reduced requirement to attend hospital means that it is particularly advocated for in rural and remote areas[50]. It can also act as a bridge to transplantation, with an association between dialysing with PD rather than HD prior to transplant and superior transplant outcomes[51]. However, PD likely carries a greater risk of technique failure and has lower durability than transplant or HD. Although comparison of research on outcomes in each modality is challenging due to the use of observational data and differing study populations with different rates of co-morbidity, and differences in the management of the competing risk of death, cohort study data suggest that PD is more vulnerable to failure than other modalities[525354]. PD can result in infective complications such as PD peritonitis, mechanical complications such as catheter blockage or displacement. It relies on some residual native kidney function and a healthy peritoneal membrane to work therefore can result in inadequate solute and volume clearances and encapsulating peritoneal sclerosis[55]. A large cohort study conducted in Australia and New Zealand found that the median duration of PD technique survival was 2.4 years, with patient death, infection and inadequate dialysis being the most common reason for PD cessation[56].

1.3.2.3 Kidney Transplant

Kidney transplant is a surgical operation that involves the transplantation of a healthy kidney from either a living or a deceased donor into a patient with end-stage kidney disease to restore kidney function. It is most commonly performed as a kidney only procedure, however can be performed in conjunction with a pancreas or islet cell transplant for a subset of suitable patients with type 1 diabetes mellitus with loss of hypoglycaemia awareness and kidney failure[57], and very rarely in conjunction with liver, small bowel transplant or other solid organs as part of a multi-visceral transplant operation[58]. Following a kidney transplant, patients are required to take immunosuppressive medication to prevent rejection.

Kidney transplantation offers considerably superior survival[59,60] and superior HRQoL outcomes[61] compared to dialysis in matched cohorts, and is therefore considered the best KRT modality for suitable patients. Suitability for transplant listing is determined by a multidisciplinary team (MDT). In order to be considered transplantable, patients must be

judged to be fit enough to survive the physiological insult of the operation and the perioperative period; be technically transplantable where it is operatively possible to establish adequate arterial inflow, venous outflow, urinary drainage and space to place the kidney; be suitable physically, psychologically, and in terms of comorbidity able to take long term immunosuppression; and considered to be likely to live long enough to enjoy a survival and quality-of-life benefit from transplantation. The only absolute contraindications to kidney transplant are uncontrolled cancer, active systemic infections, and any conditions where life expectancy is less than 2 years[62]. However, many conditions that are common in advanced CKD patients such as ischaemic heart disease, obesity, peripheral vascular disease, dementia, previous cancers, and mental health conditions can either alone or in combination form relative contraindications to transplantation[62].

Live donor transplant grafts have better long-term graft survival rates compared to deceased donor grafts[63]. Live donor transplantation is most commonly a directed donation from someone either genetically or emotionally related to the recipient, but can be altruistic or non-directed live donation allocated through national allocation[64]. Several criteria must be met to be a living donor[65]. Firstly, to donate the potential donor must be in good health primarily to ensure that they are not subject to undue risk by donating but also to ensure that the donated kidney is safe to transplant. Their pre-donation eGFR must be sufficiently high that their predicted post donation eGFR remains within sex and age specific norms within their lifetime and that their risk of KFRT is no higher than the general population. Active malignancy and active systemic infection are usually considered absolute contraindications for donation; and hypertension, diabetes, obesity, cardiovascular disease, proteinuria, active hepatitis B and C infection, exposure to endemic tropical infections, haemoglobinopathies, genetic kidney disease, unfavourable renal anatomy and previous cancers are all relative contraindications requiring careful evaluation of the risk. Secondly, it is vital that the donor is donating freely without financial reward (although expenses can be reimbursed) and that the transplant team and an independent assessor is confident that the potential donor is able to give fully informed, voluntary consent without coercion and that the relationship between the donor and recipient is as stated. Clinicians cannot approach potential donors to ask them to consider donation: donors must come forward voluntarily and make the first contact with the live donor team which puts the onus on the recipient to discuss donation with their family and friends[66]. Thirdly, the kidney must be HLA, blood group and crossmatch

compatible with the recipient. If it is not suitable or if the team believe that a more suitable kidney could be found, the donor recipient pair can be entered into the National Kidney Sharing Scheme (NKSS)[65].

Kidney transplant can either be performed pre-emptively (before starting KRT by a different modality), in patients already on dialysis, or as a second or subsequent transplant in patients with failing grafts. Pre-emptive transplantation is associated with lower rates of graft loss and better overall survival compared to non-pre-emptive transplantation[67], and is therefore considered the gold standard. However, as the average deceased donor wait time is 2-3 years in the UK[68] and patients should not be listed until 6 months prior to their anticipated KRT start date, pre-emptive transplants are difficult to achieve without a live donor.

1.3.2.4 Comprehensive Conservative Management

CCM is the only one of the four management options that is not a form of replacement therapy. KRT has both a health-related quality of life (HRQoL) and survival benefit for many patients, but this is not universal. For some patients, especially those who are frailer and have a more complex and severe pre-existing co-morbidity load, there is far greater uncertainty regarding the survival or HRQoL benefit conferred by KRT[69] and many decide that the psychological, financial, and physical burden of dialysis outweighs any benefit[70]. CCM is a comprehensive package of interventions for those with advanced kidney disease that do not wish to undertake KRT including measures to delay the progression of kidney disease, minimise complications, alleviate symptoms and maximise quality of life, detailed communication, shared decision making, psychological and family support, cultural and spiritual care, and advanced care planning[71]. It should be distinguished from choice-restricted conservative care where patients in areas with low healthcare resources or poor access to affordable healthcare are unable to access KRT, or unrecognised KFRT where advanced CKD is present but is yet to be diagnosed or managed[72].

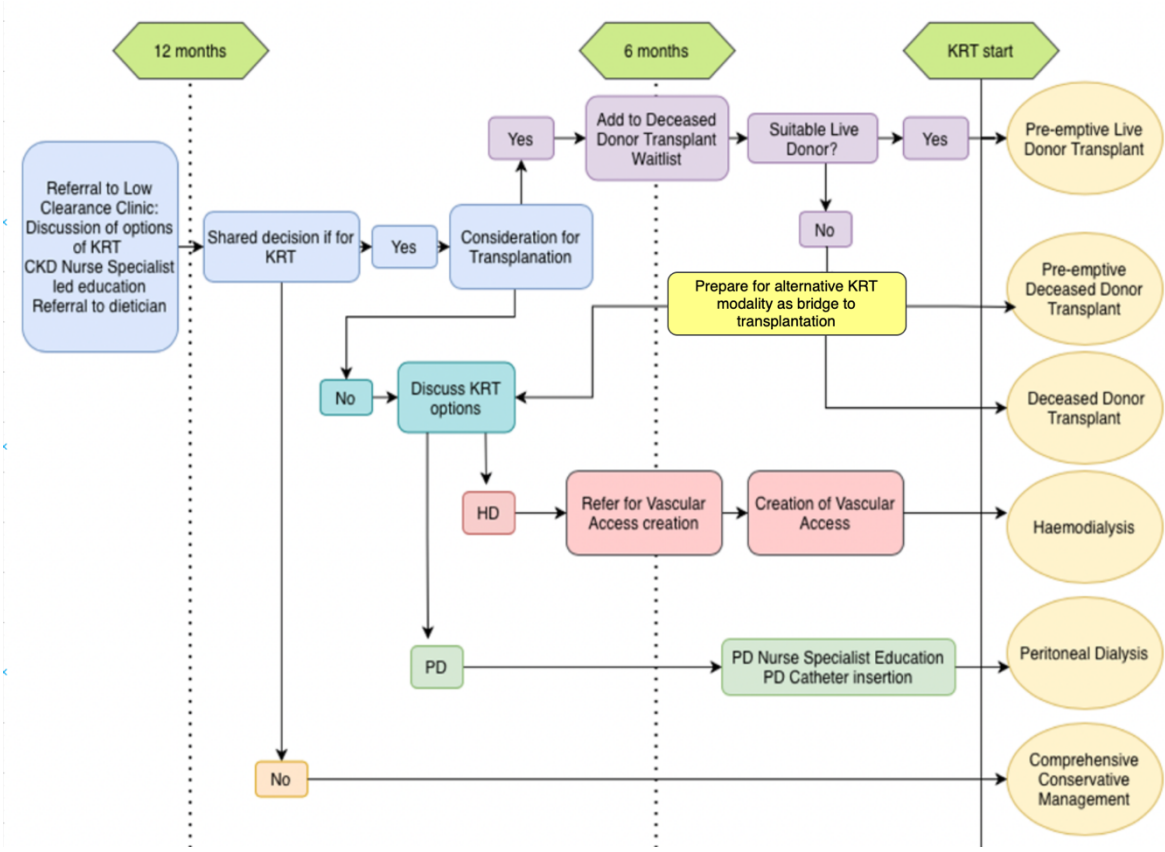
1.3.3 The processes and potential pathways of starting KRT

1.3.3.1 Optimal KRT Transition

Defining ‘optimal’ KRT transition is difficult as there are many optimal pathways influenced by the patient’s wishes, their health status and co-morbidities, their capacity,

and the resources and services open to them. The Standardised Outcomes in Nephrology (SONG) initiative has sought to define core outcomes based on the shared priorities of patients, caregivers, clinicians, researchers, and other key stakeholders across a range of kidney diseases and KRT modalities[73,74]. Patients consistently rank outcomes related to life participation, quality of life, impact on family, and treatment intrusiveness highly important. These domains were often more important to patients than mortality or biochemical outcomes, which reinforces that 'optimal' management is context specific and made holistically. A process map of optimal pathways for starting KRT is illustrated in figure 1.1.

Figure 1.1 Process map of optimal pathways for starting KRT in the 12 months prior to KRT initiation



Early and pro-active pre-emptive planning and preparation for KRT initiation is a key component of optimal starts regardless of the intended modality. NICE recommend referral to specialist nephrology services when patients are assessed as having a greater than 5% 5-year risk of needing KRT[75]. The assessment process for KRT or conservative management should start at least 1 year before therapy is likely to be needed[76]. Suitability for transplant should be considered early and potentially eligible patients should be

referred for transplant assessment early, with the aim of achieving a pre-emptive live donor transplant for eligible patients[77]. NHS Blood and Transplant (NHSBT) recommend that patients are fully assessed and activated on the deceased donor transplant waitlist six months before the anticipated KRT start, and that the process of preparing for live donor transplantation starts when the recipient eGFR falls below 20 to facilitate pre-emptive transplantation[62].

Current National Institute of Clinical Excellence (NICE) guidelines recommend that peritoneal dialysis access catheters are placed at least 2 weeks before the anticipated start of dialysis and AVFs are formed 6 months prior to the anticipated start time to allow for fully mature pre-emptive access that is ready to be used when dialysis us needed [76].

For haemodialysis vascular access KDOQI have defined several key principles to define optimal access[43]. Firstly, treatment decisions should be made in the context of a 'life plan' considering all KRT modalities, the current and anticipated medical and life circumstances of the patient, and patient preferences. The key aim is to achieve reliable, functioning, complication-free dialysis access to provide the required dialysis whilst preserving future dialysis access site options. A vascular access life plan for each patient would involve an access creation plan for their first access, an access contingency plan involving potential rescue and maintenance procedures such as angioplasties and stenting if this access has complications, an access succession plan for the next option should the first access fail, as well as a vessel preservation plan to preserve future options[43].

1.3.3.2 Barriers to optimal transition

Not all patients are able to receive the full package of careful pre-KRT preparation, and achieve a planned start in keeping with their wishes and treatment plan. Late presentation is defined as presenting to nephrology services fewer than 90 days prior to KRT initiation. The term 'crash dialysis start' refers to when a patient presents in kidney failure needing to start dialysis urgently with little or no prior contact with nephrology. 'Unplanned dialysis starts' describes a patient needing to start dialysis with a central venous catheter (except when TCVC is the planned definitive access) or during an acute hospitalisation[78]. These patients may have had prior nephrology care but experience a sudden deterioration in their renal function which necessitates earlier than planned KRT initiation or have been lost to follow up. Late or unplanned dialysis starts are associated

with increased short- and long-term mortality, increased hospitalisations, worse anaemia, much lower rates of pre-emptive access creation, and much lower uptake of peritoneal dialysis[79].

Several studies have looked at potential barriers to optimal starts. The Access to Transplantation and Transplant Outcome Measures (ATTOM) study found that in the United Kingdom patients that were older; of Asian or Black ethnicity; were divorced, separated or widowed; had no qualifications; no car ownership; and no home ownership were all less likely to receive a live donor kidney transplant[80]. Socioeconomic deprivation was associated with lower rates of live donor kidney transplant in the UK [81]. A qualitative study comparing barriers to live donor transplantation in those with higher and lower socioeconomic deprivation found that those who were socioeconomically disadvantaged described more passivity in their interactions with clinicians; greater disempowerment within the system; lack of a social support network both specifically within which a live donor could be found and more generally for support with other tasks; and a short-term focus with the need to manage immediate concerns limiting their capacity to consider what would be the optimal treatment strategy over the medium to long term[82]. Ethnicity, female gender, lack of health insurance, previous negative experiences of healthcare especially racism, low level of social support, low level of awareness of transplantation, system level issues in primary care and nephrology care providers in considering transplant referral, and rurality have all been identified as barriers to timely transplant referral[83].

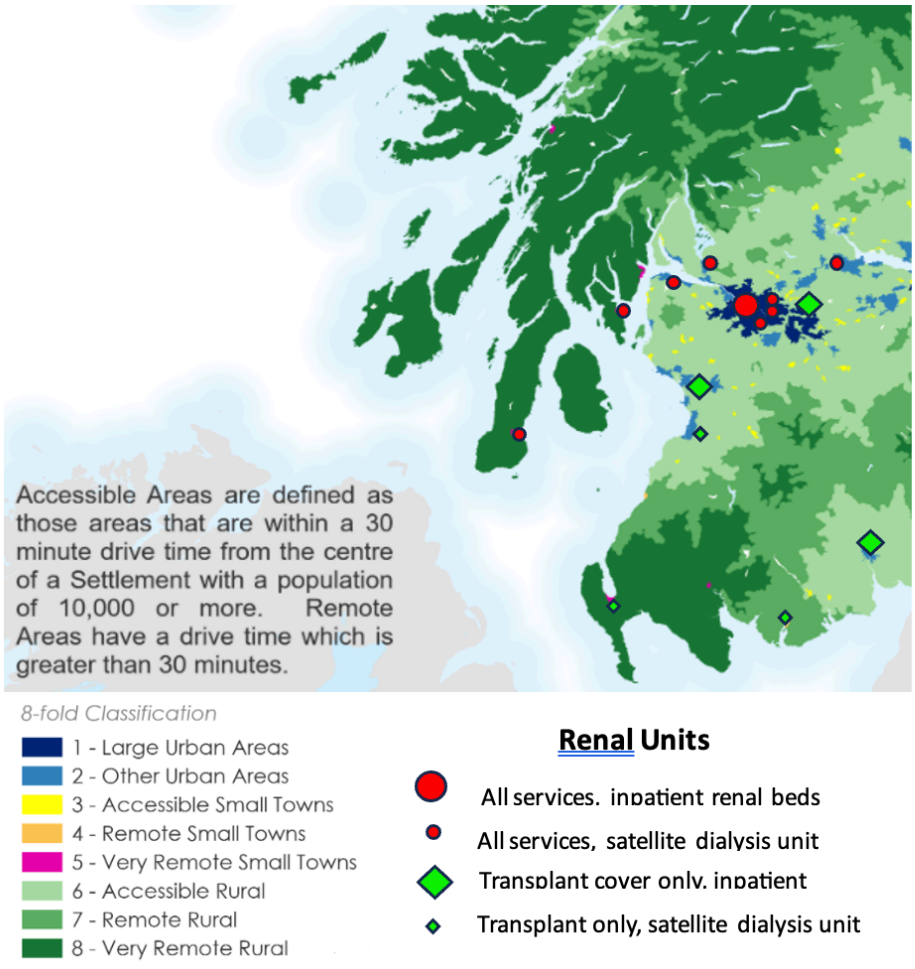
Patients' fear of dialysis, lack of symptom severity, concerns around the risks and benefit of access creation, preference for alternative modalities, negative influence of family members and other people within their social network, and negative interactions with healthcare professionals have all been identified as potential barriers to timely pre-emptive vascular access creation[84]. Lack of patient awareness of PD as a viable treatment option and fears of being a burden on their family [85] as well as fear of failing to perform PD adequately to prevent infection or medical complication, lack of physical space, lack of social support, and fears of social isolation dialysing at home rather than in-centre were all identified as barriers to PD[86]. Concerns regarding lack of suitable physical space in the home environment and concerns regarding lack of social support were more common in those who were socioeconomically disadvantaged [87].

1.3.4 The Glasgow Renal and Transplant Unit

This work was conducted in the Glasgow Renal and Transplant Unit, and therefore in this section I will briefly introduce both the unit and the area it serves to provide the context for the work.

The Glasgow Renal and Transplant Unit provides renal services for the area served by NHS Greater Glasgow and Clyde and NHS Forth Valley, a population of 1.6 million people and renal transplant services for the West of Scotland, further including the health boards of NHS Lanarkshire, NHS Ayrshire and Arran and NHS Dumfries and Galloway, covering a population of 2.7 million[88]. This area has considerable geographic diversity, containing communities that meet the definition of all 8 categories of urban and rural settings as defined by the Scottish Government[89], from the major urban area of Glasgow to very remote rural settings in Galloway, Argyll and Bute, and Arran (figure 1.2).

Figure 1.2: Map of the sites served by the Glasgow Renal and Transplant Unit and the rurality of the catchment area



The Queen Elizabeth University Hospital (QEUH) in Govan in the south of Glasgow is the main base of the unit. This is where the transplant unit is based, and where the PD clinic, vascular access clinic, interventional radiology and almost all operating is conducted. NHSGGC's inpatient renal beds are based there, and there is also a large outpatient dialysis unit. There are dialysis units and outpatient clinics in Glasgow Royal Infirmary, Stobhill and New Victoria Hospitals within the city of Glasgow, and some day case vascular access lists are conducted at Stobhill. Outwith Glasgow, the unit covers dialysis units and clinics in Forth Valley Royal Hospital in Larbert, Inverclyde Royal Hospital in Greenock, Vale of Leven District Hospital in Alexandria, and two remote and rural dialysis units in Campbeltown in Argyll and Rothesay on the Isle of Bute.

1.4 Aims and Objectives of this thesis

The central aim of this work is to examine the trajectories of healthcare workload and burden of treatment in patients with KFRT transitioning onto KRT to develop a taxonomy of treatment burden for this population and identify areas for potential intervention.

The four core objectives of this thesis are:

1. To systematically review the published literature to create a taxonomy of healthcare workload and a taxonomy of patient capacity during KRT Transition.
2. To describe patterns in treatment related workload during the six months before and the first three years following initiation of KRT, and explore the association between different demographic and clinical characteristics and workload.
3. To explore patients' experiences of treatment burden and workload-capacity imbalance during the year of KRT transition and describe how they evolve over time.
4. To conceptually model treatment burden in KRT transition and identify possible areas for intervention.

These core objectives are addressed by three work packages. Firstly, a qualitative systematic review will be conducted. The components of workload and capacity identified during transition onto KRT will be described by a systematic review of the qualitative literature. Secondly, a quantitative study will be conducted to examine in detail at the objective healthcare workload encountered by patients over the first three years of KRT

describing patterns of workload experienced over time and across modalities and identifying characteristics associated with high and low workload patterns. Thirdly, a qualitative study will be conducted involving serial interviews with patients over the first year following referral for initiation of KRT to explore the evolution of treatment burden and workload-capacity imbalance over the transition process. The findings of all three work packages will be synthesised in this thesis to conceptually model treatment burden during KRT transition, and to identify potential areas for intervention.

1.5 Overview of chapters

In this chapter I have explored the concept of treatment burden, considered the definitions and processes of kidney failure requiring replacement therapy (KFRT), and defined the population of interest for this thesis and the rationale for this. In Chapter 2, the theories underpinning treatment burden will be outlined and critiqued in further detail. In Chapter 3, the current knowledge base for treatment burden in KFRT will be outlined. In Chapter 4, the methodological underpinning of this work will be discussed. As this thesis is an alternative format submission, three core papers arising from this work will be presented in Chapter 5-7. In Chapter 5, a qualitative systematic review exploring treatment burden during transition onto KRT through examination of workload and capacity will be presented. In Chapter 6, a quantitative retrospective cohort study examining healthcare workload associated with KRT transition will be presented. In Chapter 7, a longitudinal qualitative study exploring treatment burden during transition onto KRT is reported. Lastly, in Chapter 8, treatment burden during transition onto KRT will be conceptually modelled by integrating the findings of the systematic review, the quantitative evaluation of healthcare workload and the longitudinal qualitative study. Potential areas for intervention to reduce treatment burden during KRT transition will then be explored, the results placed in the context of the surrounding literature, potential future avenues for research suggested, and the strengths and limitations of the thesis described.

Chapter 2 Theoretical Background to Treatment Burden

2.1 Introduction

2.1.1 Aims of this chapter

The aim of this chapter is to introduce the broad theoretical underpinnings of this work defining the core theories, models and concepts used and place it amongst other relevant theoretical constructs.

2.1.2 Rationale

This thesis describes an exploration of treatment burden in those transitioning onto KRT. Treatment burden is a theoretical lens through which we can seek to describe and understand the relationship between a patient, their capacity, their healthcare workload, their social network, their ability to and experiences of interacting with the healthcare system, and the effect this has on their wellbeing. Treatment burden can be thought of as the product of the interaction between healthcare workload and patient capacity, where if a patient's workload exceeds their capacity to meet it, they become overburdened resulting in suboptimal engagement with healthcare services, poorer adherence, reduced quality of life and possibly worse outcomes.

The core overarching aim of this thesis is to better understand the patient experience of transitioning onto KRT. May et al describe three main dynamic processes that influence patients' experience of their illness journey: treatment burdens, defined as the lived experiences of the work of effectively participating in care and self-care; social inequalities, defined as the lived experiences of socioeconomic disparities in health and healthcare; and illness trajectories, defined as the lived experiences of disease progression, biographical disruption, and status passage over time[90].

In this chapter, the conceptualisation of treatment burden and its different components are described along with other relevant concepts. The aim of this chapter is not to present an exhaustive review of the literature, rather to explore the relevant concepts that underpin this thesis and place the work within a wider context. Firstly, I will explore what it means to become ill and to be a patient and the sociological roles and expectations of patienthood and some of the theories underpinning that. In this section I will also briefly outline theories that help us understand patients' experiences of their illness trajectory and of biographical disruption and changes to their social status. Then I will define what is meant by healthcare workload in this thesis and explore the theories that underpin that. I will define patient capacity and explore different theoretical approaches that conceptualise how different aspect of capacity affect patients' ability to access healthcare. I will then discuss the different theories that explore the power dynamics between the healthcare system and patients.

These concepts and theories have been developed in the context of chronic illness and are therefore not specific to KRT transition. However, these are highly pertinent concepts to the context of KRT transition, with its life-long requirement of complex healthcare workload. A detailed exploration of the literature that examines treatment burden in the context of kidney disease is given in Chapter 3 and a systematic review of studies exploring healthcare workload and capacity specific to KRT transition is presented in Chapter 5.

2.2 Methods

My initial exploration of key papers in this field followed from discussion and recommendations from my supervisors. Further relevant papers were identified following: online searches using databases such as Medline and Scopus; reference and citation tracking of papers of interest; searches of grey literature; and attendance at conferences and academic talks relevant to the subject matter.

2.3 Background literature on theories underpinning our understanding of treatment burden

2.3.1 Becoming a patient: understanding the patient experience of illness and patienthood

There has been considerable debate and different schools of thought regarding what it means in sociological terms to be ill and to be a patient. Parsons conceptualised the 'Sick Role' in 1951, where he describes illness as a deviation from the norm and where a person in taking on the sick role has certain rights and obligations. A sick person has a right to not be held responsible for their condition and to be exempt from normal social roles such as work. On the other hand, they have a responsibility to seek and comply with competent medical help and to want to get better[91]. Parsons' Sick Role has been criticised for being too focused on acute illness or injury rather than chronic conditions, and for being normative in its assumptions of the power dynamic between doctor and patient, with the medical profession cast as the sole repository of knowledge and expertise and the patient as a passive and compliant receiver of care. According to Parsons, patienthood is a legitimate social role entered when illness is diagnosed.

One of the greatest weaknesses of the Parsonian conceptualisation of the Sick Role when exploring chronic diseases is how it describes illness as a single event that happens to a person. Corbin and Strauss in their Illness Trajectory Model dispute this, arguing that chronic illness is best understood not as a single event but a dynamic, non-linear, long-term process that will move through many phases over time and involve the person, their family, and the healthcare system[92].

Freidson offered an interactionalist understanding of illness. He argues that Parsons overlooks inequality, power, and everyday interactions that influence how illness is experienced. Freidson argues that illness is a sociologically negotiated state, with patients actively presenting symptoms and the medical profession acting as gatekeepers that can legitimise or deny illness states. In this theory, greater legitimacy is often conferred by society to acute physical illness compared to chronic, psychiatric, or contested conditions[93,94]. However, Freidson's work has been criticised for overstating and oversimplifying the dominance of the medical profession and of not adequately exploring

the dynamics of the doctor-patient relationship[95]. In Freidson's conceptualisation, patienthood is socially conferred through interaction.

Bury argues that chronic illness is experienced as biographical disruption: it disrupts a person's expectation of their life trajectory and their ability to make assumptions about their capacity to fulfil their ambitions and requires them to reimagine their life and their identity with a chronic illness[96]. For example, a person diagnosed with advanced CKD will need to confront the reality that they will never be disease free and the illness may have consequences for their life expectancy, ability to work, fertility, finances, relationship with their family and friends, and their expectations of life. This can be especially difficult when they are younger and so developing a serious chronic illness poses the greatest deviation from their expectations of life. According to Bury, patienthood is an ongoing biographical condition in which individuals integrate illness into their self-identity and life course.

Strauss and Glaser's Status Passage Theory[97] describes how individuals transition between different social statuses such as from child to adult, single to married, and from healthy to ill. These transitions are socially organised, institutionally controlled, and interactionally negotiated rather than being purely biological. Institutions and social actors such as doctors act as agents of passage between different statuses by administering the requisite rules, rituals, and procedures. For example, a doctor can formally diagnose an illness and thus legitimately confer patient status. They can also declare a person medically unfit for work, thus facilitating the transition from worker to being unfit for work and granting a status that allows access to support and accommodations from society. In this theory, patienthood is a status conferred through socially organised processes and rituals.

Foucault theorised that the medical profession objectifies patients through the 'clinical gaze', reducing illness into signs and symptoms to be elicited, classified, and measured. He also theorises that following the development of the Welfare State responsibility for health has transferred from the individual to the state, and through biopower is used as a mechanism for the state to control its' citizens. Patienthood according to Foucault is not an exception from social norms: all citizens are subject to responsibility to monitor, regulate, and optimise their body according to biomedical norms, and patienthood has shifted from the clinic into all facets of everyday life[98].

Many modern medical sociologists argue that high levels of interconnectivity, the datafication of previously unquantified aspects of life, well-established digital networks that permeate all aspects of daily life, deprofessionalisation, and social media have fundamentally altered the nature of patienthood[99–101]. Attitudes towards the medical profession are less deferential, and the primacy of doctors in conferring diagnoses and gatekeeping medical authority is more contested[102]. It has been argued that the online communities and social media engagement garnered by diagnoses, wearable technologies and the liberalisation of information, and the newly enhanced ability of the pharmaceutical and medical industries to reach patients directly with personalised content bypassing the traditional structures of the healthcare system, has altered patienthood so fundamentally the role is now best understood as patient-participant-consumer[103].

May argues that the changing epidemiology of diseases away from acute illnesses and injuries that were either self-limiting or rapidly lethal with few effective treatments, to multiple concurrent chronic illnesses that require patients to engage over long periods of time with services and therapeutic modalities that seek to manage rather than cure their illnesses has fundamentally re-engineered patienthood. The modern patient not the obedient receiver of care: he or she is required to be *active*, that is engaged in the shared decision-making process; *expert*, that is to possess knowledge and skills for self-management; *resourceful*, that is able to operationalise this knowledge and link it to existing patterns of service provision; and *prudent*, which is willing to minimise the load that they place on formal healthcare provision[104]. This represents a major shift of responsibility and workload away from the healthcare system onto the patient and their social network.

2.3.2 The hard work of health: understanding healthcare workload

Strauss in the seminal work “Social Organisation of Medical Work” was one of the first to conceptualise healthcare workload as work[105]. Three distinct but interrelated types of work that people undertake when managing chronic illness are described: illness related work, which is the work of managing symptoms, treatments, and preventing complications; everyday life work, which is the work of maintaining normal roles,

routines, and responsibilities; and biographical work, which is the work of reconciling their identity and life plans with their illness reality[106].

Whilst Strauss described different types of healthcare workload and recognised the work of integrating chronic illness into everyday life and self-identity, he did not discuss in detail the mechanism and processes of doing healthcare work.

Shippee et al argue that we should understand workload not just as the workload of illness or the healthcare tasks required of patient, but holistically as all the tasks and responsibilities that people grapple with on a daily basis. This means that our understanding of work should encompass everyday life as well as the responsibilities of patienthood including family life, employment, self-care, clinical appointments, taking medications, caregiving, and other responsibilities[7].

Normalisation Process Theory (NPT) was developed by Murray et al. It is a middle range theory that seeks to describe the factors that promote and inhibit the routine incorporation of complex interventions into everyday life, and describe the process in which a new intervention becomes embedded into routine practice it ceases to be new: it has become normalised[107]. This theory was initially developed to explain how organisations implemented complex interventions, but has been widely applied to explain how patients implement new healthcare workload.

NPT has four main constructs: Coherence, Cognitive Participation, Collective Action, and Reflexive Monitoring[108]. Each main construct has four subdomains, which are outlined in Table 2.1 below.

Table 2.1 Definitions of the different constructs of Normalisation Process Theory

Construct	Definition	Sub-domain	Definition
Coherence	The individual and collective sense-making work to understand the situation, options, what	Differentiation	The sense-making work in understanding how the new work differs from current work.
		Communal Specification	The sense-making work of building a shared understanding of work that needs to be undertaken and how it will affect all involved.

	could happen, and what it will mean for their life.	Individual Specification	The coherence work conducted at the level of the individual to work out exactly what this will mean for them.
		Internalisation	The value-finding aspect of the sense-making process where individuals and groups develop an understanding that the work that they are going to embark on is worthwhile
Cognitive Participation	The relational work required to work out what to do and how to do it.	Initiation	The work required to initiate the intervention
		Enrolment	The work of enrolling the assistance of others and organising people to collectively contribute to the implementation of the new practice.
		Legitimisation	The work of determining that they're doing the right thing and the decisions were correct.
		Activation	The work of sustaining the new practices once initiated
Collective Action	The operational work of enacting the work of the new practice	Interactional Workability	The interactional work of enacting the new work in everyday life.
		Relational Integration	The effect that enacting the work has on relationships and the confidence people have in each other.
		Skillset Workability	The appropriateness of the allocation and delegation of the work.
		Contextual Integration	The work of interacting with power structures such as the healthcare system or government agencies.
Reflexive Monitoring	Evaluating and appraisal	Systematisation	The work of collecting information about the effects of the intervention.

	work that people do to understand how the new practices have affected them and those around them	Communal Appraisal	The work of evaluating the impact of the new practices on their social network.
		Individual Appraisal	The work of evaluating the impact of the new practices on themselves.
		Reconfiguration	The work of refining and modifying the new practices.

NPT has been widely adopted and is recognised as having filled a key theoretical gap in understanding the implementation process. However, it has been criticised as having overly complex constructs that overlap, leading to heterogeneity in how the theory is applied and the fidelity granted to the original constructs by different researchers, and for not defining what normalisation looks like in real life[109,110].

2.3.3 Understanding patient capacity

Several different academics have broached the subject of how to define and describe a patient's ability to undertake healthcare workload, namely their capacity. The Capabilities Approach developed by Sen and Nussbaum seeks to evaluate an individual's actual ability to achieve various valuable functions as part of living[111,112]. Ten core capabilities are identified: life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; and control over their environment. These core capabilities have been simplified to five core domains by Grewal et al: attachment, role, enjoyment, security, and control[113]. The main difference between the Capabilities Approach and Patient Capacity is that the Capabilities Approach is primarily aimed at describing the domains that contribute towards quality of life whereas patient capacity is focused on describing the domains that contribute to the ability to undertake treatment workload. There is significant overlap between the concepts, however as this work is focused on understanding the burden of treatment we have elected to use capacity rather than capability as the theoretical underpinning of this work.

Social Capital Theory hypothesises that individuals have social capital, which is the resources available to them through their membership of formal and informal social

groups, network connections and means of civic engagement such as families, neighbourhoods, professions, religious communities and so forth which can in turn be mobilised[114]. There is some evidence that higher individual and area or workplace social capital is associated with better health outcomes[115].

May et al proposed the concept of Lifeworld resources. This has been developed to recognise that it isn't one thing in isolation but a combination of different factors and attributes in people's lives that interact with one another to tangibly influence their ability to meet healthcare workload. There are four different components described: personal capacity, social capacity, affective contributions, and enabling agency. A lifeworld resource is an interaction between an individual's personal capacity, described as the personal, psychological, social, and economic resources available to them. This interacts with their social capital, described as the informational, material and symbolic resources held in their social networks and their ability to secure the co-operation of others. This in turn interacts with the affective contributions available, described as the varying bonds of affection and moral obligation that make possible mutually supportive action. Personal capacity, social capital and affective contributions are fundamental features of social identity and when they're mobilised to achieve an individual or collective goal they represent lifeworld resources enabling agency[90].

Intersectional interpretations of the socioeconomic determinants of health also intersect with domains within patient capacity. This approach argues that race, class, ethnicity, sex, sexual orientation, nationality, citizenship, disabilities, and other systemic oppressions interact to create health inequities[116]. These factors do not exist or exert their effect in isolation, rather create a reciprocal and complex web of biological, cultural, environmental, and epigenetic factors that interplay to drive health inequity both by driving processes that worsen health and driving processes that make accessing appropriate and timely healthcare more difficult. Intersectional understandings of the socioeconomic determinants of health and patient capacity are highly concordant, however patient capacity allows us to have a more granular and mechanistic understanding of how different elements of a patient's capacity including their socioeconomic profile interacts with the system and what effect that has on their burden.

Patient Activation is a concept that seeks to describe the patient skills, knowledge, beliefs, and motivation required to be 'activated' to self-manage symptoms, engage in activities that maintain function and reduce health declines, be involved in treatment and diagnostic choices, collaborate with providers, select providers and provider organisations, and navigate the healthcare system[117]. It is similar to Patient Capacity in that it focuses on a patient's ability to undertake healthcare workload but differs significantly in its focus and assumptions in choosing to centre on a patient's skills, knowledge, belief and motivations rather than taking a more holistic view that also includes their social network, environment, previous experiences of healthcare, and power relationship with the healthcare system. It has been criticised for having a neo-liberal theoretical underpinning, with an overly moralistic view of what it means to be a good self-manager: to be activated is to require fewer healthcare resources, and it is the patient's moral duty to consume less resources and to take responsibility for their own care[118]. It has also been criticised for the presumption that patients are free and able to choose to take responsibility for their care without considering poverty, housing and food insecurities, mental illness, limitations in cognitive abilities and knowledge, and inadequate social support that may preclude that from ever being a real choice as well as deep seated mistrust or lack of confidence in healthcare systems that may preclude their ability to engage with care[119]. Patient Activation has also been criticised for not capturing the fluctuating nature of some chronic conditions or the collaborative nature of care[120]. For these reasons, we have elected to utilise Patient Capacity as our theoretical underpinning in this work.

Boehmer et al in the Theory of Patient Capacity (TPC) emphasise that patient capacity is not simply a set of resources available to the patient to be utilised but a product of a dynamic interaction between identifiable psychological and social mechanisms[6]. They defined five separate elements that can interact to either enhance or diminish capacity: biography, resources, environment, experiences of enacting work, and their social functioning.

Biographical capacity is the capacity to adapt their understanding and expectation of life to include living with and managing chronic illness. Boehmer theorises that patients that are unable to recreate a new biography that includes their illness and required treatments struggle to cope emotionally with their new reality, and struggle with feelings of lack of

control, anger and grief, and resentment of their condition. They therefore struggle to engage constructively with care. Those who were able to reframe their biography could function better, and were able to find hope and meaning in their future life.

Resources refers to all the resources patients have available to them to mobilise to meet the demands of their treatment. The resources described by Boehmer include physical energy, time, knowledge, transportation to and from medical appointments, physical health, physical abilities, finances, paid supportive services, literacy, and self-efficacy. Boehmer emphasises that it is not necessarily the availability of resources that directly gives patients capacity, but provides the necessary building blocks for patients with some capacity to build further capacity.

The Environment within which patients fulfil their healthcare work impacts their capacity. Patients who feel cared for in a supportive environment, who have ready access to facilities and care, and who live in safe communities can draw capacity from this. Isolation is detrimental to capacity, and the environment could contribute to this through geographical isolation, structural isolation if their housing is no longer accommodating their mobility needs, and communal isolation if communal facilities such as public transport, accessible green space, accessible communal spaces such as religious spaces, shops, and hospitality venues are not present in their community.

The realisation of necessary work is the impact that enacting healthcare work has on capacity. Work requires capacity, and if enacting the work is felt to be successful on a cognitive, emotional, and experimental level, then that positive experience can build further capacity. If on the other hand, the work is overwhelmingly burdensome, or the patient is unable to successfully navigate the complex healthcare environment, or if they experience complications or setbacks despite their best efforts, then that experience can diminish capacity and undermine the patient's confidence both in their ability to undertake healthcare work and the healthcare system. This can impair further engagement with healthcare.

Social functioning is the capacity derived from a patient's ability to socialise in the widest definition of the word: their ability to build and maintain social relationships from which they can draw upon to meet the challenges of their chronic illness. Boehmer describes four main components: the patient's personal ability to socialise; the ability of their social

network to accept the chronic condition and the changes it has caused; their social network's ability to provide instrumental support; and the social relationship with their healthcare team. This domain emphasises that a strong, proactive social network can be a source of considerable support and additional capacity for patients, and that those patients without social support that they can draw upon or who have complex family dynamics or unsupportive families, friends, and colleagues, can be particularly vulnerable. Of note in this domain is the social relationship with their healthcare team, where a well-functioning social relationship between the patient and the clinician is required for them to understand, receive treatment, and plan the self-management of their condition. Negative experiences of healthcare, especially situations where they feel not listened to or dismissed, could be highly deleterious to capacity.

2.3.4 Understanding the dynamic interaction between patient, workload, capacity and the system

Shippee et al developed the Cumulative Complexity Model (CuCoM) to explore why the relationship between workload and burden did not appear to be linear: some patients seem relatively unencumbered by tremendous workloads whilst others profoundly struggle with far less. They developed the concept of workload-capacity imbalance[7]. If a patient's workload exceeds their capacity to meet it, they become excessively burdened and start experiencing poorer health outcomes because of inefficient care. This can then promote a feedback loop where poorer health can cause their healthcare team to prescribe further treatments thus increasing the patient's workload, and their worsening health can diminish their capacity to meet that workload leading to worsening burden.

This in turn informed the development of the Burden of Treatment Theory by May et al. They developed the theory to explore the relationship between sick people, their social networks, and healthcare services[1]. The BoTT describes the mechanisms through which patients mobilise capacity, express capacity, mobilise for delegated tasks, and enact delegated tasks in the various contexts in which they are required to undertake healthcare work. These four domains will now be outlined.

BoTT conceptualises capacity as a resource to be mobilised, both at the level of the individual and the relational network[1]. It subdivides capacity into 'agency' which is the

ability to engage with health problems and with others, and 'relationality' which are the social networks through which agency can be expressed or distributed. Capacity is modulated through the opportunities offered by the healthcare system to access care and the control exercised by healthcare systems on the content and structure of services offered.

The qualities and behaviours that a patient and their relational network need to display to exploit healthcare opportunities are understood as their ability to express capacity. The degree to which a patient and their relational network possess the cognitive and material capacity to enact the work required of them is defined as their functional performance. This is mediated through their social skill, which is the ability the possess to engage and mobilise to co-operation of others, and their social capital, which is the informational and material resources available to them through their wider social network. This is also heavily influenced by their structural resilience, which is their ability to cope with adversity such as biographical disruptions, adverse health events, and social processes.

BoTT then draws upon concepts informed by NPT to explore how patients mobilise for work delegated to them by the healthcare system. It describes the process through which the patient must understand the expected work, enrol the assistance of others in their relational network, perform the task, and then monitor and appraise the effect.

Fourthly, BoTT explores the mechanisms through which patients enact the work and how this can create burden. This also draws upon subdomains of NPT. The first consideration is the interactional workability of the task at hand: can the patient and their relational network do the expected material and cognitive work. If the patient and their network possess the necessary practical skillset (termed skill-set workability) and the necessary local exploitable resources including those provided by the healthcare system (contextual integration) and have confidence and trust in the process and outcomes (relational integration) then it is likely that they will be able to successfully enact the work. However if patients are delegated work that they do not possess the requisite skills or resources to undertake, for example if they are asked to use a new digital app to request medication without the necessary digital skills or technological hardware or if they are asked to travel to a clinic that they have no means of securing transport to, or if their confidence in the

process is undermined, then their experiences of trying to undertake the delegated task is likely to be burdensome and potentially unsuccessful.

A key concept in BoTT is that instability is normal, especially in the context of chronic illness, and therefore treatment burden is an inherently dynamic concept liable to continual change in response to disease trajectories and relational instabilities.

A systematic review looking at the application of BoTT in 30 different studies across a wide variety of clinical conditions found that the theory provided a useful conceptual, analytical and sensitising lens that was adaptable and applicable across a wide variety of contexts[121]. One critique was that the theory inadequately captured the burden of *lack* of treatment in low- and middle-income countries, as it's conceptualisations of the healthcare system assumes a highly resourced system that may well be flawed but is nevertheless present and treating patients, and thus creating workload. A study in Malawi that utilised BoTT found that BoTT inadequately captured the burden of lack of access to services or treatments and required adaptation of the theory to capture this[122]. In relation to the work in this thesis however, we felt that the theory was suitable to be applied unaltered to our context.

2.3.5 The power dynamics between patients and the healthcare system

Understanding the power dynamic between healthcare and the patient is key to exploring the context in which healthcare workload is undertaken. The locus of control varies widely between theories, with neoliberal theories placing the control and responsibility on the patient through to Marxist theories that sees healthcare as means of control. These theories will be explored further in this segment, and although none have been directly used in the analysis of data in this thesis they have been considered in the development of this work.

Neoliberal praxis of healthcare transfers responsibility for wellbeing and health from the state and society onto individuals through a process that has been named 'responsibilitization'[123]. Individuals are morally responsible for navigating societal and institutional interaction using rational choice and cost-benefit calculations grounded on market-based principles to the exclusion of other ethical, social, or human interest[124]. Neoliberalism is a form of governing which seeks to shift an individual's sense-making and

understanding of where responsibility lies for problems from external agents to the self: it uses the framing of freedom and autonomy to place individuals as 'consumers' of healthcare with control over their care, while also appealing to individual responsibility taking and self-care[123,125]. Much greater focus is placed on the individual's responsibility rather than collective welfare: individuals are free to take responsibility for their own problems and are free to expect others to do the same.

Marxist critique of the power dynamics in healthcare hold that healthcare is used as a means of class control. Navarro argues that the priorities and resource allocation are determined by the corporate and upper middle classes who control the institutions of healthcare and not by the working and lower middle classes who form most of the population[126]. These priorities are set to preserve and further the interest of capitalism, namely the maintenance of an economically productive population. Marxist academics not only critique healthcare for prioritising the need of the market-based economy, but also of becoming commodified because of the marketisation of healthcare[127]. Caplan argues that applying market-based principles such as competition between institutions to the structuring of healthcare has led to the commodification of healthcare: healthcare is seen as a product to be consumed, and the priorities and availability of care is determined on what can be made profitable rather than what the true needs of society are[128]. Marxists have also critiqued the framing of the understanding of ill health on the individual level to the exclusion of considering the social, environmental, and structural context[129].

The Cognitive Authority Theory (CAT) describes the mechanisms by which a health professional's judgement of a patient and their family's competence and expertise (named their Cognitive Authority) impacts their involvement in care and the appropriateness of the care received[130,131]. It shares a common understanding of capacity with BoTT. The theory hypothesises that patients can be rendered vulnerable to inadequate care not because of their capacity but because of assumptions made about them by the system: their cognitive authority is assumed to be less valuable. Patients and caregivers need to use their knowledge and capacity to carry out healthcare work in a way that aligns with systemic expectations, and as they do, they are assessed for competency, trustworthiness and credibility by professionals who hold positions of higher power and authority. This

judgement in turn determines how much credence the system pays to their decisions and choices, and the extent to which the system will facilitate them to experience control.

The CAT expands on our understanding of how capacity can affect access to care: it hypothesises that some people can present themselves in a way that is more credible or sympathetic and operationalise their social privilege to access better care. This is not a product of their capacity but a product of how the system reacts to expression of their capacity. Conversely, patients and family members who do not present themselves or access care in a way that the system confers legitimacy- often marginalised communities- are disadvantaged as their cognitive authority is not respected.

Link and Phelan's Fundamental Causes Theory argues that socioeconomic deprivation and social support are a fundamental cause of disease as they affect multiple risk factors for developing diseases such as smoking, poor diet, environmental exposure, healthcare access, stress, and work conditions. Socioeconomic deprivation also affects disease outcomes as it reduces access to resources that can be mobilised such as money, knowledge, power, prestige, and social connections. Link and Phelan argue that the link between socioeconomic factors and poor health persist even when single risk factors or single disease exposure are modified or eliminated (such as interventions to reduce smoking or interventions to eliminate infectious diseases) and therefore argue that fundamental social conditions must change to improve population health[132].

The Health Power Resource Theory (HPRT) interprets health inequalities through the lens of power relationships[133]. Its central tenet is that health inequalities are mediated not through the direct effect of socioeconomic status, individual behaviours, and healthcare access but through health power, defined as the ability of social groups or institutions to influence how health resources are distributed and experienced in society. There are four key mechanisms through which health power relationships affect access to care: Stratification, which is how socioeconomic resources are distributed in society; Commodification, which is how the provision of healthcare is treated as a commodity open to market economics and therefore requires socioeconomic resources to access it; Discrimination, which is the mechanisms of systemic biases through which the socioeconomic resources of minoritized groups are devalued relative to their more socially advantaged counterparts; and Devitalisation, which is how systemic processes and

social conditions disempower people and reduce the utility of health resources- or put more simply, how the system grinds people down. The key distinction in HPRT is that it treats power as the property of social groups rather than individuals, and argues that health power determines the resources available rather than resources determining the power- that is the focus is not on the individual characteristics but on the underlying power dynamics that make those characteristics matter.

HPRT differs from BoTT in that the primacy of its focus on group rather than individual factors, but there is commonality in its focus on understanding the structural and sociological processes that mediate healthcare inequalities rather than which individual characteristics are associated with inequity.

2.4 Conclusion

This Chapter outlines the theoretical approaches that have informed this work and the related theoretical concepts that were explored when deciding upon which theories to utilise. A literature review of treatment burden specific to kidney disease will be explored in Chapter 3.

In summary this chapter has outlined how the understanding of patienthood has evolved from a patient being a passive receiver of care exempt from social norms, to the requirement for a patient to be an active expert in their own care to whom many healthcare tasks and responsibilities are delegated to. We have explored what constitutes healthcare workload and how one may conceptualise how new healthcare work is normalised into everyday life. We have also explored how we can understand the different factors that contribute to a patient's ability to meet healthcare workload through an exploration of patient capacity and adjacent concepts. We have considered the balance between healthcare workload and patient capacity and how this can result in treatment burden. Lastly, we have explored the impact of interaction with the healthcare system, and how power relationships and inequality both within the healthcare system and in wider society can affect a patient's ability to access care and their experiences of treatment burden.

Chapter 3 Overview of Treatment Burden in Kidney Failure Requiring Replacement Therapy

3.1 Introduction

3.1.1 Aims of this chapter

The aims of this chapter are to provide background information on what is already known about treatment burden associated with KFRT and place the work presented in this thesis within its wider context.

3.1.2 Rationale

The aim of this thesis is to explore the experience of treatment burden for those transitioning onto kidney replacement therapy.

In Chapter 2, we have explored the theoretical underpinning of treatment burden. Treatment burden is an important concept for patients undergoing KRT as they undergo an arduous, complex treatment regime that is life-long.

In this chapter a description is given of qualitative and quantitative literature that has explored treatment burden in KRT. We have chosen to narrow the scope to KFRT rather than kidney disease more broadly as kidney disease has a wide spectrum of severity, and the literature pertaining to the burdens of advanced kidney disease and the demands of KRT are more pertinent to our study population. In Chapter 6 we report a study that quantitively measures healthcare workload objectively using time as proxy for treatment burden, and in Chapter 7 we report a study that qualitatively explores treatment burden through longitudinal interviews. Chapter 5 is a systematic review of qualitative literature describing workload, capacity, and treatment burden during transition onto KRT, therefore the aim of this chapter is not to provide an exhaustive review of the literature but to offer discussion of relevant papers with the intention of placing the work described in this thesis in its relevant context.

3.2 Methods

Relevant articles were sought through searches of Medline, Scopus, and CINAHL and through reference and citation tracking. Grey literature produced by relevant agencies and charities were also searched. As the aim of this chapter is to provide a broad descriptive overview of the current knowledge base, no additional theoretical synthesis or meta-analysis have been conducted on the findings.

3.3 Background literature of treatment burden in KFRT

3.3.1 The qualitative literature

Treatment burden is a concept that is gaining recognition but is not universally used, therefore the literature that explicitly study treatment burden in KFRT is limited. However, there are many studies of the patient experience of KRT that implicitly capture many elements of treatment burden. Primary studies that have explored the patient experience of KRT and treatment burden will be described in turn, then the relevant qualitative syntheses explored. In the systematic review presented in Chapter 5 we have explored the literature specifically pertaining to the burden of transitioning onto KRT, however in this section we sought to present the literature on treatment burden in kidney failure more broadly in order to describe the wider context in which this work lies.

3.3.1.1 Early studies of the patient experience of KRT

Prior to 1990 there is a paucity of qualitative research into any aspect of the patient experience of KRT. The 1990s introduced a rapid expansion in qualitative study of the patient experience of dialysis, and growing academic exploration of what it means to be a KRT patient[134]. Studies explored how starting dialysis requires a new understanding of being that eventually becomes normalised by patients who are required to adapt to and accept new dependence on technology and the control it exerts over their life[135,136]. Three phases in the dialysis patient's life were described: the initial crisis phase of transitioning onto dialysis, the chronic living phase, and terminal phase of declining health and increasing complications[137]. The effect of dialysis on the patient's family was also recognised, with a growing understanding that the patient experience of dialysis is best

understood in the context of the network of important social relationships surrounding that patient [137,138]. Mourning lost independence and longing for normality were common themes[139]. Early studies of the experience of receiving a kidney transplant explored how transplantation is not just a treatment but a social and symbolic experience that induces a biographical and identity transformation, where recipients often feel contradictory emotions of both gratitude and a feeling that their body is no longer truly their own with an ongoing obligation to the donor and a moral responsibility towards the donated organ[140].

Most studies from this time-period are small exploratory studies using phenomenology or grounded theory aiming to understand the lived experience of KRT, and there is no attempt at conceptualizing the patient experience or the mechanisms that influence it.

Very few studies directly addressed the impact of the healthcare system on the lived experience of undergoing KRT, although Curtin and Mapes explored the characteristic behaviours of people who lived 'successfully' on long term (defined as greater than 15 years) kidney replacement therapy and found that the self-management strategies displayed by these patients were centred on how to manage the system and health professionals rather than other aspects of managing their illness and treatments[141]. Strategies included presenting themselves in a positive way to staff, minimising the demands they made so to be taken seriously when requests were made, being vigilant in their oversight of their own care, and engaging in active self-advocacy, self-proposal of treatments, and independent adaptation of therapies. Although this study pre-dates the widespread adaptation of the concept of patient capacity, it illustrates how patient capacity to navigate the system influences access to and experience of care.

3.3.1.2 Studies of treatment burden

Since 2010, several studies have been published studying treatment burden in a KFRT population, as summarised in Table 3.1.

Several studies discussed treatment burden more generally but did not apply BoTT. Karamanidou et al explored treatment burden in patients on long term haemodialysis[142]. They found that as patients started HD the distinction between illness and treatment was lost for many patients, with symptoms often ascribed to HD rather than KFRT. This

suggests that researchers and clinicians may distinguish between illness burden and treatment burden differently to patients. Although not longitudinal, the study reported that starting KRT was highly disruptive but became progressively easier to live with over time. Participants reported conflicting emotions about treatments, with dialysis seen as both a lifeline and restricting experience. Feeling in control and having a sense of agency within the healthcare system was important.

Barnes et al studied the experiences of patients on the kidney transplant waiting list and of those who had received a transplant [143]. This study predominantly focused on symptom burden and did not explore the impact of healthcare system functioning on burden. That said, the study offers an important exploration of how transplant improves quality of life and physical capacity compared to life on the waiting list, with acknowledgement of the burdens that can arise with post-transplant rejection.

Other studies have explicitly applied BoTT to a kidney disease population. Hounkpatin et al used BoTT to explore treatment burden in a CKD 3-5 population, most with less severe CKD, but some who were close to needing KRT [144]. As well as the treatment burdens associated with understanding CKD and the treatment options, and the burden of adhering to treatment regimens, participants reported that lack of interpersonal continuity of care, lack of communication between primary and secondary care and unexpected changes in healthcare were all sources of treatment burden. In their exploration of the influence of capacity factors on the experience of CKD, personal attributes such as positivity and resilience, access to a social support network, and financial and environmental factors such as financial security, access to a car, and geographical closeness to hospitals were all identified as important factors.

Javier Roberti, based in Buenos Aires, has published a body of work applying BoTT and associated theories to a KRT population. They have published three papers based on semi-structured interviews with 50 KRT patients and 14 renal healthcare professionals. The first paper explored how social and economic vulnerabilities shape the experiences of work of participating in KRT care[145]. They found that a patient's agency to meet demands is extended by relational networks that can provide logistical, financial, and emotional support. When relating with the healthcare system, patients reported scant information about treatment options, changing dialysis schedules, lack of contact with transplant

teams, and difficulty accessing medications. This study highlighted that even in universal healthcare systems, under-resourcing and healthcare policies and practices that prize self-management result in the transfer of work from the healthcare system onto patients and their family.

The second paper explored how patients negotiated treatments with health professionals and how this influenced treatment adherence[146]. In order to be able to adhere to KRT and its associated treatment workload patients must negotiate access to treatments that they can adhere to, with some being prescribed dialysis schedules and medication regimes that are beyond what they have the physical, emotional or financial capacity to meet. Roberti argues that relationally induced non-adherence can arise with healthcare professionals can't or won't discuss or negotiate with patients about their beliefs around treatment and what they have the capacity to do.

The third paper in this body of work applied Glaser and Strauss's Status Passage Theory[97] to describe life on KRT as a sequence of transitions, for example the transition to being a dialysis patient, the transition from dialysis to transplant, or possibly the transition back to dialysis in the context of a failing transplant, has on a patient's role and their perceived control over their lives[147]. They found that the initial transition from pre-KRT life onto dialysis was seen as a transition to an unknown life, sometimes accompanied with other transitions, such as transitioning out of employment or transitioning to being dependent on others for social care. Transitioning from a dialysis patient to a transplant patient reversed some of these transitions as their health improved and they regained their time and their capacity to work and resumed familial and social roles. The irreversibility of the KFRT diagnosis but the reversibility of the transition to transplant patient, living with the knowledge that the transplant could fail and they may return to life on dialysis, was difficult for many patients. Lack of control over both the course of the disease and the functions of the healthcare system was reported by many patients.

Roberti has also published a qualitative synthesis exploring the work of being an adult patient with CKD, which is explored in greater detail in Section 3.3.1.3.

Table 3.1 Summary of qualitative studies of treatment burden in a KFRT population

Study	Population	Description	Findings

Barnes 2025[143]	14 patients on the transplant waiting list, and 19 post-transplant patients, sub grouped low or high risk of antibody mediated rejection (AMR) receiving treatment in a USA transplant centre	Semi-structured interviews exploring symptom and treatment burden aiming to develop conceptual disease models for the wait list, low risk of AMR, and high risk of AMR population	Participants on the waitlist describe significant symptom burden diminishing their capacity due to fatigue, brain fog, and reduced physical function which in turn reduced their autonomy and quality of life. Post-transplant without AMR patients reported improved quality of life and increased capacity post-transplant, but ongoing burden from medications and appointments Post-transplant patients with AMR still reported lower burden than pre-transplant, but higher anxiety and depression due to the complication and ongoing impact on their ability to work.
Karamanidou 2014 [142]	7 long term HD patients in a dialysis unit in London	Semi-structured interviews exploring life with chronic renal failure and living on dialysis.	Patients do not make a distinction between treatment and illness burden once on KRT. Experiences of burden evolve over time, and often improves as HD becomes normalised into a person's life. Ambivalence about HD was common, with the duality of being both life-saving and intrusive and restrictive.

Hounkpatin 2020 [144]	29 adults over the age of 60 with CKD stage 3-5 and 10 renal healthcare professionals	Semi-structured interviews with patients and focus group discussion with health professionals using a topic guide informed by BoTT.	Treatment burden themes identified were: 1) Understanding CKD, its treatment, and its consequences 2) Adhering to treatment and management 3) Interacting with others in the management of CKD Capacity themes included: 1) Personal attributes such as optimism and pragmatism 2) Social support network 3) Financial capacity, environment, and life responsibilities.
Roberti 2022 [145]	50 patients with CKD and 14 healthcare providers in two healthcare facilities in Buenos Aires.	Semi-structured interviews exploring how social and economic vulnerabilities affect KRT, analysed by a framework informed by BoTT.	The work of kidney disease has a significant impact on patients' lives. In under-resourced settings responsibilities are shifted to patients and their relational networks, and patients without a robust network are highly vulnerable.
Roberti 2023a[146]	50 patients with CKD and 14 healthcare providers in two healthcare facilities in Buenos Aires.	Semi-structured interviews exploring treatment adherence analysed with a framework	Patients that perceived their KRT healthcare workload to be excessive or in conflict with other priorities in life entered negotiations with healthcare professionals to modify their workload.

		informed by BoTT and CAT.	Relationally induced nonadherence arose when professionals couldn't or wouldn't enter into discussions with patients about their beliefs and desires around treatment and what is possible for them to do.
Roberti 2023b [147]	50 patients with CKD and 14 healthcare providers in two healthcare facilities in Buenos Aires.	Semi-structured interviews exploring status passage as a KRT patient, analysed by a framework informed by Status Passage Theory, BoTT and CAT.	Patients experience life on KRT as a sequence of transitions, and these transitions can have a devastating effect on the patient's ability to fulfil their roles and are accompanied by fear and frustration. KRT patients often feel very little control over these transitions.

3.3.1.3 Relevant qualitative syntheses of treatment burden in KRT

The only qualitative synthesis of treatment burden in KRT explicitly informed by BoTT was published by Roberti in 2018 [148]. In this qualitative systematic review, they found that being a person with end-stage kidney disease involved high burden, time-consuming, invasive, and exhausting healthcare work. Socioeconomic status was a key determinant of the experience of CKD. When KRT is required by uninsured and underinsured patients, they faced fragmented and inadequate care, and additional workload fund-raising to meet the costs. Patients' capacity could be undermined by deficits in communication between healthcare professionals and patients, rooted in structural and systemic factors.

Several other qualitative syntheses have been published that explore concepts relevant to treatment burden (Table 3.2).

Morton et al published a qualitative synthesis that looked at factors that influenced patients and carers' decision-making for KRT modality including conservative care[149]. They identify four key themes that influence the decision-making process. Firstly, how patients confronted their own mortality in the face of a life-threatening diagnosis influenced their treatment choices. Patients considered what treatment burdens and what impact on their family and friends are acceptable to them in the pursuit of life-prolonging treatment. Secondly, the lack of real choice was identified as a key theme. Lack of information, medical paternalism, clinical eligibility considerations, resource constraints, health insurance constraints, access constraints to in centre haemodialysis and to transplantation, are all identified as system-level constraints on the choices available to patients. Thirdly, how patients gained knowledge of their options influenced the decisions they made. The timing of information was vital, with patients being presented with options when they were too unwell to process what they were being told or feeling rushed into decisions. The experiences of peers already on KRT greatly influenced patients both positively and negatively. Seeing others achieve a positive outcome such as a successful transplantation or negative experiences such as complications or poor outcomes influenced the acceptability of various treatment options for patients. Fourthly, the effect of the treatment option on their ability to maintain their pre-existing lifestyle influenced choice. Many studies reported that quality of life was more important to patients than longevity, and treatment choices were based on what was perceived to cause the least disruption to usual activities, familial responsibilities, and employment. Perceived family and carer preference had a strong influence on patient decisions. Once the decision was made, many studies reported that patients prioritised maintaining the new normal rather than continually changing and refining treatment choices.

Tong et al have also published a qualitative synthesis of perspectives of living on peritoneal dialysis[49]. Although this work was not explicitly informed by BoTT or any other middle range theory, many of the themes overlap with patient capacity and treatment burden factors. Resilience and confidence in their own ability to overcome difficulties and access to support structures from peers, family, and clinicians were identified as a protective factor for coping with PD. Conversely, those reporting social abandonment and isolation, and those reporting poor clinician-patient relationship had poorer experiences. Patients described an overwhelming responsibility with PD, and wanted to minimise the intrusion of the treatment into their home life. Many were worried about the burden

placed on their families because of their illness. For many PD was seen as a means of regaining control and achieving independence and self-efficacy, with more flexibility to integrate the treatment into daily life whilst retaining social functioning and ability to travel. PD affected patients' identity, with some struggling with the bodily intrusion of living with a PD catheter. Patients also struggled with the disablement that resulted from KFRT and from the treatment demands of PD, with patients mourning the loss of social roles, physical ability, and the biographical disruption of adapting to a new life on PD.

Sedin et al explored the lived experience of transitioning onto KRT[150]. They found that transitioning onto KRT was life-changing, and the need to confront the life threatening and potentially life-limiting nature of their illness triggered existential questions and a confrontation of their mortality. KRT profoundly limited patients' lives and encroached onto all aspects of their lives. KRT affected patients' quality of life both positively and negatively, with some studies reporting quality of life improving with improving symptoms, new social connections made at dialysis, and increasing normalisation of KRT into their daily life. Other studies focused more on the negative effects, with unwanted side-effects, fear of the future, and loss of their previous life negatively affecting patients. Relationships with their healthcare team was key to how secure patients felt with their care, with patients who felt adequately informed and secure with their team reporting far better experiences than those who felt like they lacked information or meaningful connection. Ambivalence about treatment was common, with many patients struggling to balance the benefits of KRT against the side-effects of treatment and the reality of their daily life.

Table 3.2 Summary of qualitative syntheses of treatment burden in a KFRT population

Study	No of studies	Description	Findings
Roberti 2018[148]	260	Qualitative systematic review exploring a work of being a CKD patient, analysed with a framework analysis informed by BoTT.	KFRT results in high burden, time-consuming, invasive, and exhausting healthcare workload. Socioeconomic status central to experiences, with socioeconomically disadvantaged patients experiencing

			higher workloads with less capacity resulting in higher burden
Morton 2010[149]	18	Thematic synthesis of qualitative studies of patient and carers' decision making and choice for KRT modality	Four major themes of influence on patient choice: 1) Confronting mortality. 2) Lack of choice 3) Gaining knowledge of options 4) Weighing alternatives and maintaining pre-existing lifestyle
Tong 2013[49]	39	Qualitative synthesis of patients' experiences, beliefs, and attitudes about PD.	Seven themes influenced attitudes to PD: 1)Resilience and confidence in own abilities 2) Support structures 3) Overwhelming responsibility 4) Control over life 5) Freedom and autonomy 6) Sick identity 7) Disablement
Sedin 2013 [150]	17	Systematic review of qualitative literature on the experience of transitioning onto KRT	Five themes identified: 1) Transitioning onto KRT was an existential transformative feeling 2) Starting KRT profoundly affects quality of life 3) KRT is limiting 4) Various factors impact how secure patients feel with their care 5) Patients feel ambivalence towards KRT

3.3.1.4 Summary of qualitative studies

Other than the work of Roberti, studies explicitly using BoTT in a KRT population are scarce. As would be expected with qualitative research, many of the published studies are small and specific to their cultural and geographical location, and therefore the transferability of these findings must be interpreted with caution when extrapolating to different settings and cultural contexts. However, there are notable similarities between what was described in smaller primary studies and in larger qualitative syntheses which

lends confidence to the validity of common findings. When looking at the available relevant qualitative literature, several common themes emerge.

Firstly, a common finding across all studies is that KRT in all its forms involves time-consuming, highly burdensome, intrusive healthcare workload that encroaches on all aspects of a patient's life[134-150,]. This work involves understanding kidney disease and its treatment options; understanding what it will mean for their lives; recruiting the help of others; negotiating with, and navigating the healthcare system; undertaking healthcare tasks around taking medications, attending clinics, dietary and fluid modifications; and continuously reflecting and adapting. Patients universally find KRT transition challenging and confronting.

Secondly, transitioning onto KRT has an onerous emotional workload, with many studies exploring the existential questions and exploration of their own mortality triggered by facing a life-threatening diagnosis. Many studies acknowledged the biographical disruption encountered by patients and the psychological workload of coping with the fact that life will never be the same again and their expectations of life would need to change[135,139,141,147,150]. Transplantation had a specific emotional workload, navigating the potential hope of a way out of dialysis, the uncertainty of waiting, and processing what it means to accept another person's organs[140]. Deceased and live donor transplants had particular nuances to their emotional workload, with potential recipients needing to process that they are either waiting for a stranger to die in order for a kidney to come available and the emotional turmoil of benefitting from another's death, or accepting a kidney from friends or family and the risks that entails for their donor.

Thirdly, the physical, psychological, cognitive, emotional, and financial capacity of patients and that of their social network impacts the patient's experience of KRT. Socio-economic disadvantage, lack of social support, individual vulnerability and resilience, and poor physical health were all identified as contributing to poorer patient experience of treatment in the qualitative literature[145].

Fourthly, the relationship between the patient, their healthcare team, and the healthcare system is vitally important. Patients who felt well-informed, well cared for, listened to, and understood by their healthcare team were better equipped to participate in their care and were more comfortable with the treatment decisions made. Patients who did not have a

positive relationship with their physicians were negatively impacted by this, and felt more overwhelmed and lost in an uncaring system. System factors such as the availability, expense, and travelling distance to care affected both patient experience and their ability to adhere to treatment plans. When the demands placed on patients outweighed their ability to meet them and when they couldn't adequately self-advocate and negotiate a treatment plan that was more feasible for them, patients could become non-adherent to treatment with serious consequence[145-147].

Several aspects were less explored by the available published literature. Firstly, although some studies encouraged patients who are well-established on KRT to share recollections of how their experiences have evolved over time none of the studies were longitudinal and explored the evolution of burden over time. Secondly, the impact of the healthcare system on burden was less universally explored and remains a knowledge gap.

3.3.2 Quantitative literature: use of measures of treatment burden in KFRT

How best to measure outcomes in healthcare is a matter of great debate. There has been a growing recognition that patients, clinicians, scientists, and policy makers consider different outcomes to be important, and that medical studies have often failed to capture the outcomes that are truly important to patients[151,152]. The use of narrow objective end points such as blood test results, patient and transplant graft survival, or patency of vascular access are important to determine the efficacy of treatments. The use of health economic evaluations to assess the cost effectiveness of treatments is also valid and important. However, what these approaches fail to capture is the patient experience of treatment, the impact of various treatment approaches on quality of life, and the impact of treatments on outcomes that are important to patients such as the ability to live independently or participate in social activities. This has led to the development of a wide range of Patient Reported Outcome Measures (PROMs)[153] and Patient Reported Experience Measures (PREMs)[154,155] to capture the subjective patient experience. This has also led to the development of different objective measures that seek to measure outcomes that are important to patients such as time spent attending clinical facilities[156], time spent on self-management tasks[157], the complexity of medicine regimes[158], and the administrative burden experienced by patients[159].

The need for more sophisticated demographic measures to capture the factors that influence a patient's ability to engage with healthcare has been recognised, with the development of a wide range of measures capturing domains such health literacy, patient activation, and patient wellbeing[160]. There is also growing recognition that the patient experience of treatment is important both on humanitarian grounds and on the basis that healthcare settings that deliver a good experience of care are more likely to also be safe and effective[161].

As treatment burden has become more established as a concept, there have been attempts at developing patient reported measures to quantify treatment burden specifically. The aim of this section is to explore how different authors have attempted to measure healthcare workload, patient capacity, and treatment burden in the context of KFRT. Different measures of treatment burden can be subdivided to objective measures that use objectively measurable healthcare workload outcomes such as treatment time, direct and indirect healthcare costs, and number of daily treatments; and subjective measures that seek to quantify patients' perception of the burden created by their treatment[162].

Firstly, approaches to the objective measurement of healthcare workload will be discussed. Secondly, the measurement of patient capacity will be discussed with different potential measures outlined and critiqued, and the literature surrounding their application to a KFRT population summarised. Thirdly, approaches to measuring treatment burden will be discussed. Generic measures of treatment burden and their application in a KFRT population will be outlined. KRT specific measures that capture the impact of treatment workload on wellbeing will also be outlined, as will the literature around their application.

3.3.2.1 Measuring workload in KFRT

There are very few studies that aim to measure the objective workload patients encounter during KRT transition. A study measuring healthcare activity in the first 365 days of haemodialysis; defined as all surgical and radiological activity, inpatient admission, and bacteraemia episodes; found that dialysis access type influenced healthcare activity with arteriovenous fistulas (AVF) associated with significantly lower workload than central venous catheters (CVC) [163]. A similar study looking at healthcare activity during the first

365 days of PD found that patients had a mean of 36.4 days in the first year with face-to face contact with healthcare staff[164]. These studies described the frequency of different types of workloads but did not seek to combine workloads into an aggregate measure that would facilitate better comparison.

There have been several health economic analyses of KRT transition that capture the healthcare resource use and therefore indirectly capture patient workload, combining different forms of workload to a single variable: cost. Comparison of the economic costs of PD, ICHD, and HHD in an incident dialysis population found that ICHD had the highest economic costs and PD the lowest [165–167]. An economic evaluation of kidney transplants found that healthcare resource use were 80% lower and healthcare costs were 75% lower in the four years after transplant. Higher resource use was associated with female sex, deceased donor transplant, prior HD, receipt of previous transplant, and co-morbidities[168]. Economic analyses can capture highly granular data and therefore provide a valuable insight into the healthcare workload patients are faced with, but are designed to measure the financial cost incurred by the system rather than the human cost incurred by the patient. Expensive care is not the same as high workload care, and caution is required when extrapolating from one to another.

As will be described in Chapter 4, finding a suitable aggregate measure for workload that is patient-centred and meaningful is difficult. Researchers in the field of oncology have developed the concept of time toxicity, where time spent on healthcare tasks such as co-ordinating care, attending outpatient visits, hospitalisations, and seeking urgent unscheduled care, is used as the aggregate measure for healthcare workload[169]. The concept is based on the idea that for patients with potentially life-limiting conditions such as advanced cancer time is precious, and considerable time can be spent pursuing treatment sometimes to the extent that the loss of time incurred by receiving treatment outweighs the survival gain. The work described in Chapter 6 is the first time that healthcare workload has been measured using time as a proxy in a KRT population.

3.3.2.2 Measurements of patient capacity in KRT

There are no comprehensive measures of patient capacity that have been developed and validated for use in a KRT population. That said, there are several measures that capture some aspects of capacity, as outlined in Table 3.3.

The most commonly used measure is the Patient Activation Measure (PAM) is a measure underpinned by the concept of Patient Activation, which is how activated a patient is to enact self-management of their health condition[117]. As discussed in more detail in Chapter 2, PAM overlaps significantly with patient capacity in that it seeks to understand what attributes both help and hinder patients in engaging with the management of their chronic conditions. However, it is underpinned by a significantly different theoretical underpinning which has a far more individualistic conceptualisation of the patient and the patient's responsibility to manage their own condition and require less care, and does not engage with any exploration of the impact or the roles and responsibilities of relational networks, wider society, or the functioning of the healthcare system on the patient's ability and experiences of managing chronic conditions.

Other measures, as outlined in Table 3.3, have been developed to capture aspects of patient capacity such as social network, capability, health literacy. The ICAN tool is a discussion aid developed informed by the concept of patient capacity and BoTT[170]. It is not a formal quantitative measure, rather a structured discussion aid that can be utilised in consultations to explore how different physical, emotional, personal, financial, social, and environmental capacity factors interact with the different healthcare demands placed upon patients.

Table 3.3: Summary of Measures of Patient Capacity

Measure	Primary construct	Country	Target Population	Item	Key Domains
Patient Activation Measure (PAM)[117]	Measurement of patient activation	USA	Adults with chronic disease	22	1)Belief in importance of taking an active role 2)Confidence and knowledge to take action 3)Ability to take action 4)Ability to stay the course under stress

Social Network Index [171]	Number of social connections in an individual's life	USA	Adults	4	Amount of the following forms of social contact: 1) Marriage 2) Close friends and relatives 3) Religious or spiritual group membership 4) Informal and formal group associations
Single Item Literacy Score (SILS)[172]	Single item assessment of literacy	USA	Adults	1	Single question: 'How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?' Sometimes/ often/always regarded as low health literacy.
Health Literacy Questionnaire (HLQ)[173]	Multi-dimensional assessment of health literacy	Australia	Adults	44	1) Feeling understood and supported by healthcare providers 2) Having sufficient information to manage health

					3) Ability to actively manage health 4) Social support for health 5) Appraisal of health information 6) Ability to actively engage with healthcare providers 7) Ability to navigate the healthcare system 8) Ability to find good health information 9) Understanding health information well enough to know what to do
ICECAP-A [174]	A measure of wellbeing, underpinned by the capabilities approach, seeking to define what patients can do and be in their lives	UK	All adults	5	5 capability domains: 1) Stability 2) Attachment 3) Achievement 4) Autonomy 5) Enjoyment
ICAN [170]	Discussion aid informed by TPC and BoTT	USA	Adults with chronic conditions	6	Structured exploration of whether different

					capacity factors and elements of healthcare workload are sources of burden or help.

Several studies have applied these measurements of capacity to a kidney disease population. Studies that have utilised PAM in a KRT population have found that lower PAM is associated with lower health literacy[175], higher mortality rates[176], higher symptom burden and lower HRQoL[177]. In-centre rather than home haemodialysis, unemployment, lower educational attainment, and lack of pre-dialysis nephrologist care were all found to be associated with lower PAM scores[178]. Higher PAM scores were also associated with higher social support, greater trust in physicians, and higher engagement with shared decision making[179]. That said, studies that studied the association between treatment adherence and PAM in HD populations did not find an association between better adherence and higher PAM scores[175,176]. Whilst these are all cross-sectional observational studies and acknowledging both the shortcomings of PAM as a conceptualisation of capacity and that association does not prove causation, these studies do suggest that capacity may influence treatment choices and outcomes in KRT care.

Studies looking at the impact of the patient's social network on outcomes in kidney disease have found an association between social isolation and poorer outcomes, with more rapid eGFR decline[180], higher financial burden[181], and higher mortality[182]. Although none of these studies specifically studied a KRT population, their results do suggest a link between social network and outcomes in kidney disease that correlates with the qualitative data that explore the relationship between the social network resources patients can draw upon and their experiences of treatment burden[145].

Whilst health literacy only captures some of the factors that contribute to capacity, several studies have been published in a KRT patient population. A systematic review of health literacy in a CKD population fond that limited health literacy is common, especially in patients with socioeconomic deprivation and a non-white ethnicity. This review also found that the prevalence of low health literacy was lower in transplant patients, which they hypothesised could either be due to a direct effect of greater health literacy on

access to transplantation or indirectly due to less co-morbidity and better physical health status in the transplanted group[183]. A further systematic review looking at the association between health literacy and outcomes in a CKD population including non-dialysis, dialysis, and transplant patients found that lower health literacy was independently associated with increased hospitalisations, emergency department use, missed dialysis sessions, cardiovascular events and mortality.[184] Lower health literacy has been associated with worse HRQoL[185,186] and higher risks of unsustainable treatment burden[187] in a HD population. In the context of kidney transplant, limited health literacy was independently associated with a reduced likelihood of listing for deceased donor transplant, receiving a living donor transplant, and receiving a transplant from any donor type[188].

There are no academic papers describing the use of ICANs in a KRT population.

Several limitations are apparent in the patient capacity measure literature. Firstly, the available studies are overwhelmingly in a haemodialysis patient population, with studies on PD and kidney transplant patients under-represented. Secondly, whilst there is a common theme throughout that limitations on capacity are associated with higher treatment burden, lower HRQoL, and worse outcomes, measure-based papers do not explore the causal mechanisms for these outcomes or the interaction between different domains of capacity.

3.3.2.3 Measuring treatment burden in KFRT

There are two broad categories of treatment burden measure that have been developed for use in long-term conditions: those that have been developed to capture condition or treatment specific burdens; and those that are not condition-specific but that capture the treatment burdens associated with the management of multiple long-term conditions (multimorbidity).

The benefits of using multimorbidity treatment burden measures in a KFRT population are that almost all individuals with KFRT have multimorbidity and therefore there is value in a measure that captures globally all the treatment burdens they may experience and not only those pertaining to kidney disease. Also, there are commonalities that run through the experiences of many chronic diseases with similar areas of burden such as managing

medications, travelling to appointments, and self-monitoring[189]. Additionally, they may be more familiar to researchers and allow comparison across different diseases and contexts.

However, the treatment burdens encountered in different illness contexts are not the same. Many of these multimorbidity measures were developed in a primary care or outpatient chronic disease management setting. There are concerns that the nature, volume, intensity, and complexity of the healthcare workload and treatment burden encountered in KFRT would not be adequately captured by general measures and therefore specific measures designed and calibrated to a KFRT population are more appropriate[190].

3.3.2.4 Generic treatment burden measures and their application in a KRT population

Several researchers have developed generic measures of treatment burden that can be applied to any population. The main five measures used are the Treatment Burden Questionnaire (TBQ)[191], Multimorbidity Treatment Burden Questionnaire (MTBQ)[192], Patient Experience with Treatment and Self-management (PETS) questionnaire[193], Illness Intrusiveness Ratings Scale (IIRS)[194] and the Health Care Task Difficulty (HCTD) [195]questionnaire. They are summarised in Table 3.4.

Table 3.4: Summary of Generic Measures of Treatment Burden

Measure	Primary construct	Country	Target Population	Items	Key Domains
TBQ	Perceptions of treatment burden	France	Adults with at least one chronic condition	15	Medication, Lab tests, Self-monitoring, Appointments, Relationship with healthcare providers, Administrative burden, Financial burden, Diet, Exercise, Social relationships, Intrusiveness of daily life

MTBQ	Treatment burden in patients with multimorbidity	UK	Adults with multimorbidity	13	Medications, Self-monitoring, Appointments, Out-of-hours access to care, Access to community services, Acquiring information, Lifestyle changes, Help from friends and family
PETS	Comprehensive measure of treatment burden	USA	Adults with chronic illness	48	Medical information, medications, medical appointments, monitoring health, interpersonal challenges, medical/healthcare expenses, difficulty with healthcare services, role/social activity limitations, and physical/mental exhaustion
IIRS	Measure illness and treatment induced disruption	Canada	Adults with chronic disease	13	Health, Diet, Work, Active Recreation, Passive Recreation, Finances, Relationship with spouse, Sex life, Family relations, Other social relations, Self-expression, Religious expression, Community and Civic Involvement

HCTD	Measure of burden from difficulty performing healthcare tasks	USA	Older adults with multimorbidity	12	Medications, Financial, Appointments, Transport, Information, Diet, Equipment, Community services

TBQ is short and comprehensive, but has been criticised for having aspects that are health system specific and questions that have unduly complex wording. MTBQ was developed to address this, and to tailor the questions to be more suitable for an older and more co-morbid population[192]. However, the emphasis on multimorbidity may limit its applicability in populations where most of their experienced burden is being driven by one condition. The PETS is regarded as the most detailed and comprehensive non-disease specific measure, but at 48 items it is time-consuming and burdensome for patients to complete, limiting its applicability. IIRS is a holistic measure that captures many aspects of social network and emotional domains but does not distinguish between illness burden and treatment burden which limits its applicability. HCTD is purely a measure of the burden of performing healthcare tasks and therefore does not capture the sense-making and reflective work of treatment nor many domains of capacity.

Several researchers have used TBQ, PETS and IIRS in a KFRT population (Table 3.5). No studies were identified using HCTD or MTBQ in a KFRT population, however MTBQ is part of the trial protocol in a currently active study into preparing for dialysis or CCM in multimorbid older people called Prepare for Kidney Care[196].

Table 3.5 Summary of papers using general treatment burden measures in a KFRT population

Study	Setting	Participants	Measure	Description	Findings
Al-Mansouri (2021)[197]	Large governmental hospital in Qatar	258 (223 on HD, 57 pre-dialysis)	TBQ	Descriptive cross-sectional study	39.5% of HD patients had moderate or high burden (>51/150).

					Medication Burden and Lifestyle changes domains with highest reported burden.
Edgar (2025)[187]	Vascular access clinic in large teaching hospital in Scotland	563 (263 on KRT, 300 pre-KRT)	TBQ	Comparison of TBQ scores with health literacy scores and demographics.	20% of patients had unsustainable treatment burden (>59/150). Higher treatment burden associated with dialysis dependence and greater socioeconomic deprivation.
Lorenz (2022) [198]	Three academic centres in the USA	167 KTx recipients	PETS	PETS used as part of process of developing KTx specific	Burden of exercise and physical therapy, Diet, Medical Expenses and Difficulty with healthcare service highest

					scoring domains.
Song (2019)[181]	Large outpatient dialysis centre in USA	20, all on ICHD	PETS	Descriptive cross-sectional study	Highest treatment burden domain scores on diet, exercise, financial difficulty, difficulty getting healthcare services, physical and mental exhaustion and monitoring health.
Neri (2011)[199]	Large Italian nephrology unit	1,238 HD patients	IIRS	Comparison of IIRS scores with social network scores.	Greater social support associated with lower illness intrusiveness.
Bapat (2009)[200]	Nephrology unit in India	90 HD patients	IIRS	Descriptive cross-sectional study	HD associated with high degree of intrusiveness across the domains of health, diet, work, finance and

					relationship with spouse.
Bapat (2012)[201]	Nephrology unit in India	40 CAPD patients	IIRS	Descriptive cross-sectional study	92% reported some extent of illness intrusion into daily life. Highest intrusion scores associated with health, work, finance and diet.
Boehmer (2021)[202]	Two in-centre HD centres in the USA	78 HD patients	IIRS	Mixed methods study with IIRS used to screen for high/low burden (highest/ lowest quartile of scores) then qualitative interviews to explore	Younger participants reported higher illness intrusion. High burden patients reported more negative early dialysis experience, more disruption to social roles and self-perception and more difficulty maintaining social networks

Studies that have used generic treatment burden measures in the KFRT population describe high levels of burden across many domains. However, as the questions are broad and non-specific it is not possible to ascertain any degree of granularity in what specific aspects of KRT care that the patients find burdensome which may limit their applicability in this population.

3.3.2.5 KRT specific treatment burden measures

Lorenz et al developed a KRT-specific, treatment burden-specific measure, however this is solely for kidney transplant patients. They developed a conceptual framework of treatment burden after kidney transplant, and found that the domains of the general PETS measure were relevant to the post-KTx population, however they also had significant specific burdens unique to kidney transplantation such as concerns for the donor and concerns about rejection that were not captured by the PETS[203]. They therefore developed a supplementary set of 14 questions to add to the PETS that are kidney transplant specific[198].

There are several measures that have been specifically developed for kidney disease more generally that capture elements relevant to treatment burden without being explicitly informed by burden of treatment theory as described in Table 3.6.

Table 3.6: Summary of KRT-specific Measures of Treatment Burden

Measure	Primary construct	Country	Target Population	Items	Key Domains
Kidney PREM [204]	Patient experience measure of all aspects of secondary care renal services	UK	Adults with CKD (all stages and modalities of KRT) receiving specialist nephrology care	38	Access to the renal team, Support, Communication, Patient information, Fluid, Diet, Needling, Tests, Sharing decisions about care, Privacy and dignity, Scheduling

					and Planning, How the renal treats you, Transport, Environment, Overall experience
Renal Treatment Satisfaction Questionnaire (RTSQ) [205]	Patient Satisfaction with KRT care	UK	Adult patients receiving KRT care	11	Satisfaction with: current treatment, control over condition, convenience, flexibility, freedom, understanding, time consumed by treatment, pain, fit with lifestyle
Kidney Disease Quality of Life-36 (KDQOL-36) [206]	Assess impact of kidney disease on health-related quality of life	USA	Adults with CKD (all stages and modalities of KRT)	36	Physical Component Summary, Mental Component Summary, Burden of Kidney Disease, Symptoms and Problems of Kidney Disease, Effect of Kidney Disease.
Renal-Dependent Quality of Life (RDQOL) [207,208]	Assess impact of kidney disease on quality of life	UK	Adults with CKD (all stages and modalities of KRT)	21	Leisure Activities, Work, Travel, Holidays, Physical ability, Social network, Sex life, Physical

					appearance, Self-confidence, Motivation, Spiritual life, Future, Finances, Living condition, Dependence, Diet and fluids
Patient Experience with Treatment and Self-management-Kidney Transplantation (PETS-KT) [198]	Kidney transplant specific supplement to PETS	USA	Kidney Transplant Recipients	62 (48+14)	Transplant function, Concern of return to dialysis, Rejection, Return of primary disease, Responsibility for transplant, Donor concerns, Vascular access, Infection risk, Cancer risk, Anti-rejection medication
Kidney Transplant Questionnaire (KTQ) [209]	Quality of life measure after kidney transplant	USA	Kidney Transplant Recipients	25	Physical symptoms, Fatigue, Uncertainty/fear, Appearance, Emotions
Kidney Transplant Quality of Life (KTQoL) [210]	Quality of life measure after kidney transplant	South Korea	Kidney Transplant Recipients	24	Anxiety, Pain, Infection, Function, Symptoms of ESKD, Fear for future, Finances,

					Change to daily life, Medication
Renal Transplant Quality of Life (ReTransQoL)[211]	Quality of life measure after kidney transplant	France	Kidney Transplant Recipients	32	Physical Health, Social Functioning, Medical Care, Treatment, Fear of Losing Graft
Hemodialysis Stressor Score (HSS) [212]	Physiological and psychosocial stressors associated with HD	USA	Patients on HD	29	Needling, nausea, cramps, itching length of treatment, joint stiffening, fatigue, loss of bodily function, loss of social life, diet and fluid limitations, employment, loss of sex drive, changes in family responsibilities, appearance, cost, transport, limitation on vacation, hospital admissions, dependency, loneliness
Vascular Access Specific Quality of Life Score (VASQOL)[213]	Impact of vascular access on quality of life	UK	Patients with vascular access	11	Impact of how access looks and feels, concerns about function/infection, ability to enjoy

					life, relationships, interreference with hobbies/ work, inclusion in decisions around care
Needling Patient Reported Experience Measure (NPREM)[214]	Needling specific patient experience measure	UK	HD patients with AVF or AVG	28	Needling experience, Pain, Involvement in Care, Relationship with Staff, Concerns
Haemodialysis Access- Related Quality of Life Questionnaire (HARQ)[215]	Impact of vascular access on quality of life	USA	Patients with vascular access	47	Symptoms, physical functioning, emotional impacts, social and role functioning, sleep, care-related burdens
Home Dialysis Care Experience (H-DCE) [216]	Patient experience of home HD or PD	USA	Home dialysis patients	26	Relationship with staff, relationship with home dialysis service, communication, support, treatment, access care, health status and fitness

Several studies have used PRMs to capture treatment burden in KRT patients. Hawkins et al analysed Kidney PREM scores from all UK renal centres. The core aim of a PREM is to

capture the patient experience of healthcare services whereas a treatment burden measure focuses more holistically on the impact of treatment on the patient's life including factors that fall outwith the direct sphere of influence of the healthcare system, therefore using a PREM as a proxy for treatment burden can miss some pertinent aspects despite sharing much common ground with treatment burden. Interestingly, Hawkins et al found that which centre patients receive their care in had a much greater impact on the variance between PREM scores than individual patient characteristics such as age, sex, or ethnicity[217].

Although HRQoL measures capture the impact of the illness rather than the impact of the treatment on the patient's quality of life which limits their use in the study of treatment burden, many studies have utilised QoL measures in KRT. Comparative papers between different modalities have shown that transplant, and specifically live donor transplant, is associated with higher HRQoL[218]. The difference between HD and PD is less clear with some reporting no difference[219,220]. Unemployment, lower education, living alone, high BMI, poor physical health, poor mental health, critical illness, hospitalisation, non-compliance and long pre-transplant duration of dialysis associated with lower post-transplant QoL compared to other kidney transplant recipients[221].

The most widely utilised haemodialysis specific measure was the HSS. Fatigue, limited time for enjoyment, limitations to physical activity, fistula related distress, limitation on fluid intake, treatment costs, and difficulty with transport were the most common haemodialysis related source of stress. Female sex, younger age, lower dialysis vintage and lower educational attainment were all associated with higher HSS scores[222]. There are no currently published papers other than the development and validation papers that utilise HARQ, NPREM or VASQOL.

3.3.2.6 Summary of quantitative measures

There is a paucity of studies that objectively measure health workload in KRT, and the use of time to measure workload in KRT in Chapter 6 is novel.

No specific measure exists that is tailored to measuring patient capacity or treatment burden in a mixed modality KRT population, and none capture domains specific to transition. There are several generic and condition specific PROMs and PREMs that

capture some element of treatment burden but all have short-comings. This conclusion is shared with systematic reviews into transplant specific PROMs and measures of treatment burden in dialysis[190,223].

The evidence presented in studies that have used measures to capture treatment burden and capacity all demonstrate that KRT is associated with significant burden, and that capacity factors including health literacy, activation, and social connectivity are associated with lower burden and superior outcomes. There is also evidence that the different modalities are not equal, with transplant associated with better HRQoL. There is also some evidence that capacity factors may influence access to transplantation. A significant limitation is that the studies presented here are almost invariably cross-sectional observational studies using a great heterogeneity of measures, therefore care must be taken in aggregating findings and ascribing causality where the data only support association.

3.4 Conclusion

In this chapter I have explored the available background qualitative and quantitative literature on healthcare workload, patient capacity, and treatment burden in KFRT. The aim was not to provide a series of exhaustive systematic reviews of the literature but to present a broad overview of the current literature base in order to provide the relevant context for the work presented in Chapter 5-7.

Chapter 4 Methodology

4.1 Introduction

4.1.1 Aims of this chapter

The aim of this chapter is to discuss the methods used in this thesis, the rationale for selecting the methodological approaches, and the potential advantages and disadvantages of the approaches taken.

4.1.2 Rationale

The work described in this thesis utilises a mixed methods approach. There has been a growing recognition that in healthcare, traditional positivist research methods and paradigms such as randomised control trials (RCTs) to evaluate the effectiveness of a new treatment do not and cannot on their own fully understand and evaluate the complexity involved in modern healthcare and the interaction between various illnesses, the patient, their lives, and the structures and conventions of the healthcare system, and that novel research approaches are required[224,225]. Complexity has been defined as a dynamic and constantly emerging set of processes and objects that not only interact with each other, but come to be defined by those interactions[226]. Treatment burden is a complex phenomenon[7] and therefore the move towards research methods that are pragmatic, adaptive, methodologically diverse but with a robust theoretical underpinning to explore complexity in healthcare is highly applicable to this work.

Qualitative research is a collective term for a broad range of different research methods that are united by their aim in providing an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives, and histories[227]. Quantitative research is the collective term for research methodologies that use numbers or statistics to quantify the world, and describe the numerical relationship between different variables[228].

Mixed method research involves the integration of qualitative and quantitative data[229]. Plano et al describes three main benefits of mixed methods research:

1. **Off-setting strengths and weaknesses**: using a combination of quantitative and qualitative methodology allows the researcher to draw from the strength of both approaches and use the opposing methodology to offset the weaknesses of the other. For example, the benefit of quantitative methods is that they permit the researcher to describe trends in large datasets, measure size of effects, and produce generalisable data. However, it can lack nuance and context, and its' positivist underpinning proving or disproving a null hypothesis mean that the range of outcomes have been predetermined. Qualitative research on the other hand can provide very detailed nuanced understanding of the human experience that is rich in context, and its' interpretative nature means that unexpected phenomena can be captured and explored. However, qualitative research usually has small sample sizes and is vulnerable to criticism that it is subjective. Therefore, combining the two methodologies can provide a more comprehensive answer to the research question.
2. **Triangulation:** Triangulation is the process where results from qualitative and quantitative studies attempting to answer the same research question are directly compared for convergence and divergence leading to greater insights into the validity of the conclusions drawn from both bodies of work. It has been argued that using two different methodological approaches to the same research question can lead to the fullest possible picture and convergence between qualitative and quantitative findings can lead to greater confidence in the validity of the results.
3. **Complementarity:** The use of mixed methods can develop a more complete picture by using different research methods to answer different but complementary research questions. For example, a study might use qualitative methods to study patients' experience of a new treatment regimen and quantitative methods to evaluate the outcomes.

4.2 Methods

The methods described in this section were developed in discussion with my supervisors and exploration and discussion of the literature. Relevant literature was identified through searches of MEDLINE, Scopus and Ovid databases, reference and citation tracking, expert advice, and through reading grey literature.

I will first discuss the epistemology and ontological assumptions that have underpinned this work. I will then discuss the methodological considerations for each phase of the research, the rationale for selecting the methods used and the challenges encountered and how they were overcome.

4.3 Epistemology and Ontology

Qualitative and quantitative methodologies have different philosophical approaches and make different assumption regarding what they consider to be knowledge and what they consider to be reality, and this fundamental difference requires careful thought and management when combining results derived from different paradigms.

Ontology is the field of philosophy that considers what reality is. There is a spectrum of ontological positions on the nature of reality ranging from realism, which holds that reality is something that exists in and of itself independent of human thought, to anti-realism which holds that reality does not exist objectively as an entity separate from the human mind and things become real by being perceived, conceptualized, or described[230]. Epistemology is the field of philosophy that considers what knowledge is and how things can become to be known. The spectrum of epistemological positions range from objectivist schools of thoughts such as positivism, rationalism and empiricism which holds that there is a universal truth and that knowledge is something objective and value free that can be deduced by scientific method; constructionist concepts such as relativism, interpretivism and constructivism that holds that there is no universal truth and knowledge is a construct of the interaction between the human mind and the world, influenced by culture and social interaction; and subjectivism which holds that experience and therefore meaning and knowledge is experienced entirely separately from a fixed reality[231].

Creswell describes four broad epistemological and ontological approaches to research[232], summarised in figure 4.1.

Figure 4.1: Description of different epistemological approaches to research

Postpositivism	**Constructivism**
• Determination • Reductionism • Empirical observation and measurement • Theory verification	• Understanding • Multiple participant meanings • Social and historical construction • Theory generation
Transformative	**Pragmatism**
• Political • Power and justice oriented • Collaborative • Change oriented	• Consequences of actions • Problem centered • Pluralistic • Real-world practice oriented

Postpositivism as described by Phillips and Burbules maintains that whilst research is imperfect and fallible, knowledge can be deduced from careful observation and measurement of objective reality. It is a methodological approach that functions by reducing broad concepts into discrete hypotheses or research questions that can be tested by collecting and analysing data that either supports or refutes the hypothesis. Objectivity is a central tenet of quality in postpositivist research, with emphasis placed on the validity and reliability of results, and the removal of bias and confounding[232,233]. This is the epistemological underpinning of most quantitative research.

Constructivism, and the similar concept of interpretivism, is an epistemological approach that holds that knowledge is a social construct: humans construct their understanding of life by interacting with each other and the world, and their interpretation of the world is influenced by their personal, social, cultural, and historical experiences. Rather than there

being one objective, deducible truth this epistemology holds that each person has their own equally valid understanding of the world that flows from their interaction with human community[234]. Within this approach, the researcher is not a neutral, objective deducer of fact but a co-creator of meaning with their own unique construct of reality and the aim of the research is to inductively generate meaning from data collected in the field rather than prove or disprove a hypothesis as would happen in postpositivist study[232]. This is the epistemological underpinning of most qualitative research.

Transformative research is a diverse group of theoretical approaches that centre on issues of power, social justice, and marginalisation. The focus of the research is based on the inequities that result from social oppression based on gender, race, ethnicity, disability, sexual orientation, and socioeconomic class[235]. It holds that research should be intertwined with politics and rooted in a change agenda to resist, challenge, and subvert asymmetrical power relationships[232,236].

Pragmatism is not rooted in one absolute philosophical view of the world, and holds that researchers should use the methodology that best suits their needs and purposes. It is closely related to critical realism, which holds that there can be both objective reality and socially constructed knowledge; and that these are not mutually exclusive world views[237–239]. This pragmatic approach underpins mixed-methods research, as it permits the synthesis of epistemologically diverse work[232,240].

In this work we have taken a pragmatic ontological and epistemological stance, acknowledging that there are some aspects of this work such as total amount of healthcare workload that is objectively real and are best studied through a postpositivist lens, and others such as patient capacity and treatment burden that are social constructs and are best captured with a constructivist stance, and that the whole picture is best understood by utilising a mixed methods approach.

4.4 Qualitative Systematic Review

A qualitative systematic review was carried out to fulfil the following objective:

> To explore the experience of healthcare workload and patient capacity for people transitioning onto KRT through examination of the published literature.

4.4.1 Appropriateness of a qualitative synthesis

Historically in quantitative research, systematic review and meta-analysis were seen as the highest order of evidence. Although thinking around systematic review has evolved to acknowledge that the quality of the output of the synthesis is only as good as the quality of the studies included and the methodological rigour with which the aggregation of results is conducted, a systematic review and meta-analysis remains the gold standard approach to evaluate and aggregate quantitative studies[241,242]. As qualitative research has become more common and there has been a growing recognition of its value and application, there has been an increasing move to develop methods of qualitative synthesis[243,244]. Traditionally, quantitative meta-analyses are designed to answer 'what works?' questions, but their methodology and assumptions are unsuitable to answer 'what happens?' questions, and it is from this need to find ways of combining and aggregating the findings of qualitative studies about processes and experiences that qualitative evidence synthesis was born[245,246].

Debate exists whether it is epistemologically sound to synthesise qualitative evidence. As quantitative research has a positivist or post-positivist stance it is philosophically coherent to combine results in a meta-analysis: there is a universal, objective reality that the different studies were trying to measure and although measurement techniques are fallible, 'reality' is the same and combining findings to come closer to describing that truth is epistemologically sound[247]. Some who hold an epistemologically purist stance argue qualitative research should not be combined as it is underpinned by a constructionist epistemology: if we hold that reality is a social construct influenced by personal, social, historical and political contexts and that knowledge in a study is constructed by what the researcher perceives that has happened influenced by their own sociocultural hinterland then reality is different in every study and how knowledge became to be known is different and therefore findings are not amenable to synthesis[248,249]. Others take a more pragmatic view, arguing that qualitative evidence synthesis can bring new insights[250]. Some argue that the process of qualitative evidence synthesis is an interpretive one where the researcher conducting the synthesis construct their own interpretation of why the phenomenon observed in the primary research is the way that it is, and therefore is not incongruent with a constructionist perspective [251,252].

Another critique of systematic review, especially when removed from its traditional quantitative milieu and adapted and applied to the social sciences, is that its' tight processes and terminology give the illusion of rigour and quality whilst in practice driving superficiality and group-think: a victory of technocratic process over intellectual depth. As MacLure argues:

> "*Systematic review suppresses aspects of quality in research and scholarship that are at least as important as clarity, countability and accountability- such as intertextual connectivity, critique, interest, expertise, independence, tacit knowledge, chance encounters with new ideas and dialogic interactions between researcher, 'literature' and 'data'. The tiny dead bodies of knowledge disinterred by systematic review hold little power to generate new understanding, and are more likely, I suggest, to incapacitate researchers than to contribute to research 'capacity'"*[253]

Despite the concerns of the risks of taking fragments of qualitative data out of context and the potential methodological challenges of synthesising diverse methodologies, many maintain that well-conducted qualitative systematic reviews can produce rigorous, transparent and conceptually rich insights and are a valid and valuable addition to the research armamentarium[254].

4.4.2 Deciding what to review

Careful thought was required in creating our review question, balancing the need for breadth and comprehensiveness with the risk of qualitative analysis becoming unmanageable if there was too diverse a range of studies included.

The review question we decided on is "What are the main components of workload and patient capacity experienced at the time of transition onto KRT?"

Once we had decided upon the review question, we considered what type of review we would conduct. Options we considered include:

1. Qualitative systematic review: a qualitative synthesis of evidence collected by transparent, systematic search for studies

2. Narrative review: a broad, descriptive summary of literature without a structured or replicable process
3. Mixed-methods systematic review: a review mixing qualitative and quantitative studies
4. Secondary analysis of original data from primary studies.

We decided to utilise a qualitative systematic review as a we found value in the rigour and transparency of a systematic search of the literature to fully describe the range of published material. We did not believe that a narrative review would be adequately comprehensive, and the amount and nature of the primary qualitative data included within papers was not adequate for conduction of a secondary analysis. The quantitative and qualitative data published on this was felt to be too heterogenous to synthesise.

We utilised the SPIDER tool[255] to clarify our inclusion and exclusion criteria.

Table 4.1: Summary of inclusion and exclusion criteria

Sample	Inclusion • Adults aged 18 or older transitioning onto any modality of KRT for the first time • Studies that included caregivers or healthcare professionals were if reported in a way that allowed for the selective inclusion of direct patient experiences • Transition onto KRT is defined as the time-period between identification of the imminent need for KRT and being fully established on maintenance therapy Exclusion • Studies that included children, patients with earlier stages of CKD or that were established on maintenance KRT, or discussed transition between modalities
Phenomenon of Interest	• Patient experiences of any aspect of workload or treatment burden during transition onto KRT • Any descriptors of patient capacity or the effect of patient capacity on experiences
Design	• English language qualitative studies published in 2012 or later
Evaluation	• Direct patient experiences and perceptions
Research type	• Published peer-reviewed qualitative studies • Grey literature and quantitative methodologies including patient reported measures were excluded. • Studies of interventions were excluded

The population of interest was adults over the age of 18 who were transitioning onto KRT for the first time. The decision to limit our studies to those that had an adult patient population was two-fold: firstly, paediatric care is very different to adult care with different experiences and considerations and therefore the experiences described would be too diverse to synthesise; and secondly, we wanted to focus exclusively on what patients rather than caregivers or healthcare professionals described. We decided to focus on the period of transition as this is a part of the disease journey where it is known that there is a considerable change in the amount and nature of the healthcare workload encountered and that experiences are likely to be considerably different from those with less severe kidney disease or who are long-established on KRT, and focusing on this reduced the heterogeneity of the studies.

We decided to have a broad definition of our phenomenon of interest and include papers that described any aspect of workload or any aspect of patient capacity during transition onto KRT. We decided to have broad inclusion criteria for this because of the plurality of terminology and theoretical lenses used to study this area (as discussed in more detail when discussing the challenges of constructing a search strategy) and we wanted to be maximally inclusive of all potentially relevant work.

We decided to only include primary qualitative studies because our phenomenon of interest- patient experiences of workload and capacity- was only meaningfully captured in a way that was amenable to synthesis by qualitative research. The English language requirement was because we did not have access to translation facilities. We limited our inclusion criteria to papers published in 2012 or later to capture current practice.

We limited our research type to peer-reviewed qualitative studies and excluded grey literature to ensure a minimum standard of methodological quality, enhance the comparability and consistency of the literature, and pragmatically due to considerations of feasibility and scope management.

4.4.3 Locating relevant papers

Different schools of thought exist regarding search strategies in qualitative evidence synthesis. They fall broadly into two categories:

1. Systematic searching that requires a transparent method for producing a structured review question, a comprehensive search strategy that can be used in an evidence-based and reproducible way with judicious use of supplementary search strategies to conduct an exhaustive search for every possible eligible paper[256,257].
2. Purposive sampling, which seeks a selection of studies across populations and settings to try and identify a diversity of viewpoints and to generate theories and conceptualisations without aiming to be fully comprehensive[258,259].

We decided that we wanted to undertake a traditional systematic search as we wanted to undertake the most rigorous, transparent search possible.

A significant challenge we found when attempting to devise a search strategy is that this is an area that is poorly indexed with diverse terminology. Workload, patient capacity and treatment burden are terminology closely related to Normalisation Process Theory (NPT), Theory of Patient Capacity (TPC) and Burden of Treatment Theory (BoTT). There are many different closely aligned concepts such as patient activation[117,177,178,260,261], health literacy[183,184,188,262–266], socioeconomic deprivation[82], oppression and marginalisation[267 213,268–272], patient experience[203,273–282] and symptom burden[283,284] that capture aspects of our phenomenon of interest and have been used as the theoretic underpinning of related research and are associated with a variety of terminologies and indexing conventions. There was also a diverse range of terms used to describe kidney failure requiring replacement therapy (KFRT) and kidney replacement therapy (KRT). Attempts have been made to standardise the terminology used in kidney disease, and we have adhered to KDIGO endorsed nomenclature in this thesis[285] however a wide range of terms including kidney failure, end-stage kidney disease (ESKD), end-stage renal failure (ESRF), advanced chronic kidney disease (CKD), and CKD5 have been used in the literature to describe the disease state that we name KFRT. The terminology used to describe KRT is also varied, with alternative terms such as renal replacement therapy (RRT) commonly used instead of KRT and many papers looking exclusively on one modality such haemodialysis (HD), peritoneal dialysis (PD) or kidney transplant (KTx), all of whom have alternative names or subtypes, for example kidney transplant can alternatively be called renal transplantation and there are a range of terminologies pertaining to whether it was a live or deceased donor. Terminology to describe qualitative research was also diverse, with different

methodologies such as phenomenology sometimes used in the indexing instead. Another complicating factor was that we wanted to focus exclusively on first transition onto KRT. This element was not commonly indexed at all, and was often poorly described in abstracts and required full text screening to determine if the study covered the period of interest. This meant that it was challenging to create a search strategy that was systematic, comprehensive, and concise. We identified ten key papers from scoping searches and prior knowledge of the field, and trialled different search strategies to see if the key papers would be retrieved. It was challenging to find a strategy that was sensitive enough to retrieve all relevant papers but specific enough to return a manageable number of abstracts to screen. We sought the input of an Information Scientist, and with his assistance devised a comprehensive systematic search strategy applied to MEDLINE, CINAHL and Scopus that returned 23,301 abstracts which included all our key papers. This was reduced to 21,607 abstracts following removal of duplicates, but a further 1,277 papers were found by citation and reference tracking, which were subsequently included in the screening process.

The manageability of such a high screening load for abstracts was a cause for concern. Three possibilities were considered:

1. Changing the methodology of the review to a narrative review that would permit non-systematic approaches to searching such as berry-picking[286] and different considerations such as information power determine if a search has been exhaustive[287,288], and aiming for a more conceptual rather than comprehensive review.
2. Narrowing the scope of the review to look more specifically at one modality or one aspect of workload, capacity, or burden.
3. Accepting that screening in excess of 20,000 abstracts is the only way of conducting a truly comprehensive, methodologically sound systematic review in this subject area, and that the requisite accommodations are logistical rather than methodological.

Following careful discussion and consideration we decided that our decisions to undertake a conventional systematic review rather than a narrative review was correct. Our aim was to explore healthcare workload and capacity through examination of the

published literature using NPT and TPC, rather than to generate new theories therefore a systematic review was a more suitable methodology. We considered whether we could narrow the scope of the study, but we decided that having a broad scope considering all KRT modalities and having a holistic view of workload and capacity was a vital strength of the review and trying to constrain the scope would fundamentally weaken the work. We therefore concentrated on managing the logistics of double screening such a high abstract load. We decided to use DistillerSR, a systematic review software, which greatly aided the management of the review process and reduced the administrative workload. I, as a primary reviewer, screened all abstracts but the workload of double screening was shared between four other reviewers. Proposed timelines were adjusted to allow sufficient time to conduct the screening work. To ensure that no new literature was missed in the elapsed time between the original search and publication the search was rerun prior to analysis and synthesis (initial search June 2023, rerun February 2024). A two-stage screening approach was undertaken with initial double screening of titles and abstracts, followed by a full text screen conducted by two independent reviewers. Discrepancies were settled by a third reviewer. 18 papers were eventually included in the review.

4.4.4 Quality appraisal of qualitative studies

Debate exists whether the quality of qualitative research can and should be appraised. Those who argue that qualitative research should not be synthesised in a systematic review centre many of their arguments on issues around quality appraisal, arguing that each study has its own inherent validity, and that excluding evidence based on narrow and prescriptive ideas of what constitutes quality risks missing many valuable insights and perspectives[253]. On the other hand, there is consensus that if we accept that synthesising qualitative evidence is a valid endeavour- which is the position taken in this thesis- then it is important to have some way of appraising and describing the quality of included work and distinguishing between well-conducted and poorly conducted qualitative research, and that by so doing increase the legitimacy of the review[289]. Some argue that the degree to which the findings of qualitative review are useful is dependent on the quality of the included studies, and therefore appraising and describing the quality of the research included is essential[290].

Quality appraisal of the included literature is a cornerstone of Cochrane systematic reviews[291]. However traditional ways of appraising the quality of quantitative literature are underpinned by positivist assumptions such as internal validity, external validity, reliability, and objectivity that are not directly transferrable to qualitative synthesis[292].

Lincoln and Guba argued that the key determinant of quality in qualitative research was trustworthiness, and developed the concepts of credibility, transferability, dependability, and confirmability to describe quality in qualitative research[293]. The concepts are defined and compared in the table below.

Table 4.2: Comparison of quantitative and qualitative concepts of quality

Core Value	Quantitative research terms	Qualitative research terms
Truth Value	**Internal validity**: the extent to which a study accurately establishes a causal relationship between variables without being affected by confounding or bias.[294]	**Credibility:** The extent to which there can be confidence in that the findings accurately represent participants' experiences[293]
Applicability	**External validity/ Generalizability**: the extent to which the results of a study can be generalized or applied to other settings, populations, or times[295]	**Transferability**: The extent to which findings can be applies to other contexts settings or groups.[293]
Consistency	**Reliability**: the consistency or dependability of results[296]	**Dependability**: The stability and consistency of findings over time and under similar conditions.[293]
Neutrality	**Objectivity**: The extent to which results are independent of who conducts the study or interprets the findings.[297]	**Confirmability**: The extent to which the findings are shaped by the participants rather than researcher bias or motivation.[293]

The optimal method for conducting quality appraisal of qualitative research remains an area for debate. Quality appraisal checklists are common in quantitative research, and many advocate that checklists can be a useful tool for the quality evaluation of qualitative research, facilitating the comparison of strength and weaknesses of different studies in a

succinct and standardised manner[298]. However, others argue that checklists are too reductive, and erroneously equate and elevate technical procedural elements of data collection and analysis with methodological rigour, and fail to capture less observable attributes of quality such as researcher insights. They argue that checklists reduce quality appraisal to a formulaic technical exercise perfunctorily performed to satisfy rigid academic publishing norms rather than a meaningful engagement with the data[299].

Numerous structured checklists have been developed to appraise the quality of qualitative literature; however, few have been designed for use in a qualitative evidence synthesis and none are fully comprehensive of all domains of quality[300]. The four main commonly used qualitative research appraisal tools for systematic reviews are Critical Appraisal Skills Programme (CASP) Qualitative Studies Checklist[301], Joanna Briggs Institute (JBI) Checklist for Qualitative Research[302], Evidence for Policy and Practice (EPPI) Weight of Evidence Checklist[303], and the Cochrane Qualitative Methodological Limitations Tool (CAMELOT)[304]. The advantages and disadvantages of the different checklists are summarised in Table 4.3.

Table 4.3: Summary of major qualitative appraisal tools

Tool	Criteria Assessed	Epistemology	Strengths	Limitation	Best Use
CASP Qualitative Checklist [301]	Aims, Methodology Design, Recruitment Data collection, Researcher reflexivity, Ethics, Analysis, Findings, Value	Realist- real world focus but acknowledges researches influence	Widely used, simple, user-friendly, considers reflexivity and ethics	Lacks guidance on weighting	Quick, broad appraisal

JBI Checklist [298]	Congruity between research components philosophy, methods data collection, analysis, participants, researcher influence, ethics	Pragmatic/ realist. Strong focus on methods and congruence	Comprehensive, nuanced, recognises researcher positionality	Requires expertise and is laborious	In-depth qualitative reviews; especially if congruence important
EPPI Centre WoE [303]	Three dimensions: relevance to review question, methods quality, and appropriate design	Flexible- depends on review question epistemology	Integrates relevance and methodological quality	Less clarity in describing quality therefore requires expertise	Policy or practice relevance or synthesis of diverse evidence
CAMELOT [304]	Research aims, stakeholders, researchers, context, design, theory, ethics, recruitment, data collection, analysis, presentation.	Pragmatic/ contructivist	Comprehensive tool for assessing methodological strengths and limitations, supports transparency and reflexivity	Time consuming and requires training and calibration	Assessing the quality of studies as part of a wider CERQual confidence analysis

CASP-Critical Appraisal Skills Programe; JBI- Joanna Briggs Institute; EPPI-Evidence for Policy and Practice; CAMELOT-Cochrane Qualitative Methodological Limitations Tool					

Despite valid concerns that checklists can be superficial and formulaic, we felt that the benefit of having a structured assessment tool to describe and report different domains of quality was important and therefore we decided to use a checklist. We opted to use the JBI checklist for a more rigorous and nuanced assessment of whether a study's design and conduct truly fit its philosophical underpinning.

Another debate in quality assessment is how studies of poorer quality should be managed. The decision to include or exclude based on methodological quality needs to balance the risk of losing valuable insights by excluding studies despite methodological flaws against maintaining confidence in the quality and rigour of the included studies and reducing noise from poorly conducted studies. Some would argue that poorly conducted studies with 'untrustworthy' or inadequately reported results should be excluded to protect the validity of the review[305]. Apart from the fundamental arguments regarding the legitimacy of appraising quality in qualitative research, some argue that the rigidity of the checklist approach to quality appraisal can result in studies that have interesting and valid findings being labelled as poor quality and potentially excluded as a result of loose or incorrect application of the complex terminology around qualitative research such as describing their study as using grounded theory without conforming to the requirements of that approach, and can unfairly result in older studies being labelled poor quality for failing to adhere to current conventions around presenting qualitative research that did not exist at the time of their publication[289,306].

Many quality appraisal guidelines including GRADE-CERQual recommend appraising but not excluding based on quality, and using the appraisal process to describe and inform judgements about confidence in the synthesised findings rather than as a means of gatekeeping[307,308]. This is the approach taken in this work, where all the included studies were quality appraised but none were excluded based on the quality assessment.

4.4.5 Data synthesis

Qualitive evidence synthesis is the broad term used for the process of synthesising the findings of multiple primary qualitative studies[309]. There is no clear consensus over how to synthesize qualitative data with many different options for synthesis, all with different theoretical underpinning. All approaches are on a spectrum between the purely descriptive, meaning that the approach is purely to describe the range of findings in the literature; and highly interpretative, meaning that the approach aims to use the literature to generate new theories and concepts. Summary of the different approaches in Table 4.4.

Table 4.4: Comparison between different approaches to qualitative synthesis					
Method	**Approach**	**Description**	**Advantages**	**Disadvantages**	**Best Use**
Meta-aggregation [310]	Descriptive/ Aggregative	Pools findings across studies into categories then synthesises them into overarching statements, staying close to original meaning	Transparent and systematic, minimises reinterpretation	Limited theory building, can lose nuance and context	Practice guidelines, pragmatic recommendations
Meta-ethnography [311]	Interpretative/ configurative	Translates concepts across studies to develop new conceptual categories or theories	Rich, conceptual insights. Theory generating, captures complexity	Time and expertise intensive, less suited to large datasets	Theory building, understanding complex social phenomena
Thematic Synthesis [254]	Mostly descriptive, some interpretation	Identifies and groups themes across studies, combining descriptive coding with some interpretation	Familiar, balances transparency and interpretation, can handle large datasets	Risk of oversimplification. Less depth for theory generation.	Reviews on barriers/ facilitators or where thematic patterns are useful.
Critical Interpretive Synthesis[312]	Highly interpretative/ configurative	Flexible, iterative and critical approach prioritising conceptual richness and theory generation	Highly flexible, prioritises conceptual	Less transparent, highly subjective, not reproducible	Developing new concepts or

			depth, embraces complexity		critiquing existing ones
Framework Synthesis[313,314]	Descriptive/ framework driven	Applies and adapts an existing framework to organise findings	Structured, efficient, useful for policy orientated reviews	Constrained by framework, risks missing emerging concepts	Aligning findings with policy or pre-existing theoretical frameworks
Narrative Synthesis[315]	Descriptive/ configurative	Uses narrative summary techniques to organize findings across heterogenous studies	Flexible, good for heterogeneity, usable when other methods fail	Can lack rigour and be subjective	Scoping reviews or synthesising heterogenous evidence bases
Realist Synthesis [316]	Interpretative/ exploratory	Explores how, why, for whom and in what context interventions work (context-mechanism-outcome)	Explains mechanisms and contexts, good for complex interventions.	Complex, needs detailed primary data, time sensitive	Explaining causal pathways in complex interventions
Content Analysis Synthesis[317]	Descriptive/ Aggregative	Systemic coding and categorising of text data for pattern description	Simple, efficient for large datasets, accessible	Lacks depth and theoretical insight, not suited to meaning making	Quick descriptive reviews where summarising content sufficient

We opted to use a framework synthesis informed by both NPT and TPC. The reason for opting to use a framework synthesis is that we felt that both NPT and TPC lent themselves well to describing and categorising the different domains of workload and capacity in a way that is granular and comprehensive. As other studies in other chronic conditions have used NPT or TPC to describe workload, capacity and treatment burden[6,148,318–320], using a framework synthesis to integrate and describe findings for KRT transition aids comparison across different conditions. This review is novel in its use of both theories. To overcome the potential limitation that a framework approach is too prescriptive and risks missing interesting findings that fall outside the parameters of the coding frame we coded any finding that fell outwith the coding frame separately but these were very limited.

4.4.6 Normalisation Process Theory

As described in Chapter 2 in more detail, NPT is a middle range theory that explains how new complex work is incorporated- or normalised- into everyday life. It was originally designed to explain how organisations implemented new services, but has been adapted to describe how patients implement new healthcare workload[318,319,321–323]. It described four main work processes: Sense-making or Coherence Building, which is the process of understanding their illness and what their options are and why; Cognitive Participation, which is the process of working out exactly how they're going to execute the new work and recruiting others to help; Collective Action, which is the processes involved in actually doing the work; and Reflexive Monitoring, which is the work of reflection, monitoring, adapting and trouble-shooting[107].

We decided that NPT was well-suited to describing the workload encountered in KRT transition and lent itself well to a framework analysis for three main reasons. Firstly, patients starting KRT face a rapid and considerable increase in their healthcare workload that includes sense-making process, recruiting the help of others around them, and undertaking numerous new healthcare tasks that they are required to do and subsequently reflect on, and therefore NPT lends itself well to describing the process. Secondly, a detailed coding manual has been developed[108] providing rigour and clarity in how to apply the domains and subdomains as a framework. Thirdly, because NPT has been widely used in both primary qualitative research and systematic reviews and the framework developed for this systematic review has gone on to iteratively inform topic

guide and coding framework for Chapter 7, it allows for comparison both within this thesis and across different diseases and contexts.

4.4.7 Theory of Patient Capacity

As previously described, there have been several bodies of work that have applied NPT to individual patient workload however a novel aspect of this review was the addition of TPC to the framework. As described in more detail in Chapter 2, TPC is a theory that encapsulates the different domains that contributes to a patient's capacity to undertake healthcare workload. It is summarised by the acronym BREWS: Biography, which is the impact of biographical disruption on capacity; Resources, which are the financial, literacy, medical and health system knowledge, physical health, time, transport, self-efficacy and psychological resources patients' can draw upon; Environment, which is the sociocultural, clinical and physical environment within which the patient is trying to enact the work and the impact that has on capacity; realisation of Work, which is the impact the experiences of realising work has on capacity; and Social which is the social relationships and networks encompassing family, friends, colleagues, wider community and clinicians that patients can rely on in order to meet their work[6].

Careful consideration was given to whether it was worthwhile adding a second theory to the coding framework. On one hand, adding another theory added complexity to the work and could lead to duplication. On the other hand, whilst NPT is highly applicable to workload it does not have a capacity component and we believed that in undertaking a piece of work aimed at exploring treatment burden it was important to capture both workload and capacity. Although some domains were similar- for example, there was some overlap between NPT domains looking at the enrolment of others and TPC domains looking at the impact of the social network on capacity- the focus was different and we felt that NPT and TPC were complementary theories that lead to the coding framework being more comprehensive rather than duplicative. It also permitted the iterative development of the topic guide and coding framework for the work described in Chapter 7.

4.5 Quantitative Analysis of Healthcare Workload Data

A retrospective cohort study of the healthcare workload of patients transitioning onto KRT was carried out to fulfil the following objective:

> To quantify healthcare workload during the transition onto KRT and identify patient characteristics associated with increased workload.

4.5.1 Description of the dataset

The dataset we elected to use was the Strathclyde Electronic Renal Patient Record (SERPR, Vitalpulse, UK). This is a renal specific electronic patient record that has been used across the renal network in the West of Scotland since 2010 and is the electronic patient record (EPR) used for all contacts with the renal services. It includes a wealth of detailed information that is amenable to being queried including routinely collected demographics; renal specific information such as primary renal disease, time of nephrology referral, vascular access status and transplant listing status; outpatient records for all contacts with nephrology; all investigation results including bloods, microbiology, imaging and pathology within NHS GGC; acts as the haemodialysis notes including detailed notes of all sessions; records of all inpatient renal stays; detailed records of transplant work up, inpatient stay and post-transplant follow up; and a detailed medications segment.

The benefit of using SERPR as the data source is that it provides a very rich, granular, renal specific dataset which lent itself well to a research question looking at KRT transition workload. The level of detail that it can provide is unsurpassed by other EPR systems currently used in our study area, renal registry data, or crosslinking to GP data, and therefore allows for a more detailed and renal specific examination of workload than would be possible using other datasets. However, there were some limitations to using SERPR. Firstly, it's renal specific nature meant that the healthcare workload from non-renal conditions were not fully captured. It has no access to GP records and only partial capture of hospital workload generated by other specialities: investigations would link through, but non-renal outpatient appointments and non-renal inpatient stays would not. Its capacity to capture the workload of other co-morbidities is therefore limited. Secondly, it is a system that relies on manual input of data and does not mandate that every field is

filled, and missing data was a problem we encountered with some variables. We had intended on including ethnicity, frailty, and multimorbidity, but ethnicity and frailty were so poorly recorded they were unusable. Imprecision plagued the recording of co-morbidity, with a high number of signs and symptoms rather than actual conditions recorded, for example 'pulmonary oedema' recorded as a chronic condition without any indication of underlying cause, and acute conditions such as episodes of COVID-19 or influenza recorded as chronic conditions, which rendered the data unusable. Thirdly, because this version of SERPR is specifically designed for our unit and the level of detail recorded meant that opportunities to collaborate with other units were limited.

We considered mitigating for these limitations by linking with a secondary dataset but decided that it was not feasible. Firstly, we judged that the additional information gained by attempting to link with GP records or other hospital records was likely to generate an enormous amount of work, both in getting permission to access the data and in cleaning, for little benefit. The reason for this is that although this would be a severe limitation if we were studying patients with less severe CKD, peri KRT patients tend to receive most of their healthcare through the renal services and therefore their SERPR record is reasonably comprehensive. If a dialysis dependent or recently transplanted patient are admitted to hospital for a non-renal reason they are almost invariably admitted to a renal ward or under joint care with renal to facilitate their ongoing dialysis or transplant care and therefore this episode would feature on SERPR. KRT patients will often seek advice for other acute and chronic conditions during their regular clinic visits or whilst at a HD session and have their chronic medications managed by renal, and therefore although we are almost certainly missing some primary care activity this would be dwarfed by the renal specific healthcare work. We decided therefore that time and effort were better spent concentrating on getting the most out of the data extractable from SERPR rather than trying to link across other datasets.

4.5.2 Study period and patient selection

Our study population was all consecutive patients aged 18 or older that started any form of KRT in the Glasgow Renal and Transplant Unit, Glasgow, Scotland between 1st January 2015 and 31st December 2019. We collected data for the 6 months before KRT start and 36 months after. Data collection was completed on the 31st December 2022.

The decision to set the study period as 6 months before and 36 months after was taken after some deliberation. Deciding how long before KRT start to include was a balance. We considered not looking at pre-KRT workload at all, but as KRT start is an anticipatable event for most patients and optimal treatment involves extensive pre KRT preparation[8] we worried that omitting pre-KRT work would miss a considerable amount of KRT transition workload. On the other hand, many patients are known to renal services for years prior to KRT and start preparing many years in advance. Indeed, there is great difficulty and imprecision in predicting KRT start[324–327] and a significant competing risk of death[328]. The National Kidney Foundation Kidney Disease Outcome Quality Initiative (KDOQI) best practice guidelines advise that arteriovenous fistulas should be created at least six months before anticipated KRT start date[43], and studies found that 30% of fistulas were created more than 1 year prior to KRT start[329] and only 55% of AVFs created are ever used for dialysis[330]. Therefore, it could be argued that limiting transition workload to six months before start date and only those who do go on to start KRT could miss a significant proportion of preparatory workload. However, the further back from KRT initiation we went the less accurate SERPR became as more of the workload fell outwith the renal services and less was gained from inclusion of the data. We therefore decided that six months was a reasonable compromise that would capture a significant proportion of the work directly linked with KRT transition whilst retaining feasibility. 36 months was selected because the average wait time from listing to deceased donor transplant (DDTx) was 2-3 years[68] and we wanted to capture the workload effect of DDTx both before and after transplantation.

We decided to include all modalities of KRT rather than focus on individual modalities as this is how KRT is experienced by the patient: modality changes are common, as is preparing for one modality only to start on another (e.g. getting a pre-emptive fistula created for HD but getting transplanted prior to its use) and we wanted to capture all workload.

We debated whether to include comprehensive conservative management (CCM) patients in our analysis. On one hand, CCM is a recognised management option for CKD5 and incurs some treatment workload, and especially in a thesis that asks wider questions about the burden of treatment including and comparing the workload of those who had elected for conservative management posed an interesting avenue of research. However,

there were two main issues that precluded the inclusion of these patients. Firstly, although a palliative approach has always been a common management option in advanced CKD, CCM as a deliberate package of interventions is a relative new concept [331]. The Scottish Renal Registry has only reported data on CCM since 2022[332], which is later than most the data collection period for this study. Therefore, CCM patients in this study period were not query-able in SERPR. Secondly, CCM does not have a clear start date in the same way as KRT transition has and therefore it did not lend itself well to our analysis plan. It was therefore decided that comparing the workload of CCM to that of KRT based management was better answered by a different study deliberately set up to answer that question rather than as a subgroup within this study.

We included all consecutive adult patient who had started KRT in our unit. Patients with return of function or had only had a period CVVH in ICU were excluded. Participants were included until 36 months after their start date or their death, whichever was earliest. For patients that had died, their per month averaged workload was worked out for every month they were alive was included in the analysis, censoring the months for which they were dead.

4.5.3 Study design

We decided on a retrospective cohort study of prospectively collected routine EPR data. The advantage of this was feasibility as we were able to look at a 5 year time period with a 3 year follow up within the tight time constraints of a PhD (which would have precluded the prospective collection of data), and avoid duplication of work. However, the main drawback was that we were limited to what was recorded in SERPR.

An interesting avenue that we were not able to explore was the effect of treatment intent on workload. KDOQI recommend that all KRT patient have an individualised long-term plan and that this informs their care[43]. For example, it would be interesting to be able to be able to accurately differentiate between those who were on HD as definitive management and those whose initial treatment intention was for HD to be a bridge to transplantation (regardless of whether they were transplanted). There were some proxy measures that we tried to look at such as referral to transplant clinic or transplant listing but we felt that this was inadequately complete to be usable. If we had a prospective cohort study design with purpose-built data collection we would have included questions

about treatment planning and intent as part of the data collection process. However, this work could lead to routine collection of treatment intent as part of the EPR which would allow this to be examined in future research.

Another potential avenue of research that was precluded by a retrospective design was the use of a patient reported measure (PRM) of treatment burden as the routine collection of PRM data was not part of standard practice during the data collection period. As explored in Chapter 3, there are no KRT transition specific treatment burden PRMs however there are non-condition specific measures such as the PETS or the TBQ that could have been utilised. There is a difference between objective amounts of healthcare workload and the subjective experience of burden, and the retrospective design meant that we were limited to capturing objectively measurable workload. There has been a growing call to routinely collect PRM data as part of renal registries[333], which may lay the ground for future quantitative research exploring the association between workload and patient reported treatment burden.

4.5.4 Selecting variables of interest

When deciding which demographic variables to collect and which workload exposures to collect we were faced by four main questions:

1. What aspects of demography were relevant for analysis and could influence workload?
2. What demographic variables do we have good enough data on to include in the analysis?
3. What constitutes healthcare workload?
4. What do we have good enough data on to include in the model?

The variables that we included in our study are demonstrated in table 4.5.

Table 4.5 Variables included in the analysis

Demographic and clinical variables	Workload exposure	Primary Outcome
Age	Inpatient stays	

Sex	Outpatient clinics	Average time per month spent on healthcare workload
SIMD	Radiology	
Primary Renal Disease	HD sessions	
Number of medications	Travel	
Late presentation to nephrology		
Starting modality		
Modality change		
Incident transplant		
Failed transplant		

4.5.5 Demographic variables

When deciding on variables to include we wanted demographic descriptors, descriptors of co-morbidity and health status, and descriptors of treatment trajectory.

We wanted to be able to look at socio-economic status. Debate exists regarding how best to capture socio-economic deprivation. The measure we used was the Scottish Index of Multiple Deprivation (SIMD), which is a geographical based measure that categorises small geographical areas from 1 (most deprived) to 5 (least deprived) based on assessment of income, employment, education, health, access to services, crime, and housing[334] . The benefit of using SIMD is that it is a composite measure that is easily available for each post code, and is widely used allowing for comparison between different studies. However, it has been argued that using geographically determined neighbourhood level indexes of deprivation such as SIMD as a measure of individual socioeconomic deprivation is an ecological fallacy as it assumes uniformity in socioeconomic status when none exists: not all socioeconomically deprived people live in deprived areas, not everyone living in a deprived area are socioeconomically deprived; affluence and deprivation can overlap within a post code area[335]. This is especially true in more rural settings where the post code areas are larger and pockets of significant deprivation can be missed[336,337]. The GLOMMS-CORE study conducted in the North of Scotland found that more deprived SIMD and household-level socioeconomic status

measures were both associated with higher risk of early kidney disease, but the association was stronger with household measures determined by classifying employment nature[338]. This would suggest that using a household measure might be superior to SIMD in analysing the effect of deprivation in kidney disease, however this data was not routinely collected in SERPR whereas we had a post code for all participants therefore SIMD was selected as the measure for use.

As discussed before, co-morbidity was poorly recorded in SERPR whilst long term medications were well recorded. We therefore elected to use number of repeat medications at the point of KRT initiation as a proxy measure for multimorbidity. This has the advantage of also providing more insight to the intensity of healthcare workload resulting from managing healthcare conditions compared to simple counts of conditions, as these treat each condition equally whereas one might be considerably more burdensome to manage than others. However, this approach might miss conditions that do not increase the number of medications prescribed but do affect patients' healthcare workload and capacity, for example if a patient is already on medication to manage ischaemic heart disease the addition of a stroke might not alter the number of medications but would have considerable impact on the patients' health. Equally deteriorating health and functional status can lead to deprescribing as the risks and benefits of secondary prevention shifts and therefore it isn't always true that fewer long-term medication means better health. Using number of medications at time of KRT initiation also did not capture changes in prescribing over the course of the study period, the impact of route of administration, or the number of times per day patients were required to take the medication. This is a limitation of the study, but it was felt that as this is a general overview of workload and not a specific study on medication workload adding this level of detail and complexity was not feasible. One issue we faced in categorising number of medications into categories is that definitions of polypharmacy in general multimorbidity literature proved inadequate to differentiate between medication burden in KRT patients. A systematic review into the classification of polypharmacy found that the most used definition for polypharmacy was 5 or more daily medications[339] and a major cohort study of polypharmacy in older adults in the USA classified medication use as no polypharmacy as 0-2 medications, minor polypharmacy as 2-3 medications, moderate polypharmacy as 4-5 medications and major polypharmacy as >5 medications[340]. In this study cohort the average medication number was 12.5, therefore pre-existing

classification systems would have been indiscriminatory. We therefore decided to classify medication use as low (<10 medications), average (10-15), and high (>15 medications).

We categorised Late Presentation as first presentation to renal services <90 days prior to KRT start in line with the Scottish Renal Registry[12].

We wanted to capture the impact of modality on workload. Starting modality was easily extracted and defined. However, the starting modality alone was a poor indicator of the treatment journey, with many participants changing modality. There was complexity in categorising modality changes, as some participants changed modalities three times or more and the risk of being overly granular in categorising modality changes was that we ended up with too many categories with some with very low numbers that became uninterpretable in a multivariate regression model. Most modality change was from a dialysis modality to transplant and therefore we decided that the most clinically relevant categories were exposure to incident transplant (KTx after starting KRT on PD or HD), exposure to any modality change, and exposure to a failed transplant (return to PD or HD after exposure to KTx) and these are the variables we included in the analysis.

4.5.6 Exposure of interest: healthcare workload over time

The healthcare workload variables that we selected to include were outpatient clinics, inpatient days, HD sessions, radiology, and travel to appointment. Selecting which healthcare workload to include was a balance between comprehensiveness, accuracy, and feasibility. We had detailed information that we could be reasonably confident after some cleaning and cross-checking was correct and comprehensive on number of clinics, HD sessions and radiology episodes undertaken and the number of inpatient patient days for participants, and we could estimate commute times for all episodes of care from domiciliary post code.

However, by only capturing hospital workload, we were concerned that we were missing considerable workload done at home. This was especially true for PD, where almost all the dialysis workload is done at home and not captured by SERPR whereas for in-centre HD patients every session is recorded. We considered introducing estimates for time used for PD and possibly other home tasks such as taking medications but decided that we had no reliable way of estimating this, and we risked leaning too far into the realms of

conjecture. We therefore decided that it was better to limit the study to hospital based healthcare workload where we had high quality, accurate and verifiable data and accept the lack of home-based workload data as a limitation of this study.

4.5.7 Selecting the primary outcome: using time as an aggregate measure of workload

The primary outcome for this study was average time per month spent on healthcare workload. We wanted our outcome of interest to be a combined measure of workload that we could track over time. There is no consensus over how to describe cumulative workload. We considered four possible approaches:

1. Using simple descriptive counts of workload. This is the approach used in similar papers looking at healthcare episodes in PD and HD[163,164]. The benefit of using this approach is that it is purely descriptive and stays the closest to the data without any further estimation or processing. The disadvantage is that it does not lend itself well to combining different types of workloads: it is self-evident that a routine outpatient clinic appointment is not equal to a 20-day hospital admission but differentiating between these in the data is very difficult so you either need to report different type of workloads separately or accept that you are combining very different things.

2. Devising a scoring system for healthcare workload where different types of workload are ascribed a different weighing. Patient reported measures of treatment burden in chronic conditions exist in which patients score the burden caused by different domains of workload[341–343] but there are no validated scoring systems for objectively observed renal healthcare workload which could be retrospectively applied to recorded workload. We decided that devising and properly validating a workload score was outwith the scope of this PhD and that creating a rough scoring system based on what we perceived to be more work was methodologically unsound.

3. Using health economic measures. This is the most common way of aggregating workload and has been used in KRT[165–168,344]. The benefit of using cost is that it converts diverse healthcare activity to one easily understood unit of measurement. However, it has significant disadvantages in our study. Firstly, it is not a patient centred outcome: whilst cost is highly important to health economists and service planning, in a universal, free at the point of use healthcare system such as the NHS the financial cost of treatment is largely meaningless to patients and poorly captures the human cost of enacting healthcare workload. Secondly, most of these studies have been undertaken in insurance based/commercial healthcare systems such as in the USA where detailed, itemised resource use per patient is routine for billing purposes. This data is not routinely captured in the NHS and therefore if we tried to retrospectively cost the healthcare use of individual patients it would require high levels of estimation and imprecision.

4. Using time spent on healthcare work as an aggregate measure of workload. There has been a growing recognition in oncology that especially in situations where curative treatment is not possible (and there's a prima facie case to be made that KRT is similar to this) time spent not doing healthcare work is very precious to patients, and that for some patients the impact of the time spent pursuing cancer treatments is so considerable it offsets the modest survival gains offered by said treatment. This has given rise to the concept of time toxicity[169,345–348]. The benefits of using time as the aggregate measure is that it is an easily understood and meaningful unit of measurement that is important to patients and distinguishes between the impact of different types of workloads. The disadvantage is that SERPR does not collect precise timestamps for episodes of care and therefore we needed to estimate the length of different healthcare workload which introduced an element of imprecision into the work.

We elected to use time as the unit of measurement for workload. This is novel for non-oncology workload and provides an interesting and innovative insight on workload during KRT transition.

4.5.8 Statistical techniques

As our primary outcome was total time spent in healthcare- related workload per month we needed to select statistical techniques that were appropriate for use for continuous data. On initial interrogation of the data, it became apparent that it was that was non-normally distributed and highly right-skewed, with most patients experiencing low to moderate workload but a smaller group accumulating very high levels of workload predominantly driven by inpatient stays and haemodialysis. This meant that standard parametric methods such as linear regression or ANOVA were inappropriate without substantial transformation and potentially difficult interpretation.

Descriptive analysis therefore reported both median and interquartile ranges alongside means and standard deviations. This allowed both the typical patient experience and the influence of high-workload outliers to be represented. Skewness was assessed using Fisher G1 and Bowley's quartile skew, as workload distributions were expected to be asymmetric and potentially influenced by extreme observations.

For univariate comparisons between patient groups, the Kruskal- Wallis test was utilised due to the non-parametric distribution of the workload and as most of the demographic and clinical variables were categorical with more than two groups. This rank-based non-parametric test allowed comparison of workload distributions across groups without assuming normality. Effect sizes were reported using ε^2 to provide an estimate of the magnitude of observed difference in addition to statistical significance.

Negative binomial regression was selected for the multivariate analysis as the healthcare workload data was substantially overdispersed, with variance considerably exceeding the mean. A Poisson model would have been inappropriate as it assumes equality of the mean and variance, which was not consistent with the observed workload distribution. Negative binomial regression allows for overdispersion by including an additional dispersion parameter, making it better suited to modelling heterogenous healthcare utilisation. It therefore allowed estimation of relative differences in average workload between patient groups while allowing for skewness and overdispersion. We presented the results as incidence rate ratios (IRR), which provided clinically interpretable estimates of proportional difference in workload. For example, an IRR below 1 indicates lower

average workload relative to the reference group, whereas an IRR above 1 indicates higher workload.

Separate models were fitted for the peri-initiation (months -6 to +6) and early maintenance periods (months 7-36) because the clinical situation faced by patients and the drivers of workload were expected to differ between these phases. Death-censoring was used so that average monthly workload was calculated only across months in which participants were alive, minimising error by distinguishing between no workload month due to true low healthcare workload and those caused by participant death.

Available case analysis was considered appropriate because missing data were low for the primary variables included in the analysis.

4.6 Qualitative analysis of patient interviews

Serial interviews with 30 individuals who were transitioning onto KRT were analysed to fulfil the following objective:

> To explore the interaction of healthcare workload, patient capacity and treatment burden during the process of transition onto KRT and how it evolves over time.

The third phase of this study was aimed at gaining a deeper insight into the patient experience of transitioning onto KRT, and how their healthcare workload, capacity and treatment burden evolved over time. Analysis was informed by the findings of the systematic review.

4.6.1 Participants

Appropriately selecting and recruiting a study population is a key determinant of the quality and reliability of the findings[349], and numerous approaches to sampling can be undertaken. In quantitative research, the approach that is considered to be most rigorous is random or probability-based sampling where all members of a population have a known probability of being selected and the sample is statistically representative of the whole population[227]. In qualitative research, the primary aim is to recruit a group of individuals from whom the richest possible picture of experiences can be gained rather to estimate the incidence of a particular phenomenon within a population. Therefore,

overwhelmingly the most common approach to sampling in qualitative research is purposive- where participants are deliberately selected based on their anticipated contribution- rather than probability based[350]. There are numerous different variations in approaches to purposive sampling, which are detailed in Table 4.6. The other possible approaches to qualitative sampling are: opportunistic, where researchers recruit where opportunities arise during field work[351]; and convenience sampling which is sampling based on ease of access rather than any clear strategy[352].

Table 4.6: Summary of different purposive sampling approaches

Approach	Description	Advantages	Disadvantages
Homogenous sample	Very similar participants selected to give a detailed picture of a particular phenomenon	Allows for detailed investigation of social processes in a specified context	Can be too narrow and ungeneralisable to other contexts
Heterogenous/ maximum variation sample	Deliberate approach to capture wide range of characteristics and experiences within sample	Allows for identification of central themes that cut across the variety of cases or people	May require a much larger study population to reach saturation because of the variation
Extreme case/deviant sampling	Participants selected based on being exceptional or extreme	Specifically focuses on experiences outwith the norm, which could bring enlightening insights not captured by other methods	Requires a definition of 'normal' and subjectivity in determining whether a case is truly extreme
Intensity sampling	Participants selected that are felt to strongly represent	Generates a highly information rich samples that may allow for smaller size	May miss important insights from people that have had less intense experiences of

	the phenomenon of interest		the phenomenon of interest
Typical case sampling	Selection of participants that characterise experiences that are normal or average	Deliberately focusing on what is common rather than what is interesting can bring important insights	Requires a detailed understanding from the outset of what constitutes a 'typical' case
Stratified purposive sampling	Hybrid approach where the aim is to select groups that display variation on a particular phenomenon but there is relative homogeneity within the groups	Has the benefits of both capturing variance and allowing for comparison between subgroups but also having the homogeneity for intergroup comparison and analysis	May require larger sample sizes to reach saturation
Theoretical sampling	Participants are selected based on their potential contribution to the development and testing of theoretical constructs	Facilitates theory generation and comparative analysis	Requires data to be collected and iteratively analysed and for this to inform further recruitment, with little predefined structure
Adapted from Ritchie et al[227]			

We decided to take a stratified purposive sampling approach as we wanted to be able to capture the range of different experiences but also compare between and within groups. Our initial sampling matrix is detailed in Table 4.7.

Table 4.7: Sampling Matrix for study recruitment

	Pre-emptive transplantation	**Haemodialysis Planned**	**Haemodialysis Unplanned**	**Peritoneal Dialysis**

Age group	Male	Female	Male	Female	Male	Female	Male	Female
18-34	0-2	0-2	0-2	0-2	0-2	0-2	0-2	0-2
35-59	1-2	1-2	1-2	1-2	1-2	1-2	1-2	1-2
60-74	1-2	1-2	1-2	1-2	1-2	1-2	1-2	1-2
75+	0-2	0-2	1-2	1-2	0-2	0-2	0-2	0-2
Total	5-10		10-15		5-10		5-10	
Secondary criteria								
White	15-20							
BAME	5-10							

The exposures of interest used in constructing the sampling matrix were KRT modality, age, sex, and ethnicity. We felt that it was important to capture both planned and emergency haemodialysis starts as these are very different paths onto KRT, and to capture a representation of all age groups despite an older age bias for KRT start as the experiences of KRT as a young person is quite different to that encountered in older ages. We also thought it was important to capture a range of cultural backgrounds. In constructing our sampling matrix, we needed to strike a balance between recruiting a sample that would be most symbolically representative of the breadth of experiences and perspectives within our patient population, and what was feasible within the time frame we were recruiting in and not being paralysed by being excessively prescriptive. From a methodologically puristic perspective, it could be argued that feasibility considerations meant that there was an element of convenience sampling in our approach superimposed on a stratified purposive sampling foundation. This was especially true in recruiting for less common modalities such as pre-emptive transplants and initial modality PD. Therefore, who was available and feasible to recruit was always considered alongside the sampling matrix and the recruitment approach was ultimately pragmatic.

Our actual recruitment performance is detailed in table 4.8.

Table 4.8 Actual recruitment into the study as per sampling matrix

	Pre-emptive transplantation		Haemodialysis Planned		Haemodialysis Unplanned		Peritoneal Dialysis	
Age group	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
18-34	0	0	0	1	0	1	0	1

35-59	2	2	2	3	0	1	2	1
60-74	2	2	2	2	2	0	1	1
75+	0	0	0	0	1	0	0	1
Total	8		10		5		7	
Secondary criteria								
White	27							
BAME	3							

Several challenges were faced during recruitment, especially in recruiting participants with planned haemodialysis starts which was unexpected considering this is the most common starting modality in the unit. The challenge arose because of the difficulty in predicting haemodialysis starts in relatively stable patients. Our intention was to approach and recruit participants before they started to capture the preparation phase and then subsequently interview them twice in the year after starting. This proved easy for PD and pre-emptive live donor transplant patients as they had clear cut operation dates and increased healthcare contact immediately before starting which greatly facilitated recruitment. Recruiting unplanned HD starts was also straightforward as I had a close working relationship with the nephrology team and could easily pick up and recruit inpatients that had started HD unexpectedly. However, recruiting planned starts proved challenging. Low clearance clinics included patients that were many months away from starting KRT or were unlikely to ever start, and patients were often in a hurry and less amenable to discussing potential recruitment. Identifying patients that were likely to progress to KRT in weeks to a few months was also difficult: four of our participants did not progress to starting KRT within the study period, and a further one only started KRT in time to do only one of the two post-initiation interviews. We had anticipated that recruitment and retention could be challenging in this population and therefore had a generous sample size of 30 which I would argue has allowed us to achieve sufficient information power and meaningful findings despite the challenges with follow up.

4.6.2 Data Collection

Serial semi-structured interviews were conducted. Participants were interviewed up to three times: once before or at the time of KRT initiation, once in the immediate post initiation phase (six weeks to 3 months post initiation), and once at least six months post

initiation. We had initially planned for a fourth interview at 12 months post initiation however upon reflection we decided that three interviews per participant that were more spaced out was more feasible and avoided duplication and excessive participation burden.

We adopted a pragmatic approach to interview timing, prioritising maximising participation over rigid adherence to the interview schedule: the priority was having a pre, early and late interview to capture the evolution of burden over time. Sometimes participants were unwell or busy, and providing that they still consented to ongoing participation I endeavoured to be maximally accommodating.

Interviews were conducted at a place of the participant's preference. I offered interviews either in person at their house, in person at a hospital visit for another reason such as a HD session or clinic appointment or over Zoom. Most of the patients elected for in person interviews at a hospital visit, with a handful selecting Zoom interviews. No participants elected for a home visit. Interviewing in a hospital or dialysis unit setting brought advantages and disadvantages. Interviewing when participants were attending a hospital setting regardless minimised the burden on participants. Indeed, several participants who were interviewed while on dialysis or whilst inpatient expressed that they enjoyed the interviews and welcomed the distraction. Many lacked confidence in using Zoom and expressed preference for in person interviews, and providing adequate warning had been provided the majority of participant expressed a strong preference for being interviewed when they were attending the hospital for a clinical visit. However, some challenges arose from interviewing in a clinical setting. It could be argued that interviewing in a clinical setting reinforces the power dynamic between doctor and patient and might inhibit participants from talking freely. From a practical perspective, interviewing in a clinical area meant that some interruptions were inevitable despite efforts to minimise this. This occasionally disrupted the flow of the interview. It was also difficult to ensure privacy in an open plan dialysis room, which may have limited what participants chose to share. However, on balance it was felt that this approach maximised participation whilst minimising the burden of taking part and as all participants were offered different options for their interview all interviews that took place in a clinical setting were done so because of participant preference.

4.6.3 Data analysis

There are a wide range of different approaches to analysing qualitative data, which vary greatly both in terms of epistemological assumptions, nature of the qualitative data being analysed, and the focus and aims of the analytical processes[227]. Three broad categories of qualitative analysis have been described[353]:

1. **Self- understanding:** where the researcher aims to only condense what the participants meant and understood.
2. **Critical common-sense understanding:** where the researcher uses general knowledge and contextual understanding to inform the data analysis.
3. **Theoretical understanding:** where the researcher analyses the data in line with a broader theoretical perspective.

I have summarised different approaches to qualitative data analysis in Table 4.9.

Table 4.9: Summary of different approaches to qualitative data synthesis

Approach	Description	Epistemological underpinning	Advantages	Disadvantages
Thematic Analysis [354]	Aims to analyse the data by identifying common themes.	Flexible- can be adapted to fit realist, interpretivist, or constructivist paradigms	Simple and versatile approach.	Risk of superficiality.
Grounded Theory [355]	Aims to develop new theory directly grounded in the data through iterative coding and	Constructivist/ Interpretive	Systematic, rigorous process that produces substantiative theory. Iterative and flexible to different kinds	Requires concurrent collection and analysis. Complex and labour intensive to do well.

	constant comparison.		of data and contexts.	
Framework Analysis [356]	Uses a matrix-based method informed by previous literature to organise data into themes, balancing both deductive coding and inductive theory generation.	Pragmatic	Transparent, rigorous and systematic process that facilitates comparison with other literature.	Using pre-set frameworks risks excessive rigidity and missing new insights- the data is moulded to fit the framework rather than the framework being adapted to fit the data.
Interpretative Phenomen-ological Analysis (IPA) [357]	Uses detailed case by case analysis to explore how individuals make sense of lived experience.	Interpretative/ Phenomenology	Generates rich, in-depth insights into specific phenomena.	Highly interpretative and not generalisable.
Discourse Analysis [358]	Examines the use of language as a way of understanding social reality.	Social constructionism.	Useful for analysing policy, media and social talk and understanding power relationships	Highly interpretative. Greater focus on wider social phenomena, less useful for understanding meaning at an individual level.

Narrative Analysis [359]	Uses the stories people tell as a way of analysing socially constructed accounts of meaning and identity.	Constructivist	Strongly rooted in the voice of participants. Useful for understanding meaning-making processes.	Vulnerable to subjectivity and difficult to generalise.
Qualitative Content Analysis [360]	Systematic coding and categorising of text to interpret patterns and meaning.	Positivist or interpretivist depending if classifying into objective categories or contextualising meaning.	Can handle large datasets and is flexible.	Risk of decontextualising data and superficiality.

The approach we chose for analysing our data was a two-stage framework analysis approach using a coding framework informed by NPT and TPC that had first been used in the systematic review (Chapter 5) to first develop taxonomies of both workload (NPT) and patient capacity (TPC) and then perform a second higher order coding looking at the interaction with the healthcare system and evolution of treatment burden over time using BoTT. The five key stages of framework analysis are familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation[356]. All transcripts were thoroughly read through to facilitate familiarisation. Transcripts were uploaded onto NVivo 14 and first order indexing and charting using the coding framework was performed. Coding clinics were held with senior supervisors to check and refine coding categories. Data were analysed prospectively which facilitated iterative development of sub-categories within the coding framework and additional codes to describe changes over time. The iterative process also informed the refinement of the content and focus of the topic guide used in later interviews. For example, enacting healthcare tasks had always been part of the topic guide but prior to starting interviewing the impact of digital

interfaces and of negotiating between primary and secondary care for medications was not appreciated, and as this became clearer as a recurring theme in interviews it was developed into a routine prompt in subsequent interviews. Once all interviews had been coded using the NPT and TPC framework and taxonomies created, these were used to map onto BoTT for a higher level interpretation, with the findings described in detail in Chapter 7.

Using three separate theories to inform a two-stage framework analysis could be criticised as being excessively complex. However, the three theories are highly complementary. NPT and BoTT have been developed by the same researchers and there are sub-constructs that are identical in both theories and translate directly across. BoTT does have some capacity informed constructs but does not afford the same granularity as TPC and therefore we elected to use TPC as well as NPT in the first order coding to have the same degree of granularity and rigour in coding workload and capacity domains before moving forward to integrate both in a higher order framework informed by BoTT. Any findings that fell outwith the coding framework were coded separately, but these were rare and mostly pertained to trauma responses or to better capture changes over time.

4.6.4 My role as researcher and transplant surgery registrar

I am a Welsh, female General Surgery and Renal Transplant Registrar in my mid-thirties with a medical degree and two MScs with prior qualitative research experience and training, who conducted this research as part of a PhD. I was employed in a non-clinical role as a doctoral research fellow at the time of conducting this work, but have previously worked clinically in the care of patients on KRT and had been a qualified doctor for 10 years. I have no personal or family experience of KRT, so approached this study with a professional interest and substantial prior knowledge of the clinical side of KRT transition but less insight into the patient experience. I had no relationship with any of the participants before the study and did not treat any of them clinically during the study period, therefore all my interactions have been in the context of a researcher-participant rather than a doctor-patient relationship, although my clinical background was made clear in the consent process. I have made efforts to centre the patient's voice and remain data driven at all points in this research, but it is inevitable that some of my previous

experiences, opinions and biases as a clinician and lack of lived experience underpins my world view and therefore influences my understanding of the data.

Recruitment was conducted through low clearance clinics (LCC), vascular access clinics, transplant assessment clinics, PD clinics and on the renal ward. Patients were approached to see if they were potentially interested in participation by a member of their clinical team, and then if they expressed an interest in participation by me. I wore non-clinical smart casual clothes and identified myself as a PhD researcher but it was also clear by the natural familiarity between myself and clinical staff that I was a doctor and had previously worked in the unit. I think in part this was an advantage: it was clear that I understood KRT and the system so patients could talk freely without needing to clarify and I could understand what they meant and what had happened to them. As KRT is a relatively niche area even within medicine and certainly falls outwith most people's life experiences, prior knowledge was an advantage to me as a researcher. However, my proximity to the unit may have been a disadvantage. I made it very clear in the consent process that I wanted them to speak freely and welcomed criticism and exploration of difficult and negative experiences, and reassured participants that what they said was anonymous and would not affect their care, but it is possible that some patients self-censored because I was perceived to be clinical staff. There was also a personal challenge for me in trying to maintain the persona of the neutral researcher when participants expressed their perception of how an event had occurred or a challenge that they had faced when due to my proximity to the unit I had my own perceptions of why something might have happened or had already heard an alternative version of events from the clinicians involved. In these situations I focused entirely on what the participant experienced and avoided the temptation to explain or excuse, although at times this was difficult.

4.6.5 Reliability and validity of the data

As discussed within this chapter, there is considerable debate on the appropriateness of assessing the reliability and validity of qualitative data. In order to summarise reliability and validity of the work I have applied the same JBI Checklist as I used to appraise quality in the systematic review to the study, and expand on the decisions taken in the table below (Table 4.10).

Table 4.10: JBI Checklist for Qualitative Research as applied to 'Exploration of treatment burden during transition onto kidney replacement therapy: a longitudinal qualitative study'			
	Yes	No	Unclear
Is there congruity between the stated philosophical perspective and the research methodology?	X		
We have utilised a pragmatic epistemological approach, which is wholly congruent with a framework analysis approach.			
Is there congruity between the research methodology and the research question or objectives?	X		
A longitudinal qualitative study consisting of serial individual interviews is an appropriate methodology to understand the evolution of treatment burden over time.			
Is there congruity between the research methodology and the methods used to collect data?	X		
Serial interviews are congruent with the stated methodology.			
Is there congruity between the research methodology and the representation and analysis of data?	X		
It is clear how the framework has been applied to the data.			
Is there congruity between the research methodology and the interpretation of results?	X		
Yes- the data has been interpreted in line with the stated theoretical frameworks.			
Is there a statement locating the researcher culturally or theoretically?	X		
I have discussed my cultural and theoretical position at length in Chapter 4, and more concisely in Chapter 7.			
Is the influence of the researcher on the research, and vice-versa, addressed?	X		
I have explored this briefly in Chapter 7 and in greater detail in Chapter 4, especially exploring the potential impact of my clinical background on the conduct of the research and interpretation of the findings.			
Are participants, and their voices, adequately represented?	X		
I have strived to provide representative quotes and to centre the participant voice in the research. There is a representative quote for all substantiative finding.			
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	X		

Ethical approval was granted for the study.			
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	X		
I think that they do and that by using NPT, TPC and BoTT and by creating the taxonomies of workload and capacity I think it is clear how I've reached the conclusions I have from how the data has been analysed.			

4.7 Creation of a conceptual model

In Chapter 8, two conceptual models of treatment burden during transition onto KRT are presented which is an integrative synthesis of the three studies. One is a conceptual model of how healthcare workload, patient capacity, and the healthcare system interact in the generation of treatment burden. The second is a conceptual model of how treatment burden evolves over time.

As outlined above, we have elected to utilise a mixed methods approach in this thesis. Fetters et al identified three basic mixed method research designs: exploratory sequential, explanatory sequential, and convergent (table 4.11)[361].

Table 4.11: Summary of different mixed method research designs

Exploratory Sequential Design	Qualitative data is collected first, and these findings subsequently inform subsequent quantitative data collection
Explanatory Sequential Design	Quantitative data is first collected and analysed, and the findings used to inform qualitative data collection and analysis
Convergent Design	Qualitative and quantitative data are collected and analysed during a similar timeframe, and an interactive approach may be utilised where iterative data collection and analysis drives changes in data collection procedures.
Adapted from Fetters et al, 2013 [361]	

In this thesis we have utilised a convergent design. The systematic review data collection and initial analysis was completed before the longitudinal qualitative study and informed

the conceptualisation and the content of the topic guides, the qualitative and quantitative studies were conducted concurrently and the findings merged at the end.

We selected a concurrent convergent study design rather than a sequential design for two key reasons. Firstly, from a methodological perspective, as treatment burden is a complex multidimensional construct encompassing objective workload, subjective experience, patient capacity, social network, and healthcare system factors, no single method can adequately capture all dimensions. Therefore, we wanted to utilise quantitative data to describe the scale, timing, and distribution of the workload and qualitative data to describe the meaning, experience, and consequences of the workload and how it interacted with capacity. As the aim was to understand how different dimensions of treatment burden relate to one another rather than to use one dataset to explain another, we felt that a convergent design was more appropriate. Secondly, we had feasibility considerations as this work was required to be completed within a 36 month out of programme research period. Utilising a sequential methodology would have severely constrained the time available to deliver the longitudinal study, compromising the quality of the work without adding benefit.

The conceptual models presented in this thesis were developed through integration of findings from three complementary studies. The qualitative systematic review (Chapter 5) produced both a taxonomy of workload and a taxonomy of patient capacity in KRT transition from a wide range of settings, maximising the variation of KRT transition work captured and the range of patient capacity factors that could influence the experience. The retrospective cohort study of healthcare workload during KRT transition (Chapter 6) provided a detailed description of how healthcare workload evolved over time during KRT transition and what factors were associated with higher workload. Findings from these two chapters were then verified and explored deeply over time through serial interviews in the longitudinal qualitative study (Chapter 7), with particular attention paid to exploring the relationship between workload, capacity, and treatment burden over time. Together, these studies provided complementary perspectives in the interaction between workload, capacity, healthcare systems, and treatment burden.

The development of the models followed a process of theoretical triangulation and narrative integration. Findings from all three studies were compared iteratively to identify

areas of convergence, complementarity, and divergence. Rather than seeking direct validation of findings across datasets, the synthesis aimed to develop a richer explanatory understanding of treatment burden. Quantitative findings provided evidence regarding the scale and distribution of healthcare workload, whilst the qualitative studies contextualised these observations by exploring the social, psychological, and organisational factors that influenced patients' capacity to manage that workload.

The final model was developed through an inductive process. The conceptual models represent a theoretically informed synthesis of the work presented throughout this thesis. By integrating population level quantitative data with detailed qualitative interviews of patient experience, they provide a framework for understanding treatment burden during KRT transition and identify potential opportunities for intervention at the level of the individual, their social network, and the healthcare system. These points of intervention are described in Chapter 8, following presentation of the models.

The decision to use conceptual synthesis[362] rather than an alternative integrative approach was taken as the main aim was to develop a higher order explanatory model describing the processes that influence the experience of treatment burden during KRT transition rather than formally validate or merge datasets. This approach allowed findings from each study to be treated as complementary sources of evidence that contributed different insights into the same phenomenon. This is consistent with the pragmatic ontological and epistemological stance taken in this thesis.

Alternative approaches to integration were considered. We considered the utilisation of a stricter triangulation approach, where findings from one study were compared directly against findings from another to assess convergence or divergence such as directly comparing capacity themes against demographic factors. However, as the studies in this thesis were examining related but different constructs within different populations we felt that our data did not lend itself well to direct triangulation, especially considering that treatment burden is not directly observable within routine healthcare data.

We considered utilising joint display integration, where quantitative and qualitative findings are presented within a matrix to facilitate comparison[363]. This would have provided a more explicit method of integration but would have remained largely

descriptive. As our aim was to develop an explanatory model, a conceptual synthesis approach was felt to be more appropriate.

4.8 Patient and Public Involvement and Engagement

Throughout the conceptualisation and study design process of this work the input of a Patient and Public Involvement and Engagement (PPIE) group was serially sought. The Glasgow Renal and Transplant Unit has an established PPIE group which provided detailed longitudinal input on this work. This group consists of 6-10 members who are all current KRT patients within the unit and a lay convener. The group meet online every 2-3 months. The group was recruited by seeking volunteers amongst the patient body who are interested in reviewing and supporting research work within the unit. Participation is entirely voluntary, and is recompensated with a gift voucher.

During the initial broad conceptualisation phase of this work the group was consulted extensively. The concepts of healthcare workload, patient capacity, and treatment burden were discussed with the group and an opinion was sought whether they felt that these were applicable to a KRT transition population. The group offered a strong opinion that these were highly relevant and important to them and many offered insights into how treatment burden had affected them and evolved over their treatment journey. This gave us confidence that the study subject was relevant and of interest to patients.

The PPIE group had considerable input into the design of both the quantitative and the qualitative work presented in this thesis. In terms of the retrospective cohort study, we sought the opinion of the PPIE group on which variables to include in the analysis. A particular point raised that altered the study design was the importance of accounting for travel time. We also sought their input on how to select a compound measure for workload, and their insight was important in selecting total treatment time per month as that measure. Within the qualitative study, the use of the PPIE group brought many positives to the work. Firstly, their input and opinions gave us confidence that we were researching a topic that was important and of interest to KRT patients and that the theories we were applying were relevant and valid. Secondly, their input was invaluable in deciding on the feasibility and acceptability of qualitative study design, especially in determining the frequency and location of interviews, and the acceptability of serial

interviews. Thirdly, using a PPIE group to trial patient information leaflets, consent forms, and topic guides allowed us to refine their content to maximise their understandability and accessibility for patients.

However, there are some limitations and challenges we found with the use of a PPIE group. Firstly, the group is not representative of 'typical' patients: they are a group of patients who are motivated to give up their own time to provide their opinion on research proposals, and are therefore by their very nature more health literate, more articulate, more confident within the healthcare system, and often in better physical health than most KRT patients. This could in turn bias their input, and caution must be taken in assuming that their opinions are representative of those of KRT patients more generally. Secondly, it is challenging to balance the risk of overburdening the group with excessive workload against the risk of superficial and tokenistic PPIE engagement. These concerns informed our decision to limit the PPIE input to the study design phase. We decided not to use PPIE in the analysis phase as we did not want to blur the line between PPIE oversight and being a research participant, and did not want to use a PPIE group to interrogate the validity of the perspectives of the study participants. There were also concerns around the confidentiality of study participants if PPIE group members were asked to read interview transcripts: this is a relatively small unit where the PPIE and study participants are all patients and potentially know each other, and full transcripts could be identifiable despite anonymisation. Another concern was that the analysis process of this work was complex and laborious, and we felt that the workload that would be required for meaningful PPIE engagement in the analysis process far outweighed what would be reasonable or feasible to ask the group to undertake and therefore it was better to have no PPIE involvement in the analysis than to do so superficially.

4.9 Conclusion

This chapter has described the methods used in this thesis, the rationale for their choice, and the potential strengths and weaknesses for their use. This thesis utilises a mixed-methods approach underpinned by a pragmatic epistemological stance and includes a qualitative systematic review, a quantitative analysis of healthcare workload over the six months prior to KRT start and 3 years after start, and a longitudinal qualitative study of experiences of transition onto KRT. This approach allowed a comprehensive exploration of

workload, patient capacity and treatment burden and the creation of a conceptual model. Results and discussion are given in Chapters 5-8.

Chapter 5 Exploration of treatment burden through examination of workload and patient capacity during transition onto kidney replacement therapy: a systematic review of qualitative literature

5.1 Chapter introduction

This chapter was published as a paper in BMC Medicine: Jones, C., Cairns, R., Walker, H. *et al.* Exploration of treatment burden through examination of workload and patient capacity during transition onto kidney replacement therapy: a systematic review of qualitative research. *BMC Med* **23**, 61 (2025).

Minor editorial changes have been made from the published version including formatting and referencing style to facilitate integration with the wider thesis.

5.2 Structured Abstract

Background: Patients with advanced chronic kidney disease requiring initiation of Kidney Replacement Therapy (KRT) are frequently asked to enact complex management plans. Treatment burden has been defined as the effect of healthcare workload and the capacity a person has to manage this workload has on wellbeing. The aim of this review is to examine the experience of healthcare workload and the factors that affect capacity to meet that workload for people transitioning onto KRT for the first time, using a framework synthesis of published literature informed by Normalisation Process Theory (NPT) and Theory of Patient Capacity (TPC).

Methods: Medline, Scopus and CINAHL were systematically searched with manual citation and reference searching. Studies were included if meeting the criteria of adults aged 18 or over transitioning for the first time onto any modality of KRT (haemodialysis, peritoneal dialysis or kidney transplantation), using qualitative methodologies to describe any aspect of experiences of healthcare workload or any factors that affect capacity to

manage workload were included. Abstracts and full papers were independently screened by two reviewers and data extraction and quality appraisal were also independently conducted by two reviewers. Qualitative data were analysed using framework synthesis informed by NPT and TPC.

Results: 24,380 studies were screened, 406 full texts were reviewed and 18 studies were included. There were four broad categories of workload described: making sense of KRT, working out what to do and how to do it, meeting the challenges of KRT, and reflecting on work done. Patient capacity influenced the experience of all types of workload and the treatment burden generated by the work.

Conclusions: Transitioning onto KRT is a period of very high healthcare workload and potentially high treatment burden. The relationship between healthcare workload and capacity to handle workload is complex, multifactorial and changes over time. By better understanding workload, capacity and burden during transition we can develop better ways of measuring these important aspects of care and develop interventions to reduce treatment burden in those transitioning onto KRT.

Keywords: Treatment burden, patient capacity, healthcare workload, kidney replacement therapy, haemodialysis, peritoneal dialysis, kidney transplant

5.3 Background

5.3.1 Conceptualising workload, capacity and treatment burden

For people with long-term conditions, there is considerable workload associated with following treatment regimens and managing health. In recent years there has been interest in conceptualising healthcare workload and the subsequent impact it can have on wellbeing, defined as treatment burden[364]. Healthcare workload is the objective work that patients are asked to meet. Examples of healthcare workload include demands made upon the patient to organize and co-ordinate their own care, comply with complex treatment and self-monitoring regimes, and to meet numerous expectations of personal motivation, expertise, and self-care[364]. The personal, physical, emotional, social, environmental and financial resources and abilities that a person can mobilise to meet the demands of their health management is defined as patient capacity[5,365]. Patient capacity is not fixed, but a dynamic entity that can be augmented or diminished

depending on the resources the patient has available to them[6]. Treatment burden is a product of the interaction between healthcare workload and patient capacity: it is the subjective experience of trying to realise healthcare workload and the resultant impact on wellbeing. This is closely related but different to 'symptom burden', which is the burden generated by the direct experience of symptoms related to the disease[364]. To understand and develop ways of minimising treatment burden, it is important to first understand the factors influencing healthcare workload and patient capacity, as interventions aimed at lessening workload or improving capacity have the potential to reduce burden[364].

Two middle-range theories have been used to describe how healthcare workload and capacity translate to everyday practice: Normalisation Process Theory (NPT) and Theory of Patient Capacity (TPC). NPT addresses workload: it identifies the work and processes that individuals and groups engage that promote and inhibit the routine incorporation of complex interventions into everyday life. It has four main components: coherence (sense-making work); cognitive participation (engagement work); collective action (operational work); and reflexive monitoring (appraisal work)[107]. NPT can be applied to understand how patients, their families and their wider social network meet healthcare workload, and how that impacts on their experiences of treatment burden[318,319,322]. The TPC addresses patient capacity as the product of the interaction of the five core domains: biography, resources, environment, realisation of work and social[6].

5.3.2 Treatment burden during transition onto Kidney Replacement Therapy

Chronic kidney disease (CKD) is defined as kidney dysfunction measured by both estimated glomerular filtration rate (eGFR) and/or proteinuria lasting greater than 3 months as defined by the Kidney Disease Improving Global Outcomes staging. Kidney replacement therapy (KRT) is considered in the setting of severe kidney dysfunction, usually based on symptoms, clinical and biochemical manifestations of uraemia, and as a shared decision between the patient and nephrology team. Patients can elect to initiate KRT or choose comprehensive conservative care (CCM)[285]. KRT can be performed either by peritoneal dialysis (PD), haemodialysis (HD), or kidney transplantation (KTx) [76].

The period around the transition onto KRT from the point of identification of the imminent need for KRT to being fully established on maintenance therapy could be a time of particularly high treatment burden. Healthcare workload can include making key

decisions regarding their care to enacting new complex self-care tasks such as attending the dialysis unit multiple times a week or undertaking home dialysis, managing new medication regimens and enacting dietary changes[76]. Adverse early dialysis experience can have a lasting impact on a patient's treatment burden and overall patient journey[202].

However, previous research examining treatment burden, workload or patient capacity during transition onto KRT has been very limited. One synthesis studied the work of being a patient with chronic kidney disease but included a much broader population ranging from patients with mild CKD to those long established on KRT[148]. It demonstrated that CKD patients had a high treatment burden and that capacity to meet that burden is dynamic and multifactorial, but did not discuss the period of transition in detail. Another synthesis did study transition onto KRT, but analysed the data with themes based on lived experience and did not conceptualise in terms of treatment burden, workload or capacity[150].

The aim of this review is to explore the experience of healthcare workload and patient capacity for people transitioning onto KRT, through examination of the published literature by framework synthesis of published literature underpinned by NPT and TPC.

5.4 Methods

The review protocol is registered on PROSPERO, the International Prospective Register of Systematic Reviews, registration number CRD42024513205. The methodology is reported in accordance with the ENTREQ (Enhancing Transparency in the Reporting the Synthesis of Qualitative Research) Statement[366] and the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) guidelines[367].

The inclusion and exclusion criteria described in accordance to the SPIDER tool [368] are shown in Table 5.1.

Table 5.1: Summary of inclusion and exclusion criteria	
Sample	• Adults aged 18 or older transitioning onto any modality of KRT for the first time. • Studies that included children, patients with earlier stages of CKD or that were established on maintenance KRT, or discussed transition between modalities were excluded. • Studies that included caregivers or healthcare professionals were only included if reported in a way that allowed for the selective inclusion of direct patient experiences • Transition onto KRT is defined as the time period between identification of the imminent need for KRT and being fully established on maintenance therapy
Phenomenon of Interest	• Patient experiences of any aspect of workload or treatment burden during transition onto KRT • Any descriptors of patient capacity or the effect of patient capacity on experiences
Design	• English language qualitative studies published in 2012 or later
Evaluation	• Direct patient experiences and perceptions
Research type	• Published peer-reviewed qualitative studies • Grey literature and quantitative methodologies including patient reported measures were excluded. • Studies of interventions were excluded

We used a comprehensive search strategy devised with input from an information scientist (Appendix 1). Studies were limited to those published in 2012 or later to capture current practice. Due to the subject matter being poorly indexed, a broad inclusive approach was adopted to the search strategy. Medline, Scopus and CINAHL databases were searched with additional citation and reference tracking. Databases were initially searched in June 2023 and updated in February 2024. Following removal of duplicates, a two-stage screening process (title and abstract then full text) was conducted

independently by two reviewers using DistillerSR software, with discrepancies resolved by a third reviewer.

Data were extracted independently by two reviewers for the year of publication, country, population, number of participants, KRT modality, data collection method, methodology and research question (Appendix 2). Quality appraisal was conducted independently by two reviewers using the JBI Critical Appraisal Checklist for Qualitative Research[310], with discrepancies resolved by discussion with a third reviewer. No study was excluded on the basis of quality, and the quality appraisal did not affect the weighing given to the results of a particular study in the synthesis.

Qualitative analysis was conducted using NVivo 14. Both direct participant quotations and author's descriptors and analysis in the result and discussion segments were included for analysis. We adopted an abductive approach to coding[369]. A coding framework was created informed by the domains and sub-domains of Normalisation Process Theory (coherence, cognitive participation, collective action, reflective monitoring) to describe workload[108] and the Theory of Patient Capacity (biography, resources, environment, realisation of work and social functioning) to describe capacity[6] with any phenomena that fell outside these theories coded independently (Appendix 3). One researcher coded all the papers, and 6/18 were double coded by a second researcher to ensure consistency of coding. The coding frame was refined iteratively.

Line by line coding was conducted to search for concepts, and comparisons were made within and across studies using a framework synthesis approach. Themes were derived abductively: initially there was a deductive derivation from the framework synthesis then subsequently an abductive higher order process of synthesising new findings in order to conceptualise treatment burden during transition onto KRT. This generated a taxonomy of treatment burden grounded in primary research but underpinned by NPT and TPC.

5.5 Results

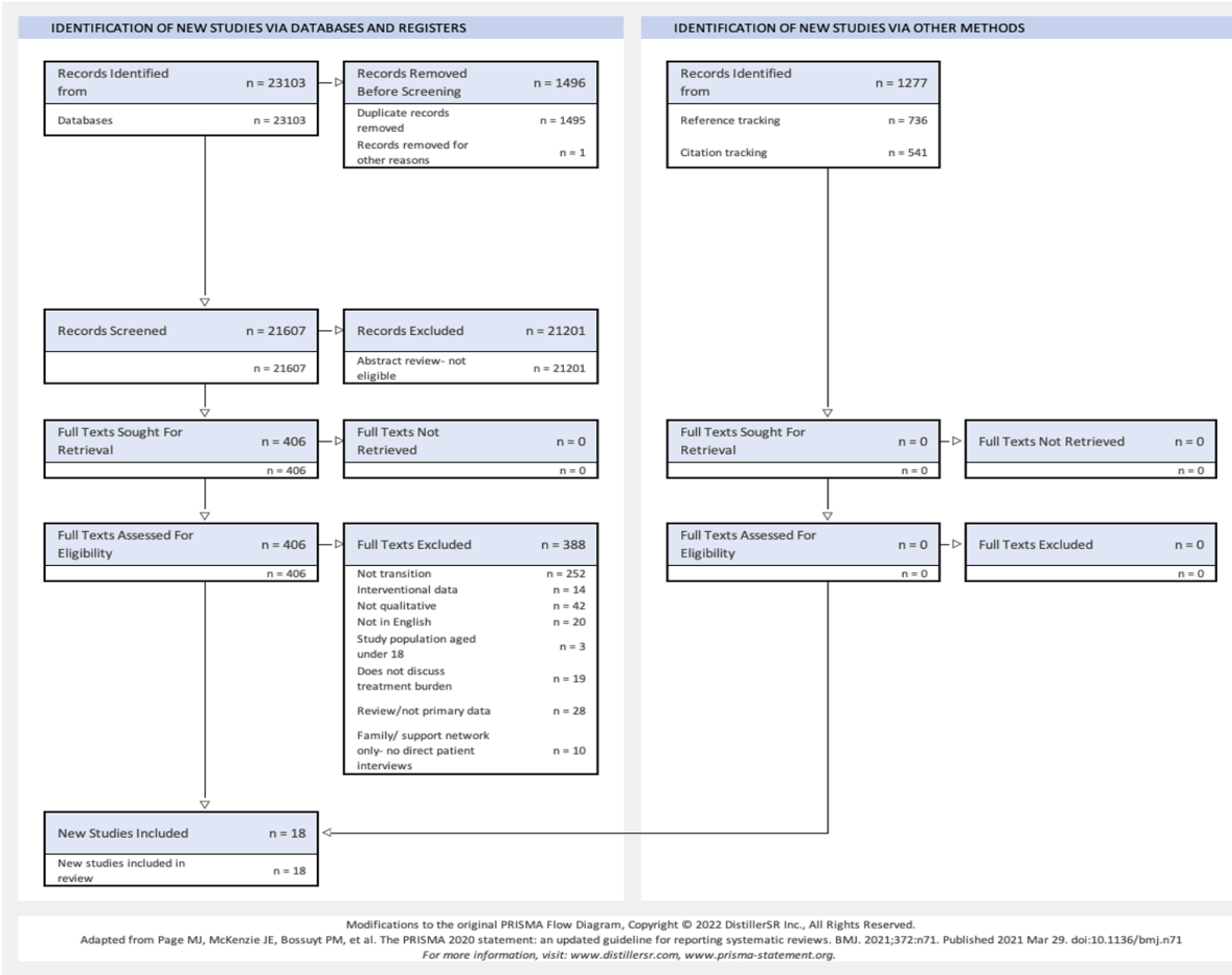
A total of 18 studies were included for analysis[84,273,278,280,281,370–382], see figure 5.1. The included studies were from a wide range of countries: Taiwan [281,372,379], New Zealand[371,374,376], Australia [377,380], Singapore [84,280], Denmark [278,382], USA [373,375], Canada [381], Iran[370], UK [378] and Sweden[273]. Participant numbers in the included studies ranged from 5-

168. 8 studies had a haemodialysis only patient population sample, 1 had only peritoneal dialysis patients in their sample and 9 studies had a mixed sample. Out of the 18 included studies, 17 used key informant interviews and 1 used focus group discussions. A total of 16 studies interviewed their participants once, 2 had serial interviews. The included studies are summarised in Table 5.2.

The studies were of mostly moderate or high quality[310]. The quality assessments of the included studies are summarised in Table 5.3.

There were 3059 items coded. Only 45 items fell outside the NPT and TPC derived framework and required separate coding, demonstrating their suitability for conceptualising treatment burden during transition onto KRT. These items were participants' recommendations for change and specific discussions of trauma.

Figure 5.1 PRISMA Flow Diagram demonstrating the identification and selection process for eligible papers



Modifications to the original PRISMA Flow Diagram, Copyright © 2022 DistillerSR Inc., All Rights Reserved.
Adapted from Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71. Published 2021 Mar 29. doi:10.1136/bmj.n71
For more information, visit: www.distillersr.com, www.prisma-statement.org.

Table 5.2: Description of included papers

Author	Year	Country	Participants	Population	KRT	Methodology	Data collection	Serial interviews	Study Aim
Alsing	2022	Denmark	8	Patients that have recently started in centre HD	HD	Thematic analysis	FGD	No	To explore expectations and experiences of patients who have recently started HD
Cassidy	2018	Canada	12	4 patients on in-centre HD, 4 on home HD, and 4 on PD in Ontario	HD PD	Content analysis	KII	No	To understand the dialysis modality decision making process
Erlang	2015	Denmark	9	Patients that have undergone a pre-dialysis educational programme	HD PD KTx	Phenomenology	KII	No	To explore patient experiences of involvement in the dialysis modality decision making process
Griva	2019	Singapore	97	People approaching dialysis or very recently started HD	HD	Thematic analysis	KII	No	To explore perspectives of various stakeholders

									on barriers to timely dialysis access creation
Gullick	2016	Australia	11	People who had commenced haemodialysis within the previous three months at a public hospital in Sydney	HD	Phenomenology	KII	No	To interpret the spatio-temporal experience of people with kidney failure and their families in the first months of haemodialysis
Hassani	2017	Iran	24	People starting HD in Iran	HD	Grounded Theory	KII	No	To explore the process of transition to haemodialysis
Henry	2017	USA	168	Patients initiating HD at Kaiser Permanente Southern California	HD	Thematic analysis	KII	No	To characterise the experiences of patients starting KRT
Ho	2021	Taiwan	31	Patients with a established diagnosis of CKD in	HD PD KTx	Thematic analysis	KII	Yes	To describe the psychological change process of CKD patients

				the process of decision making regarding dialysis					during the shared decision making process
Ho	2022	Taiwan	15	Patients who had been through a hospital based shared decision making process before starting PD	PD	Thematic analysis	KII	No	To explore the process of information acquisition and consideration during shared decision making for patients undergoing PD and compare their quality of life and expectations before and after PD at home
Lai	2012	Singapore	13	Patients starting haemodialysis using a CVC in Singapore. Age 39-63. 7 females, 6 men. Chinese and Malay speaking.	HD	Phenomenology	KII	No	To identify main concerns and needs encountered by incident haemodialysis patients during the early months on haemodialysis

Lin	2022	Taiwan	5	Patients who required emergency HD starts	HD	Content analysis	KII	No	To explore experiences of urgent dialysis patients
Monaro	2014	Australia	11	Patients within 3 months of HD start in a tertiary referral hospital in Sydney	HD	Phenomenology	KII	No	To explore early experiences of close family members and people with kidney failure commencing HD in a tertiary hospital
Nilsson	2019	Sweden	5	Patients who have experienced emergency HD starts with CVC	HD	Phenomenology	KII	No	To explore experiences of starting dialysis in an unplanned fashion
Novick	2021	USA	15	Spanish speaking patients reliant on emergency- only dialysis (no health insurance)	HD	Thematic analysis	KII	No	To understand the kidney disease educational gaps of Latinx individuals who need but lack access to

									scheduled outpatient dialysis
Walker	2016a	New Zealand	52	Mixed European, Maori and Pacific Islander population that are either immediately pre-dialysis or stated within last 12 months	HD PD	Thematic analysis	KII	No	To describe patient and caregiver values, beliefs and experiences when considering home dialysis
Walker	2016b	New Zealand	52	Mixed European, Maori and Pacific Islander population that are either immediately pre-dialysis or stated within last 12 months	HD PD	Thematic analysis	KII	No	To describe patient and caregiver perspective of the economic considerations that influence dialysis modality choice

Walker	2017	New Zealand	13	Maori patients who had received education about treatment modalities or started dialysis within the last 12 months	HD PD	Thematic analysis	KII	No	To explore and describe Maori patient's experience and perspectives of chronic kidney disease
Winterbottom	2012	UK	20	Attending low clearance clinic in a large hospital in northern England.90% White; 10%Asian.	HD PD	Thematic analysis	KII	Yes	To understand how patients with kidney failure make dialysis treatment decisions

KII-Key Informant Interview; FGD- Focus Group Discussion

Table 5.3: Quality assessment of included papers (JBI Critical Assessment Tool for Qualitative Research[310])

Author	Congruity between philoso-phical perspectiv e and method-ology	Congruity between method-ology and research question	Congruity between method-ology and methods used to collect data	Congruity between method-ology and data analysis	Congruity between method-ology and interpret-ation of the results	Cultural / theory position	Influence on research discussed	Adequate represent-ation of the participants and their voices	Ethical approval	Conclusions flow from the data analysis	Subjective Global Assessment
Alsing	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High quality
Cassidy	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Erlang	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Griva	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Gullick	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Hassani	Unclear	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	No	Low quality
Henry	No	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Ho (2021)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality

Ho (2022)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Lai	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Lin	Unclear	Yes	Yes	Yes	Yes	No	No	No	Yes	Unclear	Low quality
Morano	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High quality
Nilsson	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High quality
Novick	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High quality
Walker (2016a)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	High quality
Walker (2016b)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality
Walker (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High quality
Winter-bottom	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate quality

5.5.1 Workload

There were four broad categories of work described: Making sense of KRT; Working out what to do, and how to do it; Meeting the challenges of KRT; and Reflecting on work done (Table 5.4). These correspond to the four main components of NPT: coherence, cognitive participation, collective action and reflexive monitoring[108] but we have adapted the terminology to be more specific to KRT transition.

Table 5.4: Workload associated with KRT initiation identified from the literature: a taxonomy using NPT

NPT Category	Taxonomy
Making sense of KRT *(Coherence Building)*	
Working out how and why life on KRT will be different (*Differentiation)*	Shock and alarm at sudden transition from being asymptomatic to being very ill, denial and attempts to avoid dealing with imminent need for KRT for as long as possible
	Challenges of understanding and accepting lifelong requirement for treatment
	Grieving a lost life and the loss of future hopes and dreams
	Fears of premature death
	Anger at missed opportunities to diagnose and optimise
Understanding what KRT means for social network (*Communal Specification)*	Understanding the emotional, physical, psychological and financial burden placed on family and friends meeting the workload of KRT
	Making decisions collectively for the wider benefit of the family unit
	Impact of new dependency of family role e.g. as a parent, grandparent or spouse
	Impact of potential for live donor transplantation on family relationships

	Impact of shame and stigma of being ill and needing KRT on their ability to socialise
Understanding what KRT will mean for them as an individual (*Individual Specification)*	Key considerations with KRT decisions: •Ability to maintain employment •Location of dialysis unit and availability of transport •Available support from family and healthcare staff •Dietary changes •Ability to travel abroad, continue hobbies •Attitude to procedures: need for operation, changes in appearance, dislike of needles •Preservation of independence and social role •Confidence in personal capacity •Time commitment •Financial implications and out of pocket costs.
	Accessing and interpreting official resources (leaflets, workshops, clinical consultations and specialist nurse support) to understand their options
	Accessing and interpreting informal/alternative sources of information
	Navigating conflicting advice
	Visiting dialysis unit to see what haemodialysis involved
Finding value in KRT *(Internalisation)*	Understanding how a future life on KRT can still be fulfilling, and how adaptations can be made to preserve elements of current lifestyle
	Worsening physical symptoms demonstrating need for KRT for quality of life and survival.
	Hope of a future transplant: seeing the work created by PD/HD as a temporising measure until kidney transplantation and the hope of greater normality
	Positive and negative influence of peers and family on their expectations of life on KRT

	Seeking alternative therapies e.g. traditional Chinese medicine
	Empowerment from being supported to make their own decisions about KRT modality
Working out what to do, and how to do it (*Cognitive Participation)*	
Driving forward work required to start KRT *(Initiation)*	Adapting living arrangements to facilitate KRT: carrying out home modifications, buying new furniture, moving to new accommodation closer to dialysis centre
	Financial adaptation: changing or leaving employment, financial planning, having to sell assets including homes if unable to afford mortgage, navigating benefit system
	Attending clinics and having procedures such as creation of an arteriovenous fistula or insertion of a peritoneal dialysis catheter in preparation to start
	Emergency/unexpected KRT starts required to do all the work of starting and the work of making sense of KRT simultaneously increasing strain and feelings of disempowerment
	Overcoming anxiety about starting
	Adapting dietary and fluid consumption habits
Getting others to join in *(Enrolment)*	Recruiting friends and family to assist with activities of daily living and transport; ability of social network to meet this workload key determinant of viability of some options
	Using peers and family members as a source of knowledge and decision-making support
	Pressure of KRT destroying some relationships
	Enrolling support from the wider kidney patient community
	Complex dynamics of living donation of kidney: both from seeking donation and managing emotional and psychosocial effects of donation offers from family
Deciding that the chosen type of KRT is the right thing to do	Finding out that there's better outcomes associated with their choices (e.g. home vs in-centre dialysis, AVF vs CVC) increased

(*Legitimisation)*	confidence that they'd made the right choices and any additional work was worth it
	Improvement in physical symptoms and energy levels legitimising decision to start
	Understanding consequences of complications validates their preventative efforts
	Maintaining jobs, family and community roles increased confidence in treatment choices
	Unexpected out of pocket costs (e.g. higher electricity bills with home dialysis) and financial hardship undermining confidence in system/choices
	Ongoing fatigue and distressing physical symptoms such as itch undermined confidence
Maintaining key interventions in daily life (*Activation)*	Ability to maintain social connectedness: context dependent with in-centre dialysis allowing regular socialising with fellow patients important for some, whilst home based therapies facilitating better continuity of pre-existing social connections for others
	Successfully navigating first sessions increases confidence in manageability of life on KRT
	Reassurance and motivation in seeing others successfully establish on KRT and do well
	Pre-dialysis education left patients well equipped to manage by themselves once started
Working with their social network and the healthcare system to meet the challenges of KRT (*Collective Action)*	
Doing work required by KRT *(Interactional workability)*	Home therapies (both PD and HD) came with significantly increased workload but minimised the disruption caused to people's lives and therefore facilitated them maintaining employment and consequent financial security and their family/social role

	CAPD patients need to find suitable clean places to change the dialysate during the day, which poses significant restrictions on
	Difficulty coordinating work necessitated by KRT with other responsibilities in life
	Making the most of free time in between dialysis days to retain some pleasure in life
	Organising transportation
	Maintaining dietary and fluid restrictions in daily life
Effect on relationships and the confidence people have in each other *(Relational Integration)*	Changing relationship dynamics from one where they were equals or provided for others to one where they are dependent and require care psychologically difficult for all involved
	Familial love and support major source of sustenance
	Fatigue, geographical limitations and time taken up by KRT making socialising difficult
	Fatigue and time taken up by KRT reducing available time to fulfil family role e.g. parent
	Not wanting others to see them unwell and 'weak' leading to social withdrawal
	Financial hardship and pressure on spouse to shoulder most household work and additional care responsibilities putting significant pressure on household relationships
	Effect of involvement in decision making and preparation: families that had been involved through the process felt engage, families that had been excluded felt disconnected increasing the amount of isolation perceived by the patient
Appropriateness of the allocation of work (*Skillset workability)*	Lack of support to access benefits that the patients are eligible leaving patients with impossible choices between employment and health
	Provision of online resources unsuitable for those unable to access internet

	Appropriate support of additional work leading to patients feeling empowered
Effect of interaction with healthcare or governmental services on patients (*Contextual Integration)*	Previous poor experiences of healthcare and poor health outcomes (potentially resulting in need for KRT) undermining confidence in future ability to manage their health and confidence in clinical team
	Fears that clinicians had an agenda to push a particular form of KRT and they were not given a balanced choice
	Fears that clinicians had made incorrect assumptions about their ability to cope with certain modalities of KRT, mistrust that their options had been unfairly curtailed
	Being given information in ways that did not meet their needs: shame and stigma of having to disclose poor literacy, non-fluency in dominant regional language (e.g. English), poor digital literacy and lack of access to the internet and/or visual impairment
	Information presented in ways that are too fast and complex, and significant power imbalance leading to them not being able to understand information given or ask for the information in other ways
	Trusting and reciprocated relationship with clinicians enhancing ability to ask questions, participate in shared decision making and have confidence in decisions made
	Poor relationship with clinicians, feeling that they're not being listened to or respected undermining trust in system
	Comfort in having confidence in the skill and expertise of their clinical team and feeling that they're well cared for currently and in future
	Clinicians respecting and recognising cultural context and working to find treatment solutions that works with and respects important things for patient

	Insufficient resources provided for different cultural needs e.g. no dietary advice for cuisines other than dominant majority regional culture
	Healthcare system facilitating and supporting peer-to-peer support such as with 'Kidney Schools'
	Poor information flow with patients needing to be proactive and advocate for themselves in consultations to get the required information out of their clinical team
	Significant amount of work and costs transferred from healthcare system to patients and their families with home-based therapies with insufficient reimbursement or support
	Difficulty navigating multiple government agencies and accessing welfare grants and benefits. Obtuse and obstructive processes, people feeling worn down by being continually required to justify their need for assistance.
	Lack of health insurance, citizenship status or private financial means severely curtailing care on offer
	Healthcare professionals providing excellent information about the technical and physical side of KRT but neglecting the emotional aspects
	Poor employment rights with employers not mandated to make adjustments to facilitate KRT or pay sick leave
Reflecting on and evaluating work done (*Reflexive Monitoring)*	
Finding information about the effects of KRT and its components *(Systematisation)*	Talking with other patients about their experiences
	Searching for information online
Evaluating effect of KRT on family/social network (*Communal Appraisal)*	Ability to maintain role and responsibilities within family key motivating factor for persevering with difficult/intrusive treatments

	Working out together how to adapt their lives to make time for family
	Benefits seen from keeping their loved one alive and well outweigh burden of care
	Increasing experience increasing the family's confidence in their ability to meet the work
Evaluating the effect of KRT on themselves (*Individual Appraisal)*	Evaluating change: those who were highly symptomatic prior to starting saw a greater improvement in symptoms and therefore greater value in the treatment whereas those with a lower symptom burden and more active lifestyle more affected by disruption
	Worsening physical health despite KRT undermined confidence in the process
	Life on KRT was substantially better than what most patients' feared prior to starting
	Conflicting emotions with gratitude on one hand that they're still alive and receiving good care, and sadness and grief for their previous life on the other.
Adapting as a result of reflections (*Reconfiguration)*	Learning how to let go of any previous understandings of constructively spent time and accepting time spent on dialysis: learning to stop thinking of it as wasted or lost time
	Normalising KRT in their daily lives and finding ways of reintroducing hobbies
	Finding activities that they can do to entertain and distract during dialysis sessions
	Learning how to continuously evaluate what it possible on a daily basis and adapt
	Finding flexible jobs that can accommodate their needs on KRT

5.5.1.1 Making sense of KRT

The work of making sense of KRT was commonly reported; including understanding how life could be different on KRT, understanding what KRT means for them as a patient, their family and wider social network, and finding value in KRT.

The work involved in psychological preparation and overcoming profound fears was a common theme[273,280,281,374,375,379,380].

> *Many patients were concerned about either the surgical access procedure, dialysis itself or both. Fear of pain/discomfort, needles, seeing one's own blood and changes to their physical appearance; all of these were repeatedly mentioned as concerns driving ambivalence towards preparation and initiation of RRT.*[375]

The difficulty of first understanding their disease and then communicating what that means to their family, as well as needing to explain their social context to their medical team and working out how best to proceed in a complex and multifactorial situation was a recurring theme[273,278,280,371,372,374,376,379–382].

> *"It's really hard to explain sometimes that family are first, that I am not an individual, that I am part of a unit, that then no decision is just mine, but it's also really hard to explain to my whanau [extended family group] what is happening with my kidneys when I don't really know it so well myself"*[374]

Patients were required to understand complex treatment options and contextualise them to their own lives and work out what was desirable and feasible for them.

> "*The fact that I live by myself and I am really not medically inclined at all, made me choose [IC-HD]…I just didn't feel comfortable to be able to do it myself at home. If I had a partner, it would have been different…I think I would have gone for the peritoneal"*[381]

5.5.1.2 Working out what to do, and how to do it

Studies reported a considerable workload associated with preparing for transition. This included driving forward the work required to start KRT, enrolling the support of others,

determining that the chosen modality of KRT is the right thing to do and maintaining key interventions in daily life.

The impact of transitioning onto KRT was far-reaching, with patients required to enact a wide range of adaptations from changing or leaving employment, financial planning, adapting their diets and overhauling their weekly schedule [273,278,281,371,373,375–382].

> *Because I've put my house up for sale, erm, because otherwise I'm not going to be able to afford to pay the mortgage or anything. I've had to make that decision.*[378]

Home dialysis patients had to make considerable adaptations to their home environment[371,374,376,377,381].

> *Garry had to compartmentalise space in his home into a no-go zone, making 'home time and space' into 'treatment time and space': "We had to make changes in the house…barricade our bedroom now so that Nicholas [infant son] can get used to the fact that he can't go in that room"*[377]

Experiencing new dependency on others and the need to enrol friends and family to assist with both material and emotional support was a common finding in all studies[84,273,278,280,281,370–382]. The potential tensions caused by the possibility of live donor transplantation was also explored:

> *The issue of living organ donation further complicated family dynamics. Some participants were reluctant to ask family to consider organ donation. Others were particular about whom they would approach*[380]

5.5.1.3 Meeting the challenges of KRT

Studies describe patients working with their social network and healthcare system to meet the challenges of KRT. This includes doing the work that is required, the effect it has on relationships and the confidence people have in each other, the appropriateness of the allocation of work and the effects of interaction with the healthcare and other governmental systems.

Many different types of work were reported, from attending hospital appointments, meeting dietary restrictions, attending dialysis sessions, arranging transport, taking

medication, carrying out tasks relating to home dialysis such as exchanging dialysate, and adapting plans to accommodate the requirements of KRT[84,273,278,280,281,370–382].

> *Many participants described the need to coordinate their lives to match the efforts and challenges of replacing the dialysate (…) their lives and work must be changed to accommodate the dialysis time*[372]*.*

The work of KRT caused people's relationships to change, and often required families and friends to undertake considerable caring work to assist the person undergoing KRT[84,273,371,372,374,376,377,380–382].

> *Long-term management may mean families undertake a range of complex activities such as active facilitation of home-based HD. Families and friends often assist with activities of daily living and transport. This level of involvement places considerable pressure on personal relationship and may incur feelings of anxiety, depression and isolation from other relatives and friends.*[380]

The relationship with their healthcare team was identified as an important factor in patient's experience in many studies[84,273,278,281,370–376,378,381,382].

> *Nephrologists play a significant role in modality education and decision making. When a trusting partnership was established, patients had an enhanced sense of importance, control and respect. When patients felt like valued members of the healthcare team, they were more likely to be receptive to information, be engaged in their care, and participate in shared decision making.*[381]

Transitioning onto KRT often required patients to interact with governmental and social welfare systems which are bureaucratic and involve significant effort to access support[371,372].

> *Participants struggled to access financial support both from their dialysis service and government agencies and described difficulty in navigating the social welfare system. Many felt disempowered by the system, and worn down by the need to continually justify their requirements for assistance.*[371]

5.5.1.4 Reflecting on work done

Studies report the work involved in finding information about the effect of KRT and its components, evaluating the effect of KRT on the family and social network, evaluating the effect of KRT on themselves and adapting as a result of reflections.

Reflecting on experiences of dialysis and adapting and reframing expectations of life was a key part of reflexive monitoring in this cohort[273,278,370–372,375–377,381].

> *Dealing with 'clock time' meant letting go of any previous understanding of constructively lived time and accepting a different construct of being and time on the dialysis machine. Sharon filled her time in a measured way. She described time-filling and pacing as a learned skill.*[377]

Building on previous experiences and learning new self-management skills lead to greater confidence over time in meeting the work of KRT[273,372,377,382].

> *Learning to deal with previous hardships gave some strength and tools to accept and handle the difficult new situation. When dialysis finally became regular it became easier to feel more self-assured. The new routine gradually gave back structure to life.*[273]

5.5.2 Patient Capacity

The five factors that were reported as affecting capacity to manage health were: Biography; Resources; Environment; Realization of work; and Social functioning (Table 5.5).

Table 5.5: Patient capacity during transition onto KRT identified in the literature: taxonomy using TPC	
Theory of patient capacity category	Taxonomy
Biography	
Biographical disruption	
Fear of the future and fear of death	Fears of mortality: understanding the permanent and life-threatening nature of kidney failure, the need for KRT to preserve life and fears of dying despite dialysis
	Fear of procedures: pain, needles, alteration of physical appearance, blood
	Fears of losing quality of life: fear of suffering, fear of decline in health and capacity
Loss of meaningful life	Being tied to the rigid timetable if dialysis- losing spontaneity and independence
	Losing social connectedness as socialising more difficult as a result of the physical symptoms of kidney failure and the restrictions from KRT
	Losing their identity and sense of self
Loss of future hopes and dreams	Uncertainty making it difficult to plan and have aspirations and goals
	Difficulty planning and partaking in enjoyable things such as holidays
Loss of Role	Losing role within family especially transitioning from someone who cared/provided for others to someone dependent on others.
	Needing to retire due to ill health and give up job (and associated identity)
	Stigma of ill health, men feeling emasculated by requiring care
Biographical adaptation	
Reframing future expectations	Looking forward to symptom reduction on dialysis

	Framing PD/HD work as a positive to keep them alive until kidney transplantation
	Accepting the resulting change in relationship dynamics from new dependency
Finding a new role in life	Finding ways to adapt and continue important life activities
Resources	
Financial	Financial loss as a result of reduced working hours/ unplanned early retirement
	Needing to sell assets including homes if unable to meet previous commitments
	Need to meet unexpected out of pocket expenses: increased electricity bills with home dialysis, home adaptations, travel costs to hospital visits
	Ability to continue work and minimise financial hardship key in treatment decisions
	Insurance status affecting treatment options
	Poverty and poor quality housing limiting options (e.g. home dialysis)
Literacy	Ability to understand and communicate in the dominant regional language
	Ability to read and write (especially visual impairment)
	Ability to read long and complex information and understand medical terminology
	Digital literacy- ability to access and navigate online resources
Medical knowledge	Empowerment to engage in shared decision making gained from knowledge about their disease and prognosis
	Understanding their disease prior to progression to kidney failure allowed for better adjustment and preparation
	Knowledge gained from talking to other patients and peers
	Gap in information given: no focus on emotional/psychological factors

	Disempowerment and distress from not having adequate medical knowledge
Paid support services	Home visits support from specialist nurses to facilitate home dialysis
Physical health	Dealing with severe fatigue and fluctuating energy levels
	Difficult symptoms: itch, swelling, cramp, breathlessness, nausea, thirst, weakness
	Feeling too unwell to engage in discussions or take on and interpret information
	Insomnia and disruption to sleep patterns
	Changing physical appearance: scarring and disfigurement from vascular access procedures, weight gain from medication
	Improving health once established on KRT
	Managing other co-morbidities and their symptoms
Psychological resilience	Ability to accept and process their diagnosis and prognosis
	Ability to stay hopeful and find pleasure in life
	Ability to retain self-identity and self-worth as health deteriorate, overcome stigma
	Ability to overcome feelings of fear and/or despair
	Ability to overcome anger and regret at missed opportunities to intervene earlier
Self-efficacy	Confidence in their ability to undertake KRT related tasks
	Ability to self-advocate in discussions with healthcare staff
	Confidence in their ability to navigate healthcare services
	Confidence in their ability to negotiate with other key stakeholders such as employers/governmental agencies to access resources and support
Time	Time to prepare prior to starting KRT allowing planning, education and pre-emptive access creation
	Time involved in centre dialysis: whole week dependent of treatment timetable, losing autonomy over their own time

	Rigidity of treatment timetables heavily constraining ability to make time for other things: family, friends, work
	Negotiating treatment timings in order to be able to meet other responsibilities
Transport	Needing to depend on family/friends for lifts to hospital
	Personal ability to drive
	Challenges with accessing hospital transport
Environment	
Capacity building environments	Reliable access to clinical advice and support enhanced confidence
	Culturally competent care, with care being available in patients' native language and advice adapted for the cultural context it is being given
	Actions of employers in allowing more flexible working around KRT requirements
	Comprehensive patient education
Person centred care	Clinicians actively trying to engage with patients and enable them to develop trust and regain power and confidence in their decision making
	Being cared for in ways that accommodates and realises the importance of community, cultural and spiritual connections
	Clinicians making time to listen to patients and discuss concerns
Negative experiences	Feeling unable to discuss issues such as financial hardship due to stigma
	Feeling forced and coerced into treatment decisions
	Staff being too busy and overworked to spend time supporting patients
	Being overloaded with information and decisions when too unwell to process
Realisation of Work	

Enhancing capacity	Work realised for home dialysis enhancing capacity by minimising disruption
	Increasing confidence by successful execution of tasks
Reducing capacity	Being overwhelmed by work and not coping diminishes confidence and capacity
Social Functioning	
Ability of their social network to accept condition and effects	Strain on relationships from new dependency; perception of non-reciprocity in some relationships exacerbating feelings of burden
	Reciprocity, constancy and love in spousal relationship
	Ability of social network to understand the diagnosis and prognosis
	Ability of friends and family to adapt relationship to new constraints
	Desire to protect family and friends from the disease exacerbating isolation
Personal ability to fulfil social role	Losing ability to socialise due to fatigue and intrusiveness of the strict schedule and time commitments required on KRT
	Depression exacerbating social withdrawal
	Ability to continue in job, family and community roles key to sense of identity and self-worth; profound impact if lost
	New social connections made with other patients during KRT
Provision of instrumental support	Ability of family members or friends to act as kidney donor and ability of potential recipient to accept donation
	Ability of social network to assist with activities of daily living and transport
	Ability of social network to provide emotional support
	Ability of friends and family to discuss options and help with decision making
	Need for adaptations at work in order to be able to continue working
	Provision of peer-to-peer support from other KRT patients

Social relationship with their healthcare team	Patient-physician partnership crucial to shared decision making: mutual trust key to engagement, sense of control and ability participate in shared decision making
	Informal and formal support from dialysis nursing team
	Anger and mistrust in healthcare team from missed opportunities to diagnose and treat kidney disease earlier, potentially avoiding need for KRT
	Shame, embarrassment and unequal power dynamics leading to non-disclosure of factors such as poverty and illiteracy to healthcare team
	Trust lost if patients feel that doctors have an agenda to push one modality or didn't fully explain and explore options
	Confidence gained by demonstration of competence and compassion

5.5.2.1 Biography

Profound biographical disruption, meaning disruption to a person's ability to perform their usual roles, was a common finding[84,273,278,280,281,370,371,373–377,379,380,382]. KRT could disrupt biography which in turn affects capacity to manage healthcare workload.

The challenge of confronting their own mortality in the context of a lifelong, life-threatening illness was a common finding, with many studies describing participants' intense fear of the future and fear of death[84,273,280,370,374,375,377,380,382].

> *"It was the fear of the unknown. I thought I was going to be invalid for the rest of my life and… I was saying "No Mum, I'm going to die"*[380]

Distress from losing their previous social role either within the family or in the wider community and dealing with new dependency was a common finding, with many reporting shame, stigma and social withdrawal[273,280,370,374–376,379,380,382].

> *Many participants, often men, associated sickness with weakness and inferiority from their peers. For men who had always been physically active and perceived as*

> *strong, the need to be dependent on others and a machine made them feel ashamed and often led to withdrawing from family and not participating in dialysis education and preparation.*[374]

KRT limiting people's ability to socialise and carry out their normal daily routine was common[84,273,280,281,370–380,382].

> *Intrusiveness of haemodialysis on preferred lifestyle and activities emerged as patients' major concerns. Limitations of work, travel, social life as well as fluid and diet restrictions were discussed and linked to feelings of despair and frustration.*[280]

Biographical adaptation, or reframing, is when patients find ways to reframe their expectations of life and find meaning in their lives with a chronic illness.[6] This process where patients find meaning in their new lives was described in some studies[273,280,370,380,382].

> *Participants mentioned haemodialysis acceptance with time and insight improvement. Normalizing haemodialysis, living in dialysis ward, maintaining prior self-image, enduring haemodialysis and coping with it, complying life activities with haemodialysis and considering the dialysis machine as part of the body* [370]

5.5.2.2 Resources

Studies reported the importance of accessing and mobilising critical resources. Financial resources were commonly discussed[84,273,280,281,370–373,375–381]. Some people had already retired and were financially comfortable with reliable affordable access to healthcare which enhanced their capacity to manage health. However, KRT can disrupt ability to work and the resultant financial hardship from reduction or loss of income was profound for many. Some chose to pursue home KRT in order to be able to continue working, however the directly incurred costs of home KRT could be considerable due to the necessary home modifications and additional power and water consumption. Patients' ability to meet these costs were a major determinant of the viability of some therapeutic options.

> *She was afraid of the machine using lots of power. She was worrying it would be too expensive to run it (…) 'We have such a tight budget now, to add anything*

> *even five dollars of power, that could tip us over, so that meant the machine at home was out'.*[376]

Other directly incurred costs also created hardship such as fuel costs to drive to hospital appointments, especially if rural. In countries without universal healthcare, the cost of insurance or paying for treatments could be problematic, with some relying on emergency only HD if routine care was unaffordable[281,370,373].

Literacy and prior medical knowledge were important determinants of capacity. Patients who were able to easily access and understand information were better prepared to transition onto KRT and fully engage in shared decision making[84,278,280,281,372,374–376,378–381]. Access to information and support from peers or family members with prior experience of KRT could be a valuable resource[273,372,374–376,378]. Patients with limited knowledge of kidney disease or poor health literacy found the medical terminology and the volume of new information overwhelming. Patients who did not speak the dominant regional language (e.g. English), came from a different culture to the dominant regional culture, were visually impaired or had poor digital literacy were further disadvantaged[373,374,376].

> *Participants experienced confusion during discussions with clinicians. Their limited understanding of kidney disease made it difficult to process what they were told, ask questions, and make decisions. The large volume of information conveyed at one time made it especially difficult to process what was happening. Most participants believed they were in kidney failure because of their nutritional habits, but did not demonstrate a clear understanding of what caused their kidney disease or how it could have been prevented*[373]

Physical health and physical abilities were key resources. Distressing symptoms such as fatigue, vertigo and muscle cramps limited capacity to cope with new treatment and maintain social connection[273,280,373,375,377,378,380,382]. Patients who had to start dialysis as an emergency were often critically ill and were too unwell to process the information being given to them or participate in shared decision making[273,373].

> *Participants reported they often felt too ill to engage in discussions with clinicians. Since most education happened while they were experiencing symptoms of volume overload and uraemia, the felt too sick to understand, inquire about options or make decisions*. *They reported being only interested in feeling better, not in*

> *understanding what is happening to their bodies, and would have accepted any treatment option without resistance.*[373]

However, as patients felt better on dialysis and had fewer symptoms their capacity to engage with KRT was enhanced.

Psychological resilience an important determinant of capacity. Many studies described participants who felt that their sense of identity and self-worth had been severely undermined by illness and new dependency. Depression, withdrawal and suicidal thoughts were commonly described[273,280,281,373–375,380–382].

> *For some male participants, their gendered construct of identity was severely challenged, and in Peter's case, this led him to feelings of worthlessness: "A lot of blokes would suffer depression…like I felt..Feeling useless, that they're no good for anybody…I've always been independent felt that it was a man's place to support his family. Ever since I've been sick I've been relying on the family to keep me going..F-ing useless! I should have died [crying] and it would have been better for everybody 'cause it's so hard on everyone now".*[380]

Feelings of guilt, anger, or regret at missed opportunities for earlier intervention could undermine patients' confidence in their ability to self-care and healthcare professionals' ability to care for them leading to reduced capacity[84,373–376,382].

> *Many participants, particularly those with diabetes, expressed regret that they could have avoided or delayed dialysis. Despite many acknowledging they had not known enough to make significant changes earlier, many blamed themselves for not proactively asking about treatment or lifestyle changes, or trying to understand more about their condition to help them self-manage their care, internalising a sense of inadequacy. These experiences often led to loss of confidence in their own ability to care for themselves.*[374]

Conversely, those who were able to adjust, remain optimistic and find value and legitimacy in KRT were better equipped to meet their workload. Confidence in ability to undertake KRT related work, ability to navigate complex systems and self-advocate in interactions with healthcare professionals and other agencies influenced

capacity[84,370,374,376,378,379,381]. Self-efficacy was especially important when engaging in shared decision making around treatment choices.

> *"I'm embarrassed to say, it's actually a lot of education to learn it [home dialysis], I have to learn how to do the machine, and they say it's hard, and it takes a long time, I guess I'm just not sure if I can learn it, and I'm not that good, and I felt a lot of pressure to learn at their level and I didn't really understand, but I don't want to tell them or they'll think I'm dumb".*[374]

Time to prepare for transition to KRT was important: patients who had been aware of the likely need for KRT for months had had time to prepare practically and psychologically, and key components of an optimal start such as pre-emptive vascular access, consideration of live donor transplantation and pre-dialysis education could be enacted[371,381]. Patients who needed to start dialysis urgently did not have this preparation time which undermined their capacity[273,281,380–382].

> *The abrupt onset of treatment appeared to allow little time for expectations, increasing the initial shock. Emotional displays during the discussions gave the impression of not having come to terms with one's current life situation*[382]

The effect of time spent on KRT was also important, with some finding the time commitment and rigid schedules of KRT intrusive and overwhelming, taking them away from other aspects of their life that gave them self-worth and purpose and therefore capacity[84,273,280,281,370–372,374–378,380–382].

> *"Haemodialysis is three times per week and I have to wait (at the dialysis centre). Time for work becomes a problem…and time to spend with my family"*[280]

Available transport affected capacity, especially for patients who lived rurally and needed to travel great distances. This sometimes resulted in them needing to move to live close to the hospital, disrupting their support network and so diminishing their capacity[371,374,376,377,382].

5.5.2.3 Environment

Patients had their capacity enhanced by a person centred environment where they felt respected, understood and cared for and had easy access to support and suitable

resources[273,278,374–376,379,381]. Cultural competence was an important theme in studies that captured the experiences of minoritized communities. Being able to access care in their native language and access advice adapted to their culture (e.g. dietary guidance) enhanced capacity[373,376]. Equally for Māori patients feeling that clinicians understood and respected the importance of the spiritual connection to land and people and the importance of taking that into account when making treatment decisions enhanced their capacity[374]. Conversely, indifferent or stigmatising care or failure to meet key needs diminished capacity[273,278,371–374,376,381].

> *Participants who were illiterate or for whom English was a second language felt lost and embarrassed about being unable to read and understand the information given. As such, they indicated to clinicians that they understood the information.*[376]

> *Despite the need of guidance, some of the participants pointed out that lack of time and the busyness of staff often obstructed the possibility of engaging in dialogue. Furthermore, it seemed necessary for patients to take an active and questioning approach in the consultation at the outpatient clinic beyond just basic questions.*[278]

5.5.2.4 Realization of work

Capacity affects an individual's ability to realise work, but conversely the realisation of work has an impact on capacity: sometimes carrying out workload successfully enhanced capacity and reduced burden [6]. The effect of this relationship was clear in papers discussing home dialysis[371,372,374,376]. Home HD or PD has considerable additional workload compared to in-centre HD and therefore requires significant capacity for it to be an option. However, there is a paradoxical relationship where the emotional and cognitive reinforcement from undertaking the work required to dialyse at home and the resultant multifactorial enhancement in capacity from being able to continue employment, maintain family and community roles, and minimise life disruption results in the increased workload reducing overall burden compared with in centre dialysis.

> *Being able to dialyse when it was convenient for them allowed participants to maintain financial security and themselves and their family; this was particularly important if they were the sole provider.*[376]

5.5.2.5 Social Functioning

Patients who were able to adapt and maintain their social roles in the workplace, community or family gained confidence in the process and described features of enhanced capacity[84,371,374,376]. However, for others a loss of social role was felt profoundly and could further diminish capacity due to loss of social connectedness and biographical disruption[84,273,280,281,370–374,377,380,382].

> *For some the need of dialysis meant not being able to travel or return to work. This was a real disappointment. Dependence on dialysis also affected life at home as roles were forced to change. Some participants found their inability to contribute as much as before as very frustrating, leading to feelings of guilt. "It has become so that my wife has to do everything. Before I cooked food and fixed things and now she has to do it all…yes so I feel it's my fault"*[273]

In many studies, patients reported receiving wide ranging support from their family and community; emotional support, assistance with activities of daily living and transport, and decision-making support[84,278,374,378–381]. Those without much of a social network lacked this support. For some, new dependency led to concerns about the viability of their relationships and sometimes resulted in marital difficulty and relationship breakdown[84,278,280,374,377,380].

> *Vanessa lived with her brother who provided her with no practical help. Asking for assistance from people other than family placed dependence in a different dimension for Vanessa, "I've got to now ask for help from my friends…I'm finding it difficult to do so"*[380]

The social relationship between patients and healthcare professionals influenced capacity. A trusting and mutually respectful relationship enhanced capacity[84,273,278,370,372,374–376,378,379,381,382]. However dysfunctional patient-clinician relationships severely impaired capacity and profoundly increased the sense-making and cognitive participation workload encountered by patients[84,278,372–376,379,381].

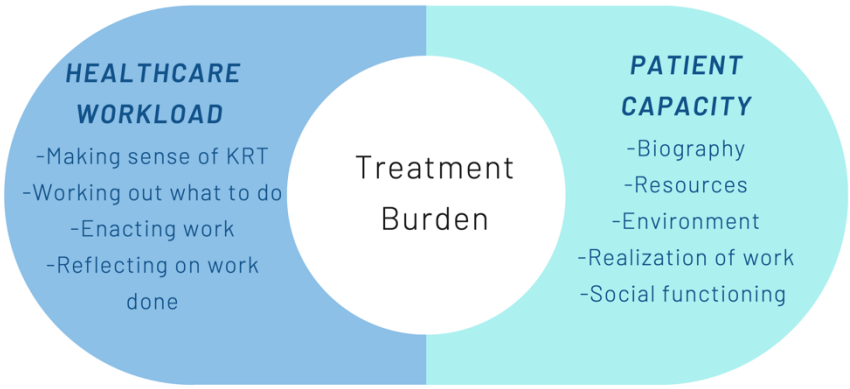
> *During clinical consultations to discuss modality preferences, some felt powerless to articulate their concerns particularly if they perceived that their doctor was 'sitting up on a ladder' talking to them. They felt unable to question or believe that*

they were expected to immediately comprehend and understand the information regarding each modality. Some participants felt so disempowered during clinical encounters that they instinctively chose the safest option, facility dialysis[376].

5.6 Discussion

Treatment burden is a product of the interaction between healthcare workload and capacity (figure 5.2). This systematic review describes a considerable healthcare workload for people transitioning onto KRT and many important factors that affect capacity to manage that workload. None of the included papers comprehensively discussed all aspects of workload and capacity across the whole patient journey but all papers captured a part of the patient experience of the transition process. Therefore, when synthesized together in this review, a broader exploration of treatment burden during transition onto KRT is provided. By developing a taxonomy of workload and a taxonomy of capacity we can describe the different components that influence a patient's experience of overall treatment burden.

Figure 5.2: Demonstration of the relationship between healthcare workload, patient capacity, and treatment burden



5.6.1 Comparison with treatment burden in other diseases

Our findings align with previous work on treatment burden that demonstrated the relationship between workload and patient capacity is complex, multifactorial, temporally dynamic and dependent on personal circumstance. It cannot be characterised as a simple

inversely proportional relationship between workload and capacity[7]. Understanding the treatment burden encountered by patients involves understanding the interaction between the totality of the multitude of different workloads they are required to meet and the range of different domains that contribute to their capacity: some enhancing it and some diminishing[7].

A systematic review looking at treatment burden across a range of long-term conditions conceptualised three common spheres of treatment burden: biographical disruption encompassing the loss of freedom and independence and restriction of meaningful activities, relational disruption encompassing social isolation and relationship strain, and biological disruption encompassing the physical side effects[383]. This fits closely with the findings of this review, emphasising the universality of treatment burden as a concept and the common features that manifest across a wide range of life experiences and diseases.

However, experiences of treatment burden described in this review did differ from studies that have examined other conditions in some aspects. In KRT transition the magnitude and intensity of the required healthcare contact involved in in-centre dialysis, the complexity of the tasks needed to be carried out to facilitate home dialysis and the intrusion of KRT related activity into daily life differed from that described for other conditions such as congestive heart failure[322], stroke[321], cancer[323] and type 2 diabetes[384]. The focus of different components of workload was also different, with greater emphasis on understanding concepts and working out what to do in the KRT transition population compared to congestive heart failure [322]. The effect on families and the wider social network differed in particular, partially because the KRT population captured a wider range of ages and included younger working age patients with young families as well as older patients. Their described workload and capacity factors were centred around managing a life-threatening disease with young families and maintaining ongoing employment more prominently than in studies of heart failure[322] and stroke[321], but was similar to that described in cancer[323]. Polypharmacy and medication workload was a more prominent feature of treatment burden in congestive heart failure[322], type 2 diabetes[384] and stroke[321] than in KRT.

5.6.2 Comparison to other studies of effect of patient capacity on transition onto KRT

A study that used a combination of patient-reported measures to quantify the relationship between different domains of capacity and illness intrusiveness on haemodialysis found that reduced physical, mental and financial capacity were robustly correlated with increased patient reported disruption[385]. Although this study had a long-term maintenance haemodialysis only population, their findings correlate with the findings of this review.

Patient activation is a different but overlapping concept to patient capacity. Patient activation has an individualistic focus on a patient's own knowledge, belief, motivation, confidence and skills in managing a chronic disease[117] and puts the onus on the patient to become 'activated' in order to become a more efficient manager of their own health needs[260] whereas patient capacity conceptualises a patient's ability to meet healthcare workload more holistically as a synergy of individual, social and environmental factors[6]. Studies of patient activation in kidney disease have found that lower activation is associated with higher symptom burden and lower quality of life[177], and that activation scores are higher in those starting home dialysis and those who had pre-dialysis nephrology care[178]. This correlates with qualitative descriptions of patient capacity in this review.

5.6.3 Strengths, limitations and future research needs

The strength of this review lies in its tight focus on transition and its exhaustive search, which allowed a detailed qualitative exploration.

Our inclusion criteria were limited to English language publications published in 2012 or later. The rationale for the temporal limitation was to capture current practice. Although our review included papers from a wide variety of countries, the English-language limitation may have excluded relevant papers from other countries. Papers were mostly published from highly developed countries, and there was a paucity of data from low and middle-income countries with no included papers from either Africa or South America.

We limited the inclusion criteria to studies of patients experiencing initial transition onto KRT and excluded papers that included experiences of patients on long term maintenance

KRT, transitioning between modalities and those who chose conservative care, which limited the scope of the review. The benefit of this is that it facilitated a focused and comprehensive discussion of treatment burden during KRT transition which has different patterns of workload and burden compared to experiences of CKD more generally described elsewhere [148]. However, a consequence of this is that only experiences of transitioning onto KRT by way of pre-emptive kidney transplantation were captured, rather than the more common scenario of a period of dialysis with subsequent transplantation. More research is required to explore the treatment burden of transition pathways to kidney transplantation.

Treatment burden is dynamic and changes over time, and as most of the included papers only interviewed their participants once, the evolution of an individual's treatment burden over the process of transition was not captured in this review and is an area that would benefit from further research.

This review describes the different workloads encountered and the different factors that underpin capacity but further qualitative research is required to gain a deeper understanding of the dynamic relationship between patient capacity and workload during transition. Specifically, more work is required to understand the complex interplay between different types of workload encountered and different patient capacity factors such as the extent of the biographical disruption encountered and ability to reframe and enact biographical adaptation; the financial, literacy, medical knowledge, physical health, psychological resilience, self-efficacy and time resources utilised; the individual's relationship with their social network and the ability of that network to support them; and the wider environment in which patients are trying to meet this workload and how this evolves over time.

We encountered less discussion than anticipated on the effect of multiple long-term conditions (multimorbidity) and managing other conditions whilst transitioning onto KRT, especially considering that the prevalence of multimorbidity in the CKD5 population is 97.5% and the prevalence of complex multimorbidity defined as 4 or more long term conditions is 66.2% [386]. More work is required to explore this aspect.

5.7 Conclusions

This review is a comprehensive examination of healthcare workload and capacity to manage that workload during patient's first transition onto KRT. This emphasises the importance of taking treatment burden into account when caring for patients preparing to transition onto KRT.

Through further research to better understand workload, capacity and burden during transition we can develop better ways of measuring burden and recognising patients at risk of becoming overburdened, and develop interventions to reduce workload, enhance capacity and reduce treatment burden, which can potentially improve care experiences for these patients.

Chapter 6 Healthcare workload associated with transition onto kidney replacement therapy: a retrospective cohort study

6.1 Chapter Introduction

This chapter was published as a paper in BMC Nephrology: Jones, C.H., Edgar, B., Thomson, P.C. *et al.* Healthcare workload associated with transition onto kidney replacement therapy: a retrospective cohort study. *BMC Nephrol* **27**, 73 (2026).

Minor editorial changes have been made from the published version including formatting and referencing style to facilitate integration with the wider thesis.

6.2 Structured Abstract

6.2.1 Background and hypothesis.

Transition onto kidney replacement therapy (KRT) is a complex, intensive phase for patients with advanced chronic kidney disease (CKD), characterised by high healthcare utilisation. Frequent outpatient visits, surgical and radiological procedures, hospitalisations, and haemodialysis (HD) sessions impose a significant time burden on patients. The concept of time toxicity is widely described in oncology, and captures the disruption to patients' lives due to treatment-related demands. We aimed to quantify time- based healthcare workload during the transition onto KRT and identify patient characteristics associated with increased workload.

6.2.2 Methods.

We conducted a retrospective cohort study including all consecutive adults initiating KRT (haemodialysis (HD), peritoneal dialysis (PD), or pre-emptive transplantation (KTx)) in the Glasgow Renal and Transplant Unit between January 2015 and December 2019. Routinely collected electronic health record data were used to estimate time spent per month on healthcare-related activities (outpatient appointments, radiology, inpatient admissions,

HD sessions, and travel) from 6 months pre- to 36 months post-KRT initiation. Workload was analysed as a time-based outcome (hours/month). Univariate analysis used Kruskal-Wallis testing; multivariate modelling employed negative binomial regression.

6.2.3 Results.

A total of 1,022 patients (58.6% male; median age 61 years) contributed over 1.1 million patient-days. Median healthcare workload peaked around KRT initiation and was highest in HD patients. Kidney transplantation was associated with markedly lower workload post-initiation (IRR 0.04). Increased workload was associated with female sex, polypharmacy (>15 medications), late referral, older age (in maintenance phase), and modality change or failed transplant. Socioeconomic deprivation and primary renal disease were not significantly associated with higher workload.

6.2.4 Conclusion.

Healthcare workload during KRT transition is substantial and varies widely. Transplantation is associated with significantly lower workload. These findings support timely transplant planning and underscore the importance of considering the time burden of healthcare experienced by patients when discussing treatment options.

6.3 Introduction

Chronic kidney disease (CKD) is a global health priority [387] with an estimated prevalence of 850 million people worldwide[388]. The prevalence of both CKD and kidney replacement therapy (KRT) are both projected to increase considerably over the next 10 years[389]. Currently 8,254 adult patients start kidney replacement therapy every year in the UK, giving an incidence of 154 persons per million[390]. The transition from advanced CKD to KRT- either haemodialysis (HD), peritoneal dialysis (PD) or kidney transplantation (KTx)- is a complex phase in the patient journey with significant healthcare utilization [163164 391]. This has considerable economic and systemic resource allocation implications[165,392], but also has a very human cost borne by the patients navigating this phase of their illness. The disruption caused by hospitalisations, frequent appointments, and investigations, and attending dialysis are described as being particularly burdensome[393].

Treatment burden is the impact that fulfilling healthcare workload has on wellbeing[394]. There is growing recognition of the importance of recognising treatment burden but as it is the subjective experience of patient of the impact of healthcare workload, burden cannot be directly inferred by only quantifying workload[395]. Time toxicity is defined as the time impact of medical treatment, including the time spent co-ordinating care, attending clinics, inpatient stays, imaging, travel to and from healthcare facilities, seeking urgent care for side-effects or deteriorations, and follow up tests [169,396]. It has been widely described in oncology, where it has been noted to be a patient centred measure that encompasses the temporal burden of treatment, the disruption of daily life, the opportunity cost of losing time to do other things such as spending quality time with loved ones, the cumulative impact of a consistently high temporal burden on wellbeing and the emotional and psychological strain of treatment which can impact the efficiency of healthcare utilization[345–348,397]. For some patients the impact of the time spent pursuing cancer treatments can be so considerable it offsets the modest survival gains offered by treatment[169]. The temporal burden of healthcare workload and time toxicity has not been explored for patients in the context of KRT transition, however the Standardised Outcomes in Nephrology (SONG) initiative identified that life participation was a key patient priority for PD and KTx patients. It also highlighted that dialysis free time was an important priority for HD patients, and that hospitalisations and ability to work and travel were important concerns for all KRT patients highlighting the relevance of time toxicity as a consideration in this population[73].

The aim of this study is to describe patterns of healthcare workload as measured by time per month spent in healthcare contact in the six months leading up to KRT initiation and in the first 36 months of KRT, and describe patient characteristics associated with higher workload.

6.4 Materials and Methods

6.4.1 Study Settings

This was a retrospective cohort study of healthcare workload during transition onto KRT. All consecutive patients aged 18 or older that started any form of KRT in the Glasgow Renal and Transplant Unit, Glasgow, Scotland between 1st January 2015 and 31st December 2019 were included. The unit provides comprehensive nephrology services for

NHS Greater Glasgow and Clyde and NHS Forth Valley health boards and kidney transplant services for the West of Scotland, serving an estimated population of 1.5 million for general nephrology services and 2.6 million for kidney transplantation. Participants were identified by interrogating the Strathclyde Electronic Renal Patient Record (SERPR, Vitalpulse, UK) system for all patients that had started KRT within the study period. Data were extracted for all recorded hospital-based workload in SERPR from 6 months prior to starting KRT and for the first 36 months of KRT or until death, and categorised by the month in which they occurred relative to the KRT initiation date from Month -6 to Month 36. Data collection ended on 31st December 2022. We elected to use 6 months prior to KRT initiation as it would capture most of the workload involved in KRT transition, and to follow up for 36 month as the mean wait time on the deceased donor kidney-only transplant waitlist in the UK is 15.6 months[398] and therefore a follow up period of 36 months would capture the majority of the workload experienced by patients pursuing their first kidney transplant. For analysis we subdivided the study period to two phases: peri-initiation (Month-6 to Month 6) and early maintenance (Month 7 to 36). Caldicott approval was granted to access and analyse the anonymised data.

6.4.2 Healthcare workload and predictor measurement

Baseline demographic data were extracted including age at KRT initiation, sex, ethnicity, primary renal disease, and number of repeat prescription medications at time of initiation. Home postcodes at time of initiation were used to categorise socioeconomic status using Scottish Index of Multiple Deprivation (SIMD) quintiles. The SIMD is a Scotland-specific composite area-level measure of deprivation that combines data on education, employment, household income, health, access to services, crime, and housing to determine a deprivation quintile score from 1 (most deprived) to 5 (least deprived)[334]. Initial contact with nephrology services was noted, and patients who presented to nephrology less than 90 days prior to KRT initiation were classified as late presenters. The exact date of KRT start was noted as well as the starting modality: HD, PD or KTx. Data on modality changes in the first 36 months of KRT were extracted including number of modality changes and type of change: PD or HD to Transplant (Incident Transplantation) and Transplant to HD or PD (Failed Transplant). For patients that died during the 36 month follow up period, date of death was recorded and converted to month of death relative to KRT initiation. All kidney disease related clinic visits including general

nephrology, vascular access, transplant assessment, transplant follow up or PD clinic were recorded. All hospital inpatient admissions and length of stay were recorded, as were all diagnostic and interventional radiology workload, and all HD sessions. Commute times for all episodes of care were estimated from domiciliary post code.

The outcome of interest was average time per month in hours spent on healthcare workload. The decision to use time as outcome was done following consultation with a Patient and Public Involvement and Engagement (PPIE) group. The length of inpatient stay was calculated from the admission and discharge date recorded on SERPR, we estimated that an outpatient clinic appointment lasted 30 minutes, imaging appointment lasted 1 hour, and a HD session lasted 5 hours from average appointment duration. Travel times were estimated by querying the Google Maps application programme interface (API) using an anonymised list of postcodes to provide coordinates to enable geocoding. All coordinates were then geographically masked by a process known as 'jittering' to preserve patient anonymity. The API was then further queried for driving times between each set of coordinates and the hospital attended. These techniques are slightly less precise than using the exact street address for each patient, but were necessary to preserve anonymity[399,400]. Total time per month per participant from Month -6 to Month 36 was calculated and this is our outcome measure. We censored the data for death to ensure accuracy and minimise bias from missing values.

All variables were treated as categorical. Continuous variables were categorised for analysis. Age was categorised as 18-44, 45-64, 65-74 and 75+ in keeping with classification used by the Scottish Renal Registry[12] . Number of medications were categorised as <10, 10-15, and 15+ as the average number of medications in our cohort was 12.5 and these categories reflect lower, average, and higher medication burden.

6.4.3 Statistical Analysis

All statistical analyses were conducted using R Statistical Software. Skew was measured with Fisher G1 and Bowley quartile skew. Univariate statistical analysis was undertaken with Krukal-Wallis test and effect size was calculated using ε^2. Negative binomial multiple regression models were fitted for both the peri-initiation and maintenance periods and Incidence Rate Ratios (IRRs) were calculated to compare workloads. Statistical significance was set as $p<0.05$. As our dataset had low levels of missing data we conducted available

case analysis. We censored the data for death so that average time per month was calculated only for the months patients were alive for in the analysis periods.

6.5 Results

6.5.1 Demographics

1022 consecutive patients who started KRT for the first time between 1st January 2015 and 31st December 2019 were recruited. Healthcare workload data were collected for all for the six months prior to KRT start and for 36 months after or until death, giving a total of 1,104,158 observed days. 317 patients (31%) died during the follow up period. Data was complete for all included primary values for 964/1022 participants (94.3%), with missing age data for 53 (5.2%) and primary renal disease for 5 (0.5%). Ethnicity data was missing for 65.9% and therefore ethnicity was not included in the analysis but has been reported in Table 1 for completeness.

The demographic characteristics of the patients are categorised in Table 6.1. Median age at KRT start was 61 (IQR 50-71; range 18-90), 599/1,022 participants were male (58.6%) and 389/1,022 participants (38.2%) lived in SIMD 1 post codes which is the most deprived quintile. The most common primary renal disease (PRD) was diabetic kidney disease, reported in 319/1022 (31.2%) of participants. The median number of long-term medications at KRT start was 13 (IQR 9-16, range 0-36). Median distance from the hospital was 5.4 miles (IQR 3.2-11.3; range 0.3-145 miles), with a median travel time of 21 minutes (IQR 15.2-30.6; range 2.5-479 minutes).

Table 6.1: Demographic characteristics of participants

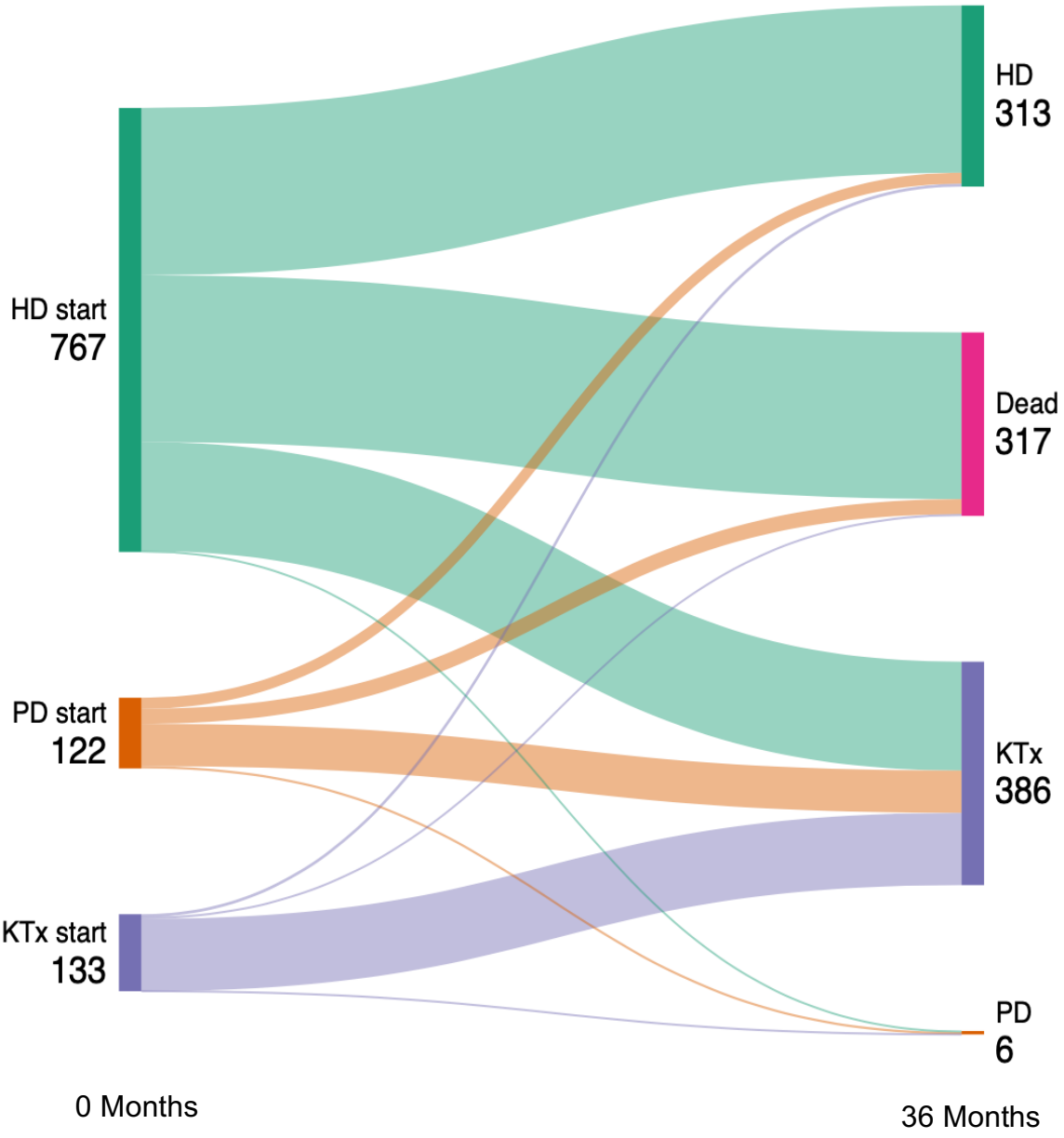
Age	18-44: 176 (17.2%) 45-64: 403 (39.4%) 65-74: 225 (22.0%) 75+: 165 (16.1%) Not recorded: 53 (5.2%)
Sex	M 599 (58.6%) F 423 (41.4%)
SIMD	1 389 (38.2%) 2 203 (19.9%)

	3 166 (16.3%) 4 135 (13.2%) 5 126 (12.4%)
Ethnicity	White 287 (28.0%) Asian 38 (3.7%) Black 11 (1.1%) Mixed 3 (0.3%) Other 9 (0.8%) Not recorded 674 (65.9%)
Primary Renal Disease	Glomerular Disease 211 (20.7%) Tubulointerstitial Disease 148 (14.5%) Diabetes 319 (31.2%) HTN/Renovascular Disease 119 (11.7%) Other systemic disease affecting the kidney 33 (3.2%) Familial/ hereditary 86 (8.4%) Miscellaneous 100 (9.8%) Not recorded 5 (0.5%)
Number of medications	<10: 263 (25.7%) 10-15: 485 (47.5%) >15: 274 (26.8%)
Distance from hospital	<10 miles: 749 (73.3%) 10-20 miles: 109 (10.7%) 20-30 miles: 116 (11.4%) 30+ miles: 42 (4.1%)
Travel time	<15 minutes: 245 (24.0%) 15-30 minutes: 513 (50.2%) 30-60 minutes: 206 (20.2%) 60-120 minutes: 30 (2.9%) 120+ minutes: 22 (2.2%)
Late presenter	Late: 86 (8.4%) Not Late: 936 (91.6%)
Starting Modality	Haemodialysis 767 (75.0%) Peritoneal Dialysis122 (11.9%)

	Kidney Transplant 133 (13.0%)
Modality changes	No changes: 730 (71.4%) 1 change: 230 (22.5%) 2+ changes: 62 (6.1%)
Exposure to transplant after PD/HD KRT start	Yes: 245 (24.0%) No:777 (76.0%)
Exposure to failed transplant	Yes: 21 (2.0%) No: 1001 (98.0%)
Status at 36 months	Haemodialysis: 313 (30.6%) Peritoneal Dialysis: 6 (0.6%) Transplant: 386 (37.8%) Dead: 317 (31.0%)
SIMD- Scottish Index of Multiple Deprivation; PD- Peritoneal Dialysis; HD-Haemodialysis; KRT- Kidney Replacement Therapy	

Most patients were known to nephrology services for more than 3 months prior to starting: only 86/1,022 (8.4%) were late presenters. HD was the most common starting modality with 767/1,022 (75.0%) starting on HD, 122 (11.9%) started on PD and 133 (13.0%) started KRT with a pre-emptive transplant. In the subsequent 36 months, 292 participants (28.6%) changed modality at least once and 317 (31.0%) died meaning that at 36 months post initiation 386 participants (37.8%) had a functioning transplant, 6 (0.6%) were on PD and 313 (30.6%) were on HD (figure 6.1).

Figure 6.1: Sankey diagram demonstrating changes in modality over 36 months



6.5.2 Temporal trends in workload

Total time per month was calculated for every participant for every month from Month -6 pre KRT to Month 36 post initiation or until death both overall and subdivided by type of workload (Outpatient, Radiology, Inpatient, HD, Commuting), as shown in Table 6.2. Inpatient stays and HD sessions were the predominant drivers of workload. Overall time data had extreme right skew (Fisher g1= 15.94, 95%CI 15.92-15.97; Bowley skew=0.85, $p<0.001$) signifying that a small number of patients had very high workload. Degree of

skewness varied between workload type: inpatient care was extremely right skewed with Fisher g1 of 17.73, 95%CI 17.71-17-76, and an unquantifiable quartile skewness as more than 75% of patient-months had no inpatient stay. HD sessions had a borderline right skew on Fisher g1: 0.49, 95%CI 0.47-0.52) but strong right skew on Bowley quartile skew (1.00), which is in keeping with those not on HD not having any HD based workload but those on HD having consistently high and similar workloads. Similarly Radiology (Fisher g1= 4.22 , 95%CI 4.12-4.24; Bowley skew= unquantifiable, p<0.001), Outpatient clinic (Fisher g1= 2.96 , 95%CI 2.93-2.98; Bowley skew=1.0, p<0.001) and Commute (Fisher g1= 6.70 , 95%CI 6.67-6.72; Bowley skew=0.44, p<0.001) workloads all demonstrated marked right skew, but less extreme than inpatient workload.

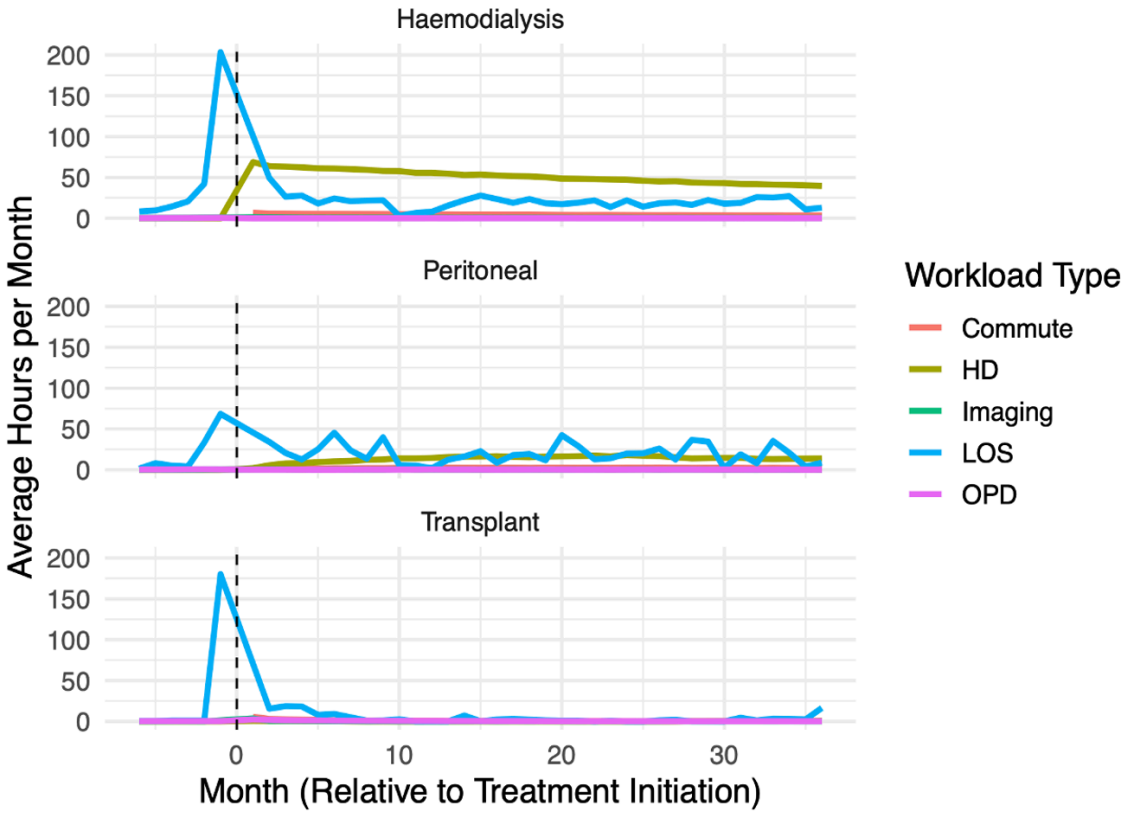
Table 6.2: Total average death-censored time per month spent per activity (hours)

Activity	**Peri-initiation (Month -6 to 6)** *(Mean/SD; Median/IQR)*	**Early Maintenance (Month 7 to 36)** *(Mean/SD; Median/IQR)*
Total Time	Mean: 59.7 (164) Median: 3.53 (0.8-71.6)	Mean: 50.5 (113) Median: 42.8 (0.0-71.0)
Outpatient clinic	Mean: 0.36 (0.54) Median: 0.0 (0.0-0.5)	Mean:0.22 (0.47) Median:0.0 (0.0-0.5)
Radiology	Mean: 0.66 (1.36) Median:0.0 (0.0-1.0)	Mean: 0.41(1.02) Median:0.0 (0.0-0.0)
Inpatient care	Mean: 36.4 (169.0) Median: 0.0 (0.0-0.0)	Mean: 16.1 (106.0) Median: 0.0 (0.0-0.0)
HD sessions	Mean: 23.3 (32.6) Median: 0.0 (0.0-60)	Mean: 36.8 (32.5) Median:55.0 (0-65.0)
Commute	Mean: 2.70 (4.79) Median:1.1 (0.3-3.7)	Mean: 3.42 (4.89) Median:2.5 (0.4-4.6)

When considering temporal patterns of workload, workload patterns differed depending on starting modality (Figure 6.2). All modalities had an acute initiation workload spike at between Month -1 and Month 1 mostly driven by inpatient stay, but this is less pronounced in those who started on PD. The increase in inpatient workload starts earlier for HD and PD patients in the pre-KRT period as compared to transplant, likely representing inpatient admissions for vascular access creation, PD catheter insertion and

medical optimisation. Post KRT initiation, transplant workload rapidly decreases over first six months and settles to a very low baseline. Haemodialysis workload also settles, but to

Figure 6.2: Death censored average workload per month by modality



This is a figure demonstrating average workload per month from Month- 6 to Month +36 subdivided by modality. The different coloured lines denote different types of workload. The dashed line denotes the point of KRT initiation.
HD- Haemodialysis; LOS- length of inpatient stay; OPD- Outpatient department appointment

a higher baseline with regular HD sessions. Peritoneal dialysis hospital-based workload is lower in the immediate initiation period but has ongoing spikes in inpatient stays and a slowly increasing rate of HD workload which is in keeping with patients experiencing PD complications and transitioning onto HD or being transplanted: of the 122 patients that start KRT on PD only 6 remain on PD at 36 months.

6.5.3 Association between patient characteristics and workload

On univariate analysis every categorical domain except sex for both peri-initiation and maintenance, and failed transplant for maintenance, had a signal for association with a difference in workload (Table 6.3).

Table 6.3: Patient characteristics associated with higher workload: Kruskal-Wallis univariate analysis

	Peri-initiation		Maintenance	
	ε^2	p-value	ε^2	p-value
Modality	**0.39**	**<0.001**	**0.34**	**<0.001**
PRD	**0.07**	**<0.001**	**0.12**	**<0.001**
Age	**0.06**	**<0.001**	**0.09**	**<0.001**
Late Presentation	**0.05**	**<0.001**	**<0.01**	**0.04**
Modality change	**0.04**	**<0.001**	**0.07**	**<0.001**
Incident Transplant	**0.03**	**<0.001**	**<0.01**	**<0.001**
Medications	**0.03**	**<0.001**	**0.03**	**<0.001**
SIMD	**0.02**	**<0.001**	**0.02**	**<0.001**
Failed transplant	**<0.01**	**0.031**	<0.01	0.985
Sex	<0.01	0.287	<0.01	0.657

E^2 effect size: <0.01 neglible, 0.01-0.06 small, 0.06-0.14 moderate, >0.14 large

PRD- Primary Renal Disease; SIMD- Scottish Index of Multiple Deprivation

In the negative binomial multivariate regression model (Table 6.4, Figure 6.3) PD and Transplant were associated with significantly lower workloads compared to HD. The difference between Transplant and HD in Months 7-36 was particularly marked (IRR 0.04 (0.03-0.05)), which means that the average monthly workload was 96% lower in pre-emptive transplant patients compared to those who started on HD. Incident transplantation- being transplanted within the 36 month follow up period after starting

KRT on either PD or HD- was also associated with lower workload (peri-initiation IRR 0.73 (0.57-0.92), maintenance 0.37 (0.28-0.49). Female sex was associated with a small increased workload (peri-initiation IRR 1.16 (1.07-1.24), early maintenance 1.17 (1.05-1.31)), and being on more than 15 long-term medications was also associated with a consistently higher workload (IRR 1.36 (1.20-1.55) peri-initiation, 1.35 (1.15-1.59) maintenance).

Table 6.4: Association between patient characteristics and workload: a negative binomial model

Variable	**Peri initiation**		**Maintenance**	
(*=reference)	IRR (95%CI)	p-value	IRR (95%CI)	p-value
Sex				
Male	*	*	*	*
Female	**1.16 (1.07-1.24)**	**<0.001**	**1.17 (1.05-1.31)**	**0.006**
SIMD				
1-3	*	*	*	*
4-5	0.97 (0.88-1.07)	0.539	1.10 (0.97-1.25)	0.122
PRD				
Glomerular	*	*	*	*
Tubulointestitial	0.92 (0.79-1.07)	0.292	0.88 (0.73-1.07)	0.193
Diabetes	**1.15 (1.01-1.31)**	**0.031**	1.12 (0.96-1.32)	0.160
Hypertension	1.02 (0.87-1.20)	0.774	1.00 (0.82-1.22)	0.999
Other systemic	1.13 (0.88-1.46)	0.339	1.02 (0.75-1.42)	0.893
Familial	0.86 (0.72-1.03)	0.104	0.90 (0.72-1.13)	0.360
Miscellaneous	1.03 (0.87-1.22)	0.741	1.07 (0.87-1.33)	0.535

Unknown	0.83 (0.48-1.59)	0.537	0.41 (0.19-1.06)	0.043
Late Presentation				
Not Late	*	*	*	*
Late	**1.39 (1.18-1.65)**	**<0.001**	1.01 (0.82-1.26)	0.905
Incident Transplant				
No	*	*	*	*
Yes	**0.73 (0.57-0.92)**	**0.007**	**0.37 (0.28-0.49)**	**<0.001**
Failed Transplant				
No	*	*	*	*
Yes	1.04 (0.77-1.44)	0.794	**2.30 (1.61-3.41)**	**<0.001**
Modality Change				
No	*	*	*	*
Yes	0.98 (0.79-1.23)	0.888	**1.44 (1.08-1.94)**	**0.008**
Age				
18-44	*	*	*	*
45-64	1.06 (0.93-1.20)	0.382	1.16 (1.00-1.36)	0.055
65-74	1.12 (0.97-1.29)	0.127	**1.24 (1.03-1.48)**	**0.028**
75+	1.16 (0.98-1.36)	0.082	**1.27 (1.04-1.57)**	**0.023**
Medications				
<10	*	*	*	*

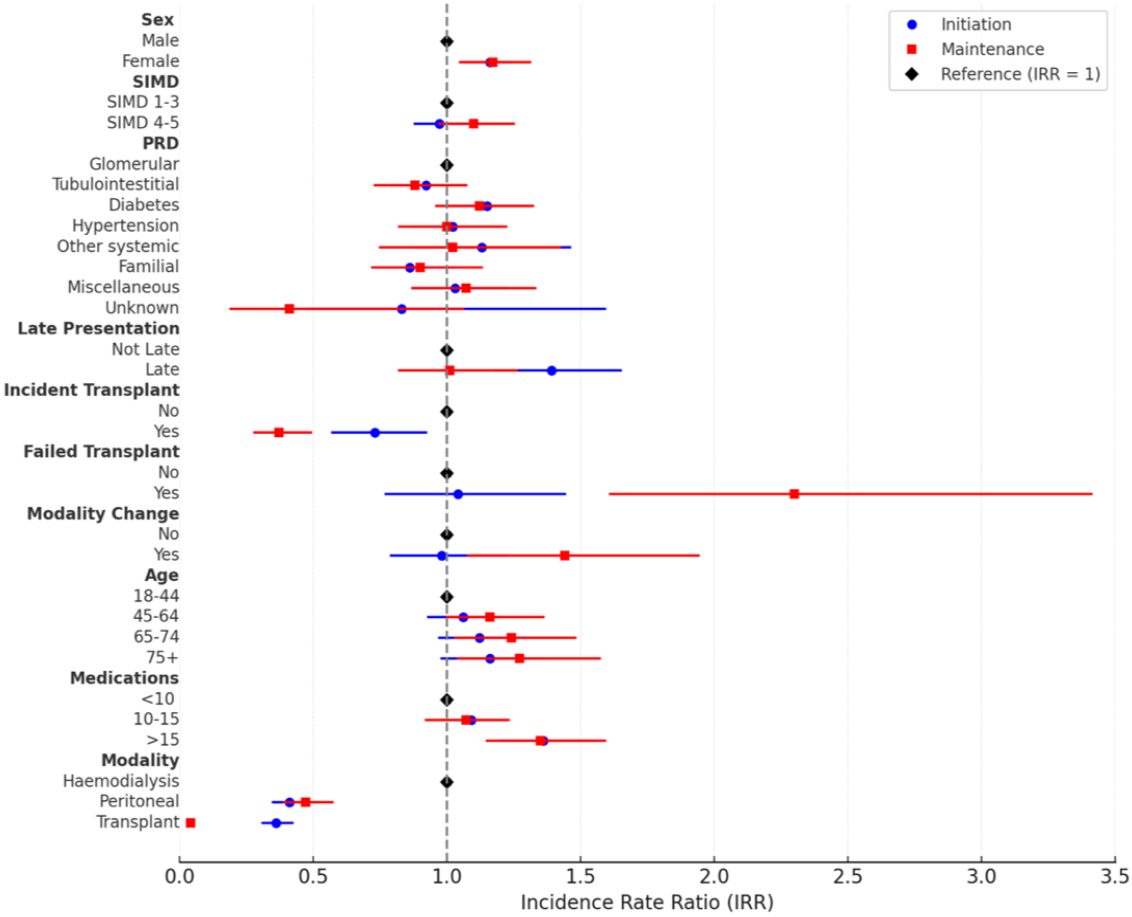
10-15	1.09 (0.98-1.22)	0.123	1.07 (0.92-1.23)	0.380
>15	**1.36 (1.20-1.55)**	**<0.001**	**1.35 (1.15-1.59)**	**<0.001**
Modality				
Haemodialysis	*	*	*	*
Peritoneal	**0.41 (0.35-0.47)**	**<0.001**	**0.47 (0.39-0.57)**	**<0.001**
Transplant	**0.36 (0.31-0.42)**	**<0.001**	**0.04 (0.03-0.05)**	**<0.001**

SIMD- Scottish Index of Multiple Deprivation, PRD- Primary Renal Disease

Late presentation to nephrology (IRR 1.39 (1.18-1.65)) was associated with higher workload in the peri-initiation period but was not associated with a difference in workload in the maintenance period. Conversely, age had no significant effect on workload in the peri-initiation period but older age (65-74 (IRR 1.24(1.03-1.48)), 75+ (IRR 1.27(1.04-1.57))) was associated with higher workload in the maintenance period. Modality change (IRR 1.44(1.08-1.94)) and failed transplant (IRR 2.30 (1.61-3.41)) were also associated with higher workload in the maintenance period whilst having no significant effect on workload peri-initiation.

There was no association between SIMD and workload, and with the exception of a small increase in workload for those with diabetic kidney disease peri-initiation (IRR 1.15(1.01-1.31)), there was no association between workload and PRD either.

Figure 6.3: Incidence rate ratios for healthcare workload during peri-initiation and maintenance phases for KRT patients



This is a figure comparing the incidence rate ratio of workload between different variables on multivariate regression analysis. The peri-initiation period (Month-6 to +6) is in blue and the maintenance phase (Month +7 to +36) is in red.
SIMD- Scottish Index of Multiple Deprivation, PRD- Primary Renal Disease

6.6 Discussion

This study provides a detailed analysis of hospital-based healthcare workload derived from an EHR in the 6 months leading up to KRT initiation and the 36 months following. This allows for visualisation of the time burden of hospital-based healthcare workload and how it evolves. We have demonstrated considerable variation in healthcare workload across the cohort; with haemodialysis, older age, high medication burden, late presentation, and complications such as modality changes and failed transplant all associated with higher workload. The use of time as a proxy measure for the burden of healthcare workload is novel in this population.

High medication burden, which could be seen as a surrogate measure for multimorbidity[401–404], was consistently associated with higher workload. The interaction between patient factors such as multimorbidity, frailty and older age with disease severity factors requiring more intensive treatment regimens creating subsets of patients with very high healthcare utilization is reflected in both renal specific[405] and general [406,407] health economics literature. Frailty and severity of comorbidity could also curtail suitability for transplant and mark a high risk for ongoing high healthcare workload, and the data from this study could help delineate populations for whom the burden of ongoing kidney care outweighs benefit to their quality of life, and inform discussions around conservative care[408].

Patients who present 'late', defined as being referred to nephrology less than 3 months from KRT start, often miss out on outpatient pre-dialysis education and opportunities to prepare for optimal KRT starts such as pre-emptive transplantation, pre-emptive vascular access creation and PD counselling[409,410]. It is therefore not surprising that their peri-initiation workload is higher than those referred earlier. It is interesting that their workload in the maintenance period (7-36 months) is no longer higher, suggesting that the increased workload around initiation is being driven by the lateness of their presentation and clinicians and services should be mindful of the higher needs of those with unexpected KRT starts especially around the time of initiation.

The most striking finding of this study is the marked reduction in healthcare workload associated with kidney transplantation. The beneficial effect of kidney transplantation on reducing healthcare utilisation and on improving quality of life is already known[411], and this study contributes to the body of evidence that the timely pursuit of transplantation in potentially eligible patients is key in reducing workload and burden in advanced CKD patients.

As demonstrated in Figure 6.1, only 6 patients remained on PD at 36 months despite robust 36 month survival within the PD initiation cohort, with the majority transplanted by 36 months. This is in keeping with the PDOPPS study, that demonstrated a median time on PD of 1.7 years in the UK (IQR 0.8-2.9)[412]. This emphasises the importance of not only

considering the workload of the current KRT modality but also the potential workload of preparing for, and transitioning onto, different KRT modalities when counselling patients.

Females had significantly higher average workload than men both in the peri-initiation (IRR1.16) and maintenance phase (IRR 1.17). It is unclear why this is the case, however there are several known areas of sex disparity that could be contributing factors. Women are less likely than men to be listed for transplantation within 2 years of starting dialysis in the UK[413]. Women are more likely to be sensitised by previous pregnancies and therefore are harder to match for a kidney transplant, especially for a live donor kidney transplant with a spousal donor[414]. Younger women (<45 yrs) are more likely to experience transplant graft loss, especially if their donor is male[415]. Women are also less likely to achieve primary patency in arteriovenous fistula, and therefore incur more vascular access related workload[416]. It has also been hypothesised that women are more pro-active in their health seeking behaviour and more conscientious with clinic attendances than men and are therefore less likely to have an inappropriately low amount of contact with renal services[417].

The use of time as a patient-centred aggregate measure of healthcare workload in kidney disease is novel. The impact of the time commitments involved in commuting to treatment and the considerable time burden of hospitalisation for the minority that require it is similar to that found for metastatic breast cancer care[418] and multiple myeloma[346]. The negative impact of hospitalisation on patients' psychological wellbeing is well documented[419]. However, care must be taken in inferring that all time used on healthcare workload is detrimental or that lack of time is necessarily superior: kidney failure is a life-threatening disease state that requires extensive healthcare input. Difficulty accessing healthcare could be a detrimental reason for less time spent on healthcare workload. Premature discharge from hospital or insufficient clinic appointments could constitute an inappropriate transfer of work from hospital clinicians to patients or to primary care[7,420]. Further qualitative work is required to understand what aspects of healthcare workload are most burdensome, how patient capacity affects experiences of workload, and how the burden of treatment could be mitigated.

Patients who elected for comprehensive conservative management of their kidney failure were excluded from our analysis as data had not been routinely collected for their workload and outcomes during the study period. This is a limitation of the study, and

further work is required to evaluate the time costs of this model of care especially to inform discussions and shared decision making considering time toxicity, possible futility of aggressive active management and patient wishes and desires for their future care.

A further limitation of this study is that by placing the point of recruitment at KRT initiation and then retrospectively capturing the workload of the six months prior to KRT initiation, the only KRT preparation work captured is that of patients that did initiate KRT. This risks introducing immortal time bias as the workload of those who undertook KRT preparation work but died prior to initiation is not captured by this study, which could lead to an underestimation of the true workload of KRT preparation.

The use of SERPR as a data source brought both strengths and limitations. The use of SERPR as a renal specific EPR provides highly granular and accurate data for healthcare workload within the Glasgow renal services which is a strength of this study. However, it does not capture outpatient clinics with other specialities, hospital workload in other health boards, home visits by specialist nurses, healthcare contact with primary care and other local authority delivered services such as social work, or work undertaken at home which is a particular limitation when considering PD or home HD. SERPR also only captures the number, date and type of healthcare episode and does not capture the exact time spent by the patient in the hospital and therefore we needed to extrapolate estimated time from the SERPR data which introduced a degree of imprecision into our study. There are likely to be additional demands on time in hospital-based healthcare not taken account of such as waiting-room time in clinics or challenges with transport therefore workload time may be underestimated.

SERPR also does not capture healthcare workload that takes place in the home, which could lead to the workload associated with home therapies such as peritoneal dialysis and haemodialysis being severely underestimated. This is a single-centre study, albeit covering a wide geographical area with multiple sites and teams, and this potentially limits its generalisability.

6.7 Conclusions

In conclusion, this study is a comprehensive exploration of healthcare workload associated with transition onto kidney replacement therapy. A key finding is the profound

protective effect of transplantation on workload, reinforcing the importance of timely and proactive pursuit of transplantation for potentially eligible patients and the vital importance of strategies improving the availability of both live donor transplantation and organ availability and utilisation in deceased donor transplantation. Secondly, there are a group of older multimorbid patients on haemodialysis who have a much higher than average workload. This study could help inform discussions around wishes around care, and if the benefits of undertaking time consuming treatment still outweighs the burden.

Chapter 7 Exploration of treatment burden during transition onto kidney replacement therapy: a longitudinal qualitative study

7.1 Chapter Introduction

This paper has been submitted and is currently under consideration by Plos One.

Minor editorial changes have been made from the manuscript submitted for consideration including formatting and referencing style to facilitate integration with the wider thesis.

7.2 Structured Abstract

7.2.1 Background

People with kidney disease who need to transition onto kidney replacement therapy (KRT) face a life-changing diagnosis. This process involves complex decisions about treatment and a high volume of healthcare work. Little work has been done looking at KRT transition through the lens of treatment burden. This study aims to explore how treatment burden evolves during KRT transition in a population recruited from a large nephrology and kidney transplant unit in Glasgow, Scotland.

7.2.2 Methods and Findings

Serial in-depth qualitative interviews were conducted with 30 participants. Using a framework analysis informed by Normalisation Process Theory (NPT), Theory of Patient Capacity (TPC) and Burden of Treatment Theory (BoTT) to explore the interaction between workload, capacity, and the system, five main themes affecting treatment burden arose: engaging personal and social resources to navigate KRT transition, being able to meet the challenges, preparing to enact the healthcare workload, undertaking KRT transition related workload and the evolution of burden over time.

Conclusion

Transitioning onto KRT is a process that entails a high volume of healthcare workload and significant treatment burden. Experiences of treatment burden are influenced by the nature of the work required; the patient's capacity including physical, psychological, financial and cognitive factors; the capacity of their social network; and the functioning of the healthcare system. Particular focus should be placed on understanding the impact of the healthcare system on experiences of burden, as it represents a potentially modifiable driver of treatment burden that clinicians and healthcare policy makers can directly influence.

7.3 Introduction

Patients who need to start kidney replacement therapy (KRT) face a considerable increase in their healthcare workload. Treatment burden is the impact of healthcare workload on patient wellbeing[394]. Three middle range theories have been developed to better conceptualise workload, patient capacity and the burden of treatment. Normalisation Process Theory (NPT) describes the processes through which patients 'normalise' healthcare workload, meaning the process through which patients incorporate new complex healthcare tasks into everyday life. It has four main domains: Coherence, which is the work of understanding and making sense of healthcare work; Cognitive Participation, which is the work of planning and enrolling others; Collective Action, which is the work done by the patient and their network to ensure the work occurs; and Reflexive Monitoring, which is the work of monitoring, evaluating, and adapting their execution of the work [107]. The theory of patient capacity (TPC) was developed to describe the factors that influence the ability to undertake healthcare work. It categorises patients' capacity as five different elements: Biography, which refers to the ability to navigate changes in their social roles as a result of chronic illness; Resources, which are the material and personal resources including financial, physical health, cognitive, medical and health system knowledge, transport and time resource that a patient can mobilise; Environment, which is the influence of the home, community, and healthcare environment within which the patient is trying to undertake the work; Realisation of work, which is the effect of patients' experiences of performing healthcare work on their

capacity to undertake further work; and Social, which is the effect of the patients' social network on their capacity[6].

Burden of Treatment Theory (BoTT) conceptualises the relationship between the healthcare workload delegated to patients to undertake, their capacity to undertake it, and the healthcare system. It describes the interaction between workload and capacity in terms of 'agency' which is the patient's ability to engage with health problems and with others, 'relationality' which are the social networks through which agency can be expressed and distributed, 'control' which are the things that healthcare systems do to determine the structure and content of services, and 'opportunity' defined as the availability of services in different areas at different times. It also describes the interactions between the patient, their social network, and the system as they mobilise their capacity and enact healthcare tasks. The theory postulates that the demands placed on patients to enact healthcare work can be experienced as treatment burdens, and patients become overburdened if their workload exceeds their capacity to meet it[1].

We have previously created taxonomies of workload and capacity during transition onto KRT in a qualitative systematic review[421]. This review identified that transitioning onto KRT was a period of high healthcare workload and the factors that impacted patient capacity, but was limited in its ability to understand the relationship between capacity and workload, the evolution of burden over time or the effect of the healthcare system. The aim of this study is to describe the interaction of healthcare workload, patient capacity and treatment burden during the process of transition onto KRT and how it evolves over time.

7.4 Methods

Ethical approval was granted by the Proportionate Review Sub-Committee of the North West Preston Research Ethics Committee, IRAS project ID 322865, REC reference 23/NW/0267. Written consent was obtained from all participants.

7.4.1 Study Design

7.4.1.1 Recruitment of participants

This study is a longitudinal qualitative study underpinned by framework analysis. The population of interest are adults over the age of 18 approaching the need to start KRT for

the first time in a single large health board area in Scotland. Participants were selected using a purposive stratified sampling approach; stratified by age, sex, starting modality, planned or unplanned start, and ethnicity. The aim of the sampling strategy was to capture a diverse range of experiences of KRT transition. Potential participants were identified from nephrology clinics, vascular access clinics, peritoneal dialysis (PD) clinics, transplant assessment clinics and inpatient admissions and approached in person. Inclusion and exclusion criteria are detailed in Table 7.1. Information power was used to guide our sample size[422]. Five factors were considered: study aim, sample specificity, use of theory, quality of dialogue, and analysis strategy. We also considered the risk of clinical deterioration or death of participants during the study period due to the nature of advanced kidney disease. The study has a narrow and focused aim, and although we needed to capture a range of modalities the population of interest was highly specific. The longitudinal design with rich, in depth interviews over time gave us confidence that the quality of the dialogue was likely to be high, and the framework approach grounded in previous work gave us confidence that the analysis strategy was likely to have a high yield. We therefore estimated a sample size between 25-40 followed up for up to 12 months would provide sufficient information power whilst remaining feasible, and we stopped recruiting at 30 participants.

Table 7.1: Inclusion and exclusion criteria for recruitment

Inclusion	Exclusion
Adults aged 18 or over	Children aged under 18
Capacity to consent	Already established on KRT (>1 month) prior to recruitment
Starting any modality of KRT for the first time with an anticipated start date within next 6 months	Anticipated recovery of kidney function e.g. KRT in ICU in context of critical illness
Sufficient English language skills to be able to understand consent process and participate in interviews without the aid of a translator	

7.4.1.2 Data collection

Semi-structured interviews lasting approximately 30-45 minutes were conducted either in person or online depending on the participant's preference. Participants were interviewed up to three times: once prior to the initiation of KRT (or peri-initiation in unplanned starts) to capture the burden of preparatory workload, once 6 weeks to 3 months after starting to capture the burden of transition, and once 6 to 12 month after initiation to capture evolution of burden over time. Separate semi-structured topic guides were developed for each of the three interviews, which were informed by NPT and TPC and developed with input from a patient-public engagement group and clinicians. Interviews were conducted between 1st January 2024- 30th June 2025. Interviews were recorded on an encrypted digital recorder and transcribed verbatim. Field notes were made after the interview. Transcripts were not returned to participants for comment, and there was no further participant checking. The majority of interviews were conducted solely with the researcher and the participant, but a minority elected to have a caregiver with them. Questions were directed at the participant but spontaneous contributions and clarifications from the caregiver were included for analysis.

7.4.1.3 Analysis

Data analysis was facilitated by Nvivo 14. The five stages of framework analysis (Familiarisation, Identifying a Thematic Framework, Indexing, Charting and Mapping) were adhered to[227]. Following familiarisation, line by line coding of all transcripts using a coding framework developed using NPT to describe workload domains and TPC to describe patient capacity domains was conducted by the first author, with regular coding clinics with the senior author to enhance the reliability of the coding. The initial coding framework was developed informed by a published NPT coding manual[108] and a prior systematic review [421] and applied deductively. Any concept falling outwith the NPT and TPC were coded separately, and specific separate codes were developed iteratively to characterise changes to workload, capacity and burden over time. There were no workload or capacity concepts that fell outwith the initial coding frame, but all transcripts had themes relating to the evolution of burden over time which were coded inductively. We charted the output from the first order coding and developed taxonomies of workload and of capacity. We subsequently applied the BoTT domains of mobilising capacity, expressing capacity, mobilizing for delegated tasks and enacting delegated tasks

to the coding framework along with an additional higher order theme that pertained to the evolution of burden over time. This higher order analysis of how workload and capacity interact in the context of a healthcare system and the evolution of treatment burden over time during KRT transition informed our five themes.

7.4.2 Research team and reflexivity

The primary researcher who conducted all the interviews (CJ) is a female General Surgery and Renal Transplant Registrar in their mid-thirties with prior qualitative research experience and training. She holds a MBChB and a MSc. At the time of conducting the research they were employed in a non-clinical role as a doctoral research fellow, but had worked clinically in the unit previously. They had no prior relationship with the participants, and participants were aware that this was research conducted as part of a PhD. They have no personal or family experience of KRT, so approached this study with a professional interest and substantial prior knowledge of the clinical side of KRT transition but less insight into the patient experience. Having a clinical background may have had both a positive and negative effect on the interviews and the analysis. Familiarity with kidney disease and its treatment could mean that patients felt at ease discussing complexities and nuances in their treatment journey confident that they would be understood. It could also aid with the analysis due to a prior deep understanding of the subject matter, and mean that the researcher is less likely to misunderstand or misinterpret the participants clinical course than a researcher without a relevant clinical background. However, it is possible that having a clinical background in KRT care could have negatively influenced the interviews and their analysis. Participants may have been more guarded in criticising the service or the staff. When analysing the data, it is possible that independent professional relationships with the clinicians involved and prior understanding of the strength and weaknesses of the KRT services from previously working in the unit may have sub-consciously coloured the interpretation of the data. Conscious efforts were made to centre the patient's voice and remain data driven at all points but it is inevitable that a clinical background and lack of lived experience influences the understanding of the data.

7.5 Results

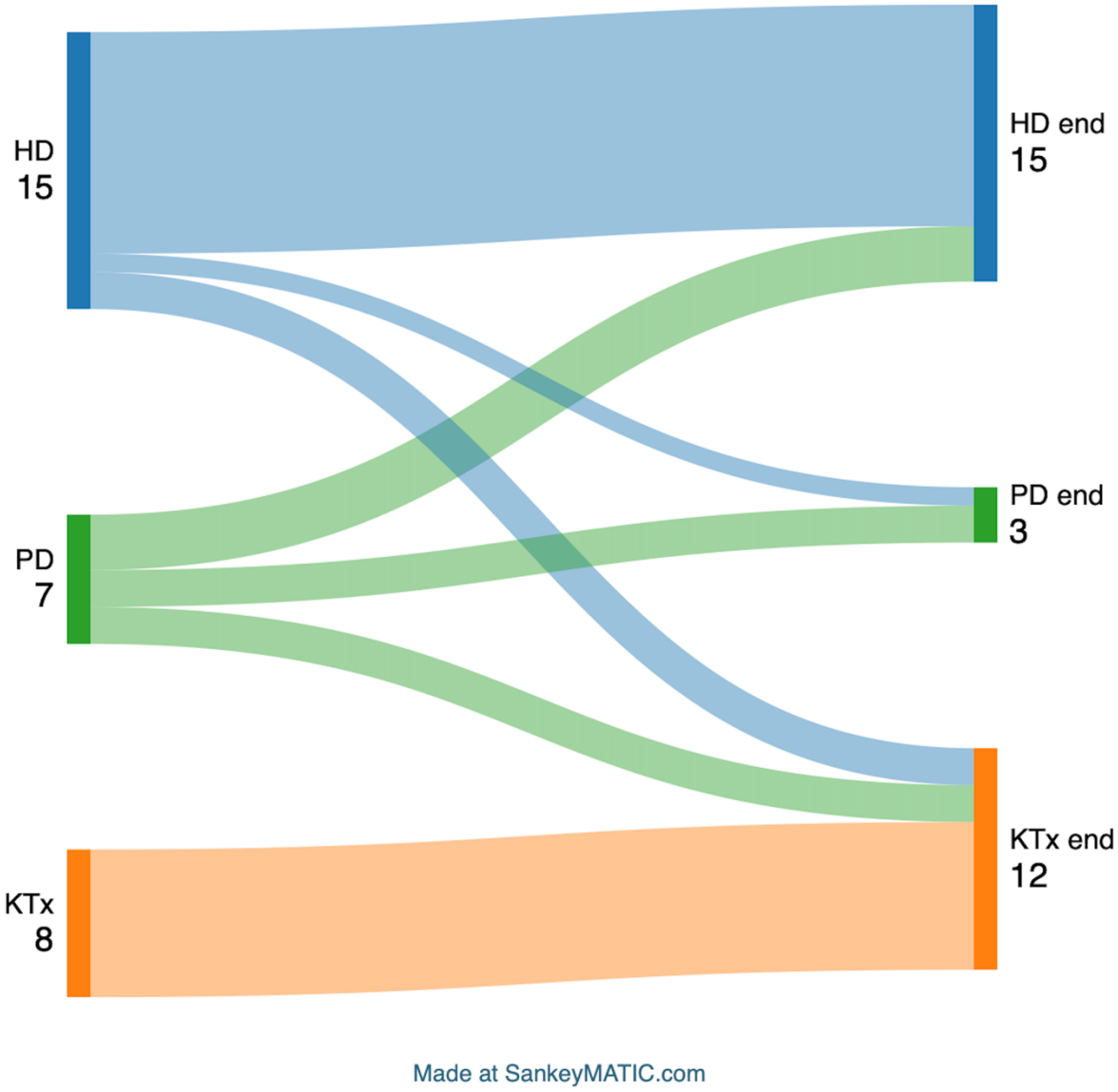
30 patients were recruited and completed the initial interview (Table 7.2), of which 26 completed a second interview (4 did not progress to start KRT within the study timescale), and 20 completed a third interview (2 died, 2 started KRT too late to reach 3rd interview timepoint within study period, 1 withdrew consent for participation and 1 was lost to follow up), giving a total of 76 interviews included in the analysis.

Table 7.2: Participant characteristics by starting modality

	HD(n=15)	PD (n=7)	KTx (n=8)
Sex			
Male	7	3	4
Female	8	4	4
Age			
18-44	5	3	0
45-64	5	1	4
65-74	4	2	4
75+	1	1	0
Modality change			
PD/HD to KTx	2	2	0
PD⇔HD/ HD⇔PD	1	3	0
Ethnicity			
White	13	6	8
Asian	2	1	0
Black	0	0	0
Other	0	0	0

Of the 30 patients recruited, 8 changed modalities (figure 7.1).

Figure 7.1: Sankey diagram of changes in modality participants experienced over study period from initial starting modality to KRT modality at 12 months



HD-haemodialysis; PD- Peritoneal dialysis; KTx- Kidney Transplant; KRT- Kidney Replacement Therapy

When looking at how treatment burden is experienced through a BoTT lens five main themes arose: four distinct theme (themes 1-4), and one cross-cutting (theme 5). Different elements of the taxonomy of workload and the taxonomy of capacity were mapped onto the BoTT themes as detailed in Table 7.3.

Table 7.3: Workload and Capacity taxonomy domains mapped on to Burden of Treatment themes.	
Workload taxonomy domain	**Capacity taxonomy domain**
Theme 1: Engaging personal and social resources to navigate KRT transition (*Mobilising Capacity)*	
Appropriateness of allocation of work	Biographical disruption
Effect of interaction with healthcare or governmental services	Biographical adaptation
Recruiting others	Literacy
Understanding what KRT means for their social network.	Medical and health system knowledge
	Physical health
	Psychological resilience
	Capacity building environments
	Negative experiences of the care environment
	Ability of social network to accept condition and effects
	Personal ability to fulfil social role
Theme 2: Being able to meet the challenges of KRT transition (*Expressing Capacity)*	
Recruiting others to help	Financial resources
	Literacy
	Medical and health system knowledge
	Access to paid support services
	Physical health
	Psychological resilience
	Self-efficacy
	Time
	Transport
	Ability of their social network to accept condition and effects

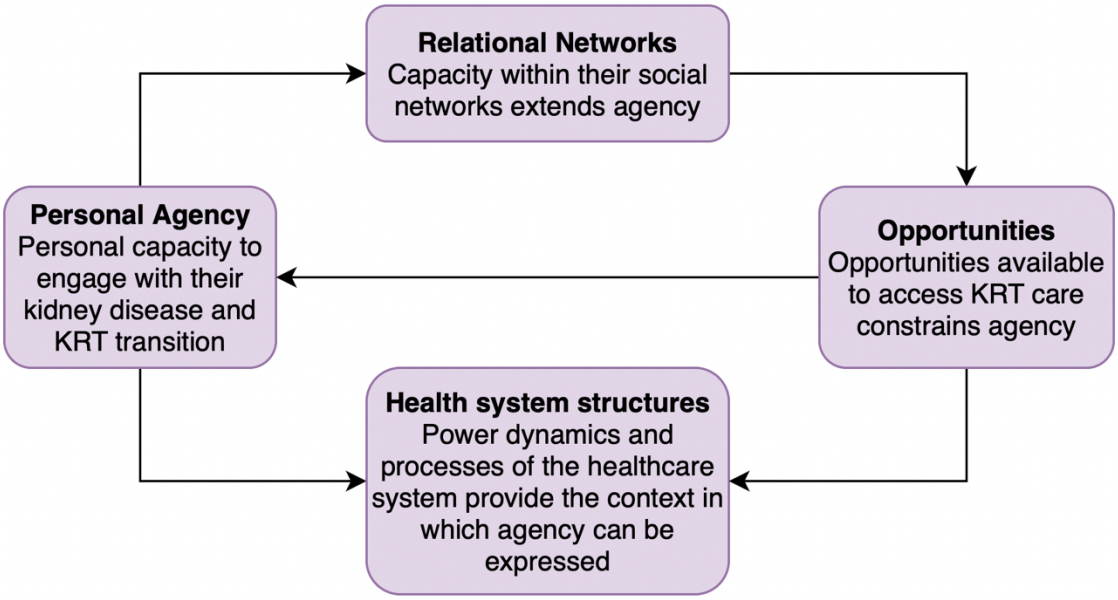
	Social relationship with their healthcare team
Theme 3: Preparing to meet the healthcare workload of KRT transition (*Mobilizing for delegated tasks)*	
Working out how and why life on KRT will be different	Experiences of the realisation of work
Understanding what KRT means for their social network	
Understanding what KRT will mean for them as an individual	
Finding value in KRT	
Driving forward work required to start KRT	
Recruiting others to help	
Deciding that their chosen modality of KRT is the right option for them	
Maintaining key interventions in daily life	
Monitoring the impact of KRT	
Evaluating effect of KRT on family/social network	
Reflecting on how they feel about KRT	
Theme 4: Undertaking KRT transition related work (*Enacting delegated tasks)*	
Doing the work required by KRT	Experiences of the realisation of work
Effect on relationships and the confidence people have in each other	Capacity building environments
Appropriateness of the allocation of work	Negative experiences of care
Effect of interaction with healthcare or governmental services on patients	Provision of instrumental support

7.5.1 Theme 1: Engaging personal and social resources to navigate KRT transition

The interaction between personal agency, capacity held within family and wider social networks, and the opportunities and constraints on access to care mediated by the

structures and provisions of the healthcare system had a profound impact on participants' experiences of navigating the process of transitioning onto KRT (figure 7.2).

Figure 7.2 Engaging personal and social resources to navigate KRT transition



Personal agency was heavily influenced by psychological and physical factors. All participants described sadness and apprehension at receiving the news that they would imminently require KRT, and all found the nature of the decisions they were required to make and the prospect of the healthcare work they would be required to undertake daunting.

The time between first diagnosis of kidney disease and the need to start KRT was an important influence on agency during this period. Some participants had known for many years that they were likely to require KRT and therefore had opportunity to prepare both psychologically and practically, maximising their potential agency. For some, their kidney disease progressed rapidly and they were required to make decisions regarding KRT urgently at a time where they were confronted with a life-changing diagnosis as well as a significant symptom burden constraining both their capacity and their opportunity to pursue certain avenues such as pre-emptive transplantation. Biographical disruption, which is the impact caused by the deviation from expectations of life caused by illness, had a profound impact on some participants, especially those that were younger or had developed advanced CKD unexpectedly.

> *It was completely out of left field, 'cause I was still very active, I surfed the weekend before I got diagnosed. Erm, it was a tough, tough pill to swallow even more so because everyone kept saying you don't fit the regular patient…[I was] very taken aback and obviously thrown my life into turmoil at this stage* PDM2

Relational networks, especially close family and friends, were an important source of support and therefore capacity for many participants. Relational networks act to extend individual agency, and a key part of enacting the complex work of KRT was building and maintaining relational networks that could be relied upon. However, the potential negative impact of their condition on their loved ones was an area of grave concern for many, as well as the changing relationship dynamics from care-giver to care-receiver and from provider to dependent. Live donor transplantation brought this to the fore, with a unique emotional workload processing what it means to have a loved one donate a kidney, and balancing their concern and love for them against their desire for a transplant.

> *The most difficult part of this illness… you don't want anybody to give you the kidney and you pray for somebody to offer you a kidney, at the same time. It's very difficult because your natural instincts are saying, do everything to save yourself, to save your life, to survive. And your heart, and emotions, and attachment to [potential live donors] because these are usually the closest family members or friends, the dearest people. So, you don't want them to suffer. Er, and at the same time, you put them in this position, and it's hard.* KTF2

The quality and accessibility of services influenced participants' ability to mobilise their capacity. Many described deriving great value from the input of specialist nurses as they prepared to transition onto KRT, with home visits and extended appointments enhancing their understanding of their condition and increasing their confidence in the system. Others described difficulty in getting information from clinicians and feeling disempowered and frightened in an indifferent system. Some described feeling like they needed to do extensive independent preparatory work prior to consultations to successfully self-advocate.

> *There's been times where I think, not through deliberate action... there's not been the communication or the explanation of things for me. And when I've asked, not everyone has been forthcoming with their answer. So, I've actually done an awful*

> *lot of reading myself. So, before it came to the choice of what my options were, I had read up on it, and I knew what my options were... So that, when I come into the doctor, I'm not saying to the doctor, what is this? I'm saying to the doctor, I know what this is, but what about that.* HDF3

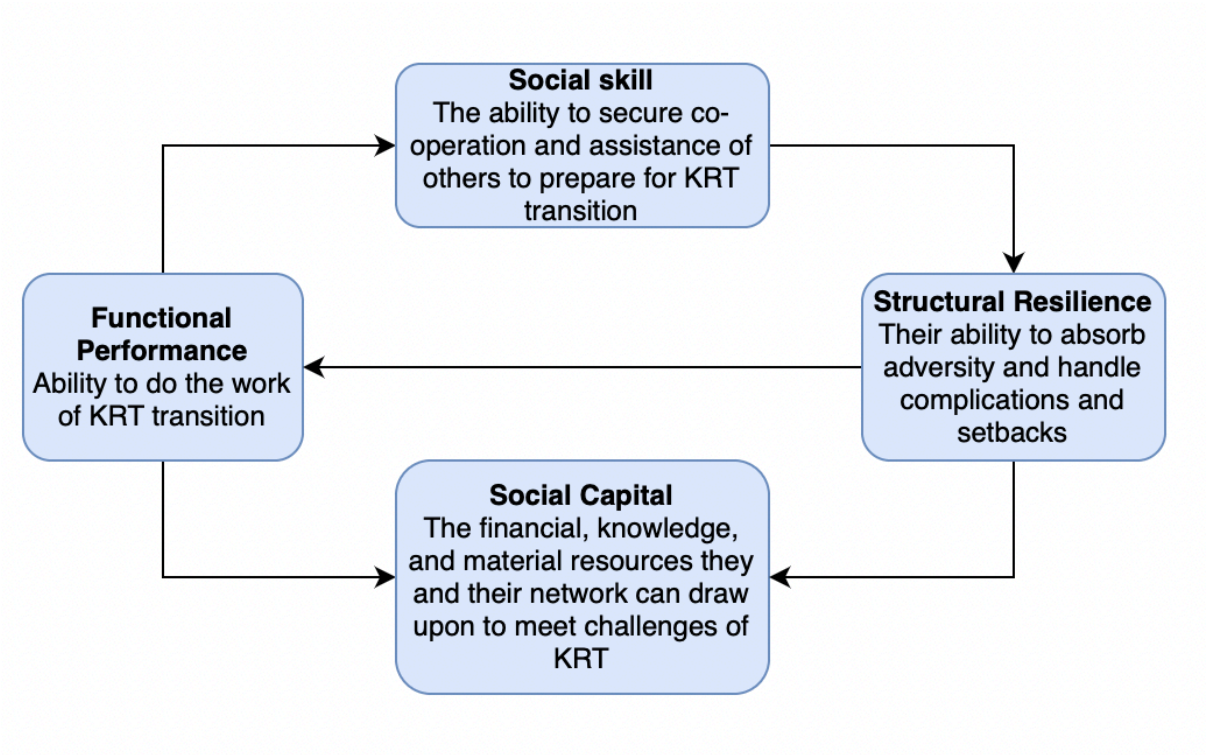
On the other hand, some described long-term holistic relationships with clinicians enhancing their agency, for example in supporting the emotional burden of accepting a living donation.

> *I was refusing a live donor…I wouldn't take a kidney from my son…I couldn't countenance putting him through it…you know naturally through evolution I'm there to protect him and he's not there to protect me. [The nephrologist] got me in contact with somebody who'd actually been through transplant, it just helped me to speak to someone who'd been through it. Who wasn't ashamed or embarrassed to say, look, I took something from my boy because it was going to help me live better.* KTM2

7.5.2 Theme 2: Being able to meet the challenges of KRT transition

Participants' ability to function in the different contexts that KRT transition work is undertaken, their social skills securing co-operation, and their ability to absorb adversity heavily influenced their ability to meet the challenges of KRT transition (figure 7.3).

Figure 7.3 Being able to meet the challenges of KRT transition



The financial, educational, cognitive, and psychological resources participants had to draw upon as well as their current health status and physical capabilities all contributed to their functional performance. Those with prior understanding of how the healthcare system worked and had prior medical knowledge were better equipped to navigate KRT transition. Financial concerns were a considerable source of burden especially for younger participants who were unable to work due to their illness, with the practical impact of a sudden loss of income compounded by the biographical disruption caused by the loss of career and social role. Personality was also important, with several participants crediting their psychological resilience for helping them cope with the impact of KRT transition.

A close-knit family network provided not only material assistance but comfort and a sense of purpose. Participants often described family and friends assisting materially with transport and activities of daily living such cooking and cleaning, and being sources of information and support. Those without a robust, mobilizable social network had noticeably weaker structural resilience, often highly vulnerable to single point failure. For example, those without family and friends that could be called upon were reliant on hospital transport and if that failed then they would miss important appointments despite considerable efforts on their part to attend.

> *Today, I was due to go to an access nurse interview. And, erm, somehow, there was a miscommunication, the person that came to pick me up couldn't take wheelchair patients. So, they had to cancel it, and get somebody to come over from somewhere else to pick me up, to bring me in for dialysis. But it meant I missed my appointment for the access clinic.* HDF3

Those who had recently migrated were particularly vulnerable, often describing social isolation on top of a lack of system's knowledge and additional work managing the concerns of, and for, their family back home.

> *Because of me, everybody worried. My parents in India worried…my mum is too much worried… it's very hard because they live there, I live here, so they can't come here. I can't go there because of my dialysis gonna start soon… From childhood my parents help me to grow… I too much depended on my parents. But when I came here I work, I try to become to stay alone and manage myself. But now again, I come to that point I need my parents.* HDM8

The mobilizability of a person's social network was a key determinant of the feasibility of pre-emptive live donor transplantation. Some described having multiple potential donors coming forward proactively, their donor using their health system knowledge and self-efficacy to drive forward the assessment process, and their wider social network rallying around to support the process. Others described not having anyone suitable for live donation, being unsure how to have the discussion, or difficulty navigating the assessment process especially in the context of international donation.

> *I spoke to my brothers, and they all decided that they would go forward for the test… I put it on the family group chat...I just said that I'm getting to the stage where I either need to get a kidney, or go on dialysis. They've mentioned about the living donor scheme. I said, now if any of yous are interested, let me know. Er, and three of them got back to me straightaway, and I gave them the details.* KTM4

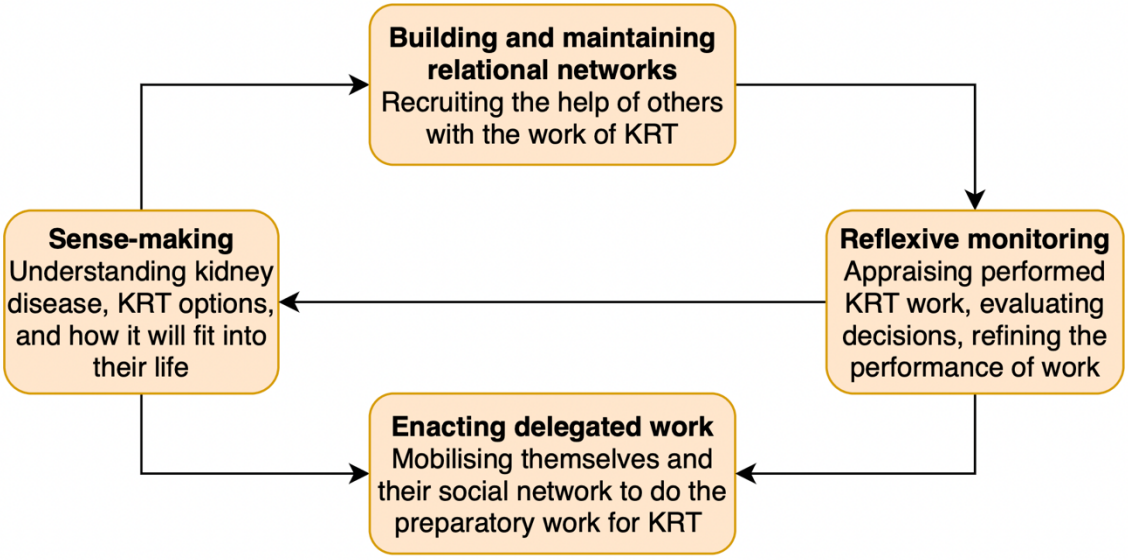
Healthcare staff formed part of the mobilizable social network. Having consistent long-term doctor-patient relationships especially with nephrology was highly valued by participants. System processes that did not facilitate continuity of care inhibited the recruitability of trusted clinicians into participants' network, inhibiting capacity.

Other people talk to you and they say about your renal team, but it's like I don't have a renal 'team'. When you go to clinics…its whatever doctor's ready comes out and gets your sheet and calls you in. And I find that frustrating. I suppose it's the way that the NHS works 'cause the GPs is the same, but it's like you feel they never really know your set up…I've seen one doctor twice but everyone else only ever once. So there's no connection. HDF7

7.5.3 Theme 3: Preparing to meet the healthcare workload of KRT transition

Preparing to meet the workload of KRT encompasses the work of sense-making, building and maintaining social networks that can help with this work, and constantly monitoring and adapting as their situation evolves over time (figure 7.4).

Figure 7.4 Preparing to meet the healthcare workload of KRT transition



Sense-making around KRT initiation focused on understanding what different KRT modalities mean in terms of the resources required to do the work, the opportunities available, and how these fit with their wishes and expectations of life. This was particularly prominent in decisions around home therapies (PD and home HD), where two main aspects determined participant's decisions. Firstly, practical and logistical considerations were considered: whether they had the necessary physical space, manual dexterity, and social support to undertake home dialysis. Secondly, psychological and emotional consideration predominated, especially considerations around undertaking medical work in their home. Some found the delegated responsibility and freedom

offered by home therapies liberating, and some found the concept intrusive and frightening, preferring the compartmentalisation and safety offered by in-centre dialysis.

> *The girls came out to the house to discuss potential types of dialysis, but when they talked about the other types I felt as a blind person they were not remotely practical…we felt very strongly that hospital was the right way to go… [I'm] desperately keen to get a transplant… so the plan is to get hospital haemodialysis until a transplant becomes available* HDM2

Deciding on the best KRT option for them depended on understanding how various options would fit into the context of their life and how things could develop over time, for example the likelihood of a future transplant. Some participants also put a great deal of importance on understanding what had superior outcomes.

> *We'll be doing home haemodialysis. So, at some point, I'll start the training to learn how to do that. [My wife] will get involved. They'll then come and set up a dialysis station at home for me, and then I can dialyse at home. Because my understanding is, is that long term, the outcome for people who dialyse at home is slightly better than people who come to hospital to dialyse. And then, obviously, I then wait for a suitable kidney to become available for a transplant.* HDM1

Evaluating and reconfiguring the work of KRT encompasses all the work of monitoring, identifying issues and finding solutions, refining their workload, and reflecting on their experiences. Patients who felt a significant benefit from KRT felt increasing confidence in their choices and their ability to do the work. Negative experiences could undermine confidence in their ability to manage their care. For example, participants who had been successfully performing PD at home but subsequently went on to develop complications reported lower confidence in their ability to undertake the work.

> *I think [PD peritonitis] might have [reduced my confidence] for a wee bit at the beginning, because I was trying to figure out how it had happened... It's made me wary of is every time I change the dressing…It made us worry that it was something that we'd done, that we hadn't been meticulous to our cleaning or washed our hands or we'd touched something.* PDF3

Several participants reported distress in the face of multiple setbacks and the realisation that life on KRT and the path to transplant can be uncertain and vulnerable to complications. Participants who had been transplanted had a much lower workload by their third interview, and a growing normalisation of their remaining workload into everyday life. But several had a persistent psychological burden. Reaching a point of greater stability often provided the opportunity to reflect on how difficult KRT transition had been. It also brought to the fore the reality of a new worse normal: that transplant offered a better quality of life than a life on dialysis but would never return them to life as it was before they developed advanced CKD. The burden of gratitude and the burden of the expectation to be a 'worthy' transplant recipient could be considerable: the perception of a societal expectation to be grateful of the 'gift' of transplantation even when they were still burdened by significant symptoms and grieving their lost life.

> *I was quite low for a while, it was consuming me, really… [the doctors] are really happy, and everything's going well with my kidney, which is amazing. But me, myself, still feel tired, and all my bones are sore, and there's things that are pulling me down…You know, I have had this lifeline thrown at me, and if I didn't have it, then the outcome could be completely different. And I think that's quite a sobering thought as well, you know, it's been a necessary life-saving procedure… but there are all these life changing things that are quite hard to process. I'm not back out doing what I did before, I've got limits… it's really, really difficult, because although I'm so grateful, and everybody is like, oh my goodness, what a gift your sister has given you and I'm going, 'I know, it's just incredible'. It's not really connecting with me, you know, that way, it's like, I'm, I'm saying it, I'm saying all the right things, but underneath it all I'm like, eugh.* KTF4

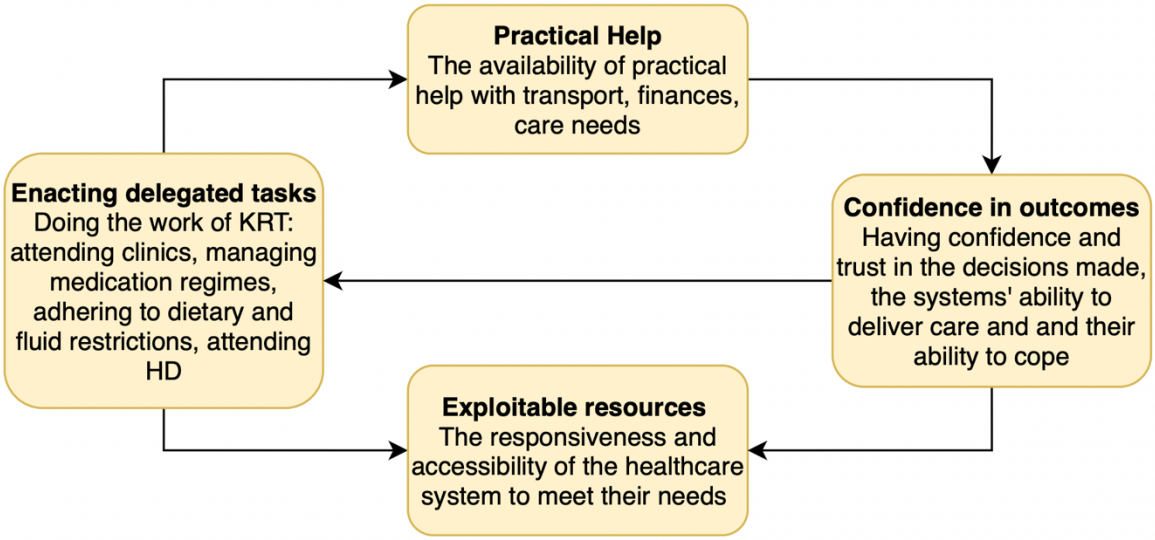
Participants who had undertaken the sense-making and mobilising work for a certain treatment option only to have to change to another were especially burdened. This was particularly marked in participants that perceived that this deviation from what they had worked towards was as a result of the system not working as it should. Feeling that the system had control over their lives but they had no control over the system was highly attritional to their perception of their own agency, undermined their relation with clinicians, and placed greater stress on their social network.

My dad's my living donor. I didn't want to do dialysis so I held on as long as I could. But then I think it got to a point that my body was too weak, that even if surgery was to go ahead in the next few days, that the doctors felt that I probably wouldn't make it through the surgery… they basically pulled the plug and said, enough is enough. I feel that dialysis has made me feel worse… I said in the beginning I didn't want it, and I was determined not to have it. Erm, and then I felt as though everything was just, kind of, dictated by the doctors. HDF8

7.5.4 Theme 4: Enacting KRT transition work

Implementing the work of KRT encompasses the experience of enacting the practical work of KRT such as implementing dietary changes; attending clinics, dialysis, and procedures; undertaking the work of home therapies; rehabilitating after transplant surgery; managing medication regimens; seeking care for deteriorations; and liaising with employers and the welfare system for necessary accommodations (figure 7.5).

Figure 7.5 Enacting KRT transition work



Participants described significant workload that encroached on every element of their lives. The fluid restriction on dialysis was often described as being particularly onerous, requiring constant vigilance and disruption to long embedded social routines.

The most important determinants of participants' experiences of implementing the work of KRT were the practical help and the local exploitable resources available to them,

especially the accessibility and responsiveness of the healthcare system. The interface between different components of the system were a particular area of disjointed care where considerable onus was placed on the patient to bridge gaps in provision and communication. Some patients described being asked to attend appointments that they had no means to travel to or arrange tests in the community that community services couldn't provide, sometimes resulting in serious harm. Participants also described experiencing discrepancies between the care that they expected and the care they received, with safety nets they had been assured existed failing to materialise.

> *When I phoned up and said, I'm really not very well, getting sent to my local GP for my bloods, I didn't think was particularly helpful, especially since the hospital knows I've got rotten veins…But they wanted me to go through the process of going to the GP, it not working, and then I could go back to the hospital. And that, that felt pretty rough…it's quite difficult as well, because when I've been in hospital before, various doctors have said to me, if you feel unwell for anything at all, phone up and come straight in, and we'll get you sorted. And the last two or three times where I've really been very unwell, I've phoned up, and they've not taken me in you know, they've asked me to do something else…each time, it's kind of, had to get to a crunch point before I've ended up in hospital. And I'm not sure that's always been necessary.* HDF3

Managing the supply of vital medications that were recommended in hospital, prescribed by general practice, and dispensed by community pharmacies was a constant battle for several participants. This was exacerbated by the increasing use of digital platforms that excluded those with lower levels of digital literacy and increased the complexity and inefficiency of ordering systems.

> *I don't understand [why it's so difficult to get medications] because they say that you can do it on the website by creating an NHS account, but we have an NHS account because we can see all the results on Patient Access. But for some reason, because we've created an account with the NHS through Patient Access, it doesn't allow us to use the email ordering system with our surgery so we have to phone it in. So we phone it in…and a week later we'll go, more often than not, the pharmacy hasn't received it, and we phone up the surgery and they say we never got your request. Luckily, my pharmacist knows me now … she'll give me an*

> *emergency script to keep me covered. But that shouldn't be happening. I think I'm gonna have to change my practice purely because they can't get my scripts right or get it out on time.* HDM1

The physical geography of healthcare provision was a source of burden for some patients, especially in the context of the hub and spoke transplant model where patients are required to travel to the central hospital for frequent follow up for the first 12 months post-transplant. Other services were also fragmented, and many participants described needing to attend different appointments at different hospitals, often encountering heavy traffic and difficulty parking. Most participants did not feel well enough to take public transport and the provision of hospital transport was unreliable and not universal, therefore arranging travel to appointments was a source of considerable burden.

The complexity, inflexibility and facelessness of the system could be highly burdensome to patients. Experiences of expending considerable energy mobilising themselves and their network to enact work only to be frustrated by an inflexible and unresponsive system were deleterious to patient capacity. Participants were entirely dependent on the system to provide them with life-saving KRT and therefore the control the system could enact over participants' lives and the effects that the limitation in opportunities could have upon them was considerable.

> *There's nothing I can do. There's certain things within my control and stuff that is outside my control so I accept it and carry on…It's a big machine with so many moving parts, very difficult to influence which way it goes...There's definitely parts of the process which could have been expedited and been illogical, it seems…Sometimes you feel like you're in the dark…it was impossible to get information on [transplant dates], we went round in circles for about a week. So it's an instance of being frustrated again and also the…the process itself just seems like it's out of antiquity, like it needs to be updated and realise that people are going through quite stressful times and trying to organise their life as well… it's really frustrating.* PDM2

7.5.5 Theme 5: Evolution of burden over time

When evaluating the evolution of burden over time in longitudinal interviews, the interaction between individual, social network, and healthcare system factors and the

progress and outcomes of the healthcare work undertaken heavily influenced ongoing burden (figure 7.6). We have further illustrated this with three clinical vignettes (Table 4). Relative stability was key to participants' ability to incorporate KRT into daily life and 'normalise' the work. Those who had normalised KRT workload and incorporated it into their routine were less burdened and had greater confidence in their ability to undertake healthcare workload, their social network's ability to support, and the healthcare system.

> *Ah it's just…pretty easy. I come off [the PD] in the morning and that's me. I don't need to do anything else with it until night time, and then what I do normally is I go up about half eight/nine o'clock at night and I'll set the machine up so it's just sitting ready just to press the button for the priming, so that's it sitting ready and then I go to my bed maybe half eleven/twelve, press the button and start draining it off and that's you, away you go, and then it's finished about half eight in the morning. In terms of socialising and, kind of, hobbies and stuff I'm still managing to play football. I've played for the last four weeks… I'm going to play golf this Saturday for the first time in a year.* PDM1

Those who experienced complications or needed to change modalities had difficulty normalising their work as it kept changing, therefore they had to restart sense-making and planning for a different modality as well as dealing with workload generated from the complication and the resulting decrease in capacity from worse physical health. This workload directly and indirectly increased burden, by both increasing the healthcare workload required and undermining confidence in their choices, the healthcare system and their ability to undertake healthcare work.

> *The PD was horrific. I didn't want dialysis, I didn't want it in my house that was hard for me, because this is your safe space… I felt that the, the hospital was coming in here and in my mind, it was making me sick, which is really silly, because I know I've been really sick. But I didn't allow myself to think I was…I don't really do hospitals very well. So that was hard, going in for the operation to get the wee tube put in. And then, I had, I had problems with it from day one, I was in excruciating pain and just horrendous side-effects with my bowel, it was awful. Then obviously, it didn't work. And it not working, et cetera, then getting the peritonitis, which was really terrifying… I was uncontrollably shaking, and in excruciating pain...Then getting the news that the transplant was a couple of*

> *weeks away which is incredible and I should be really, really happy and delighted…but I've just been through hell and here I am again, it was just all so much… What bothers me with that is, it, I feel it could have been avoided had the transplant gone ahead when it was all good to go… that whole episode wouldn't have happened.* KTF4

All participants described high workload and experiences of treatment burden but the severity and evolution of the burden differed between modalities. Kidney transplant patients often described higher sense-making and planning workload initially, especially the emotional work of coming to terms with accepting a transplant and managing the symptoms of advanced CKD, but a considerably lower burden compared to HD and PD patients when they were interviewed when they were living with a well-functioning transplant kidney. With PD and HD, workload differed depending on whether dialysis was their intended definitive KRT or whether it was a bridging KRT whilst they awaited transplantation. Patients who started on PD or HD and were subsequently transplanted all reported a reduction in their treatment burden, but the period before the transplant when simultaneously managing the workload of starting KRT on a dialysis modality and the workload of preparing for transplantation was especially burdensome. For HD patients the stability of their vascular access for dialysis had a significant impact on burden, with pre-emptive stable access highly protective. Vascular access complications could be a source of considerable burden. For PD patients, all reported a high initial workload learning how to perform PD and preparing their homes and family life to undertake the work. This workload reduced over time as PD became normalised into their daily routine. Once established on PD, treatment burden was primarily driven by experiences of complications such as PD peritonitis or PD inadequacy rather than by performing routine PD.

Table 7.4: Clinical Vignettes illustrating the evolution of burden over time			
Participant	Pre- KRT	Post initiation	Follow up at 6-12 months
KTF4	Preparing for pre-emptive live donor transplantation burdensome. Two main sources of burden: 1) Significant sense-making burden in both processing the implications of CKD, the need for transplantation, and the emotional workload of accepting a donation from a loved one. 2) Navigating the live donor process. Difficulty getting information about progress of work up necessitating multiple phone calls to self-advocate. Delays resulted in deteriorating physical health and an unsuccessful and unwanted	Treatment burden evolved away from sense-making and system navigation to dealing with practicalities of recovering from a major operation. Burden driven by: 1) Understanding and implementing new medication regime 2) Wound management 3) Co-ordinating transport for regular clinic attendances 4) Managing side-effects of medication 5) Physical recovery and rehabilitation 6) Understanding and adapting to immunosuppression: food hygiene and dietary considerations, avoiding crowded places, sun safety	Notably less burdened. Physical health much improved, medication side-effects largely resolved, and taking immunosuppressants normalised into daily life. Able to take on far more social roles, making plans for holidays, quality of life much higher. Remaining burden predominantly driven by biographical disruption: accepting that this is the 'new normal' and that physical health may never be good enough to return to full prior function (especially full time work). Burdened by emotional aspects of being a transplant recipient: feeling indebted, burden of gratitude, guilt for having

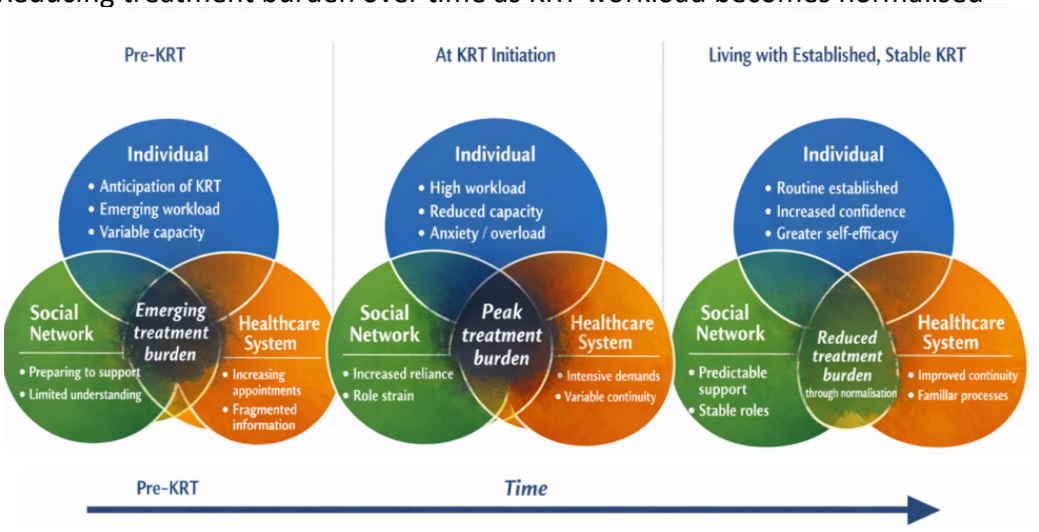
	attempt at initiating PD.		negative feelings about life when a loved one had donated to her.
PDM2	Rapid development of kidney disease: biographical disruption, sense-making work around future implications, huge unexpected disruption to professional and personal life. Decision to pursue PD as bridge to live donor transplantation: sense-making and co-ordinating work for PD initiation and starting LDTx process. Lots of information to seek out and process, but also hope that a fairly rapid live donor transplant will improve things soon. Self-directed research around nutrition optimisation. Intensive training to prepare to perform	Healthcare workload high in establishing PD routine in the home, but well supported and slowly gaining confidence. Unforeseen work such as managing storage of supplies and waste disposal of PD consumables requiring troubleshooting and refining routine. Considerable emotional and practical workload navigating LDTx process, with growing frustration and mistrust of the integrity of system processes. Financial and professional implications of extended period unable to work starting to become more pressing.	PD failure resulting in unplanned start on HD and hospitalisation. LDTx process protracted with several potential transplants falling through for a combination of recipient, donor, and system factors. Very frustrated and burdened by failure to progress to LDTx despite being highly proactive. Biographical disruption exacerbated by delays to transplantation. Further loss of autonomy with move to ICHD. System factors major exacerbator of burden, especially poor communication and poor processes. Feels very disempowered. New sense-making work with HD, new vascular access

	PD independently empowering and not overwhelming: able to do something to help himself.		decision making and care, new stricter fluid and dietary restrictions. Capacity to undertake this notably diminished from earlier: having previously applied considerable effort and resources to facilitate PD and KTx which had so far proven unsuccessful confidence in self and system diminished.
HDM4	Decline in kidney function slow then fast, therefore although kidney disease longstanding KRT start somewhat unexpected. Critically ill at KRT start therefore physical and cognitive resources limited. Biographical work in understanding and accepting that he has a life threatening illness. Sense-making work relatively limited: too unwell to either have	Physical symptoms much improved from acute crisis that required hospitalisation and start on dialysis, but learning to manage new symptoms such as fatigue and itch that fluctuate with dialysis timetable. Now feels well enough to engage with sense-making around dietary and fluid restrictions. Co-ordinating family help with activities of daily living such as shopping and cleaning.	Settled in his dialysis unit, with weekly routine established. Developed relationships with staff members and other regular patients- now part of social network. Perfected dialysis set up: with preferred snacks, entertainment downloaded on his tablet, chair set up, vascular access care, transport all optimised. Making plans for a holiday abroad with dialysis visits.

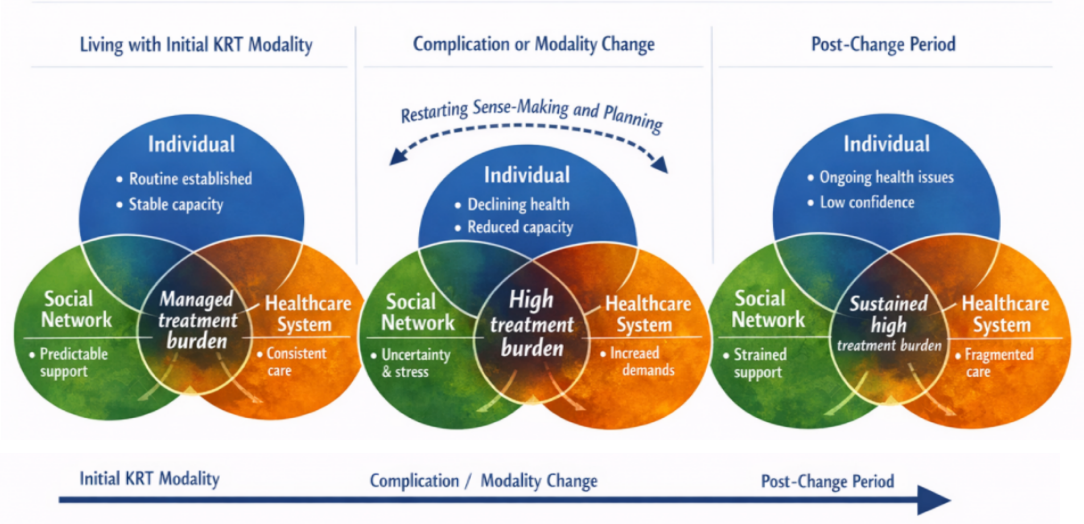
	many options or to engage with nuances of decision making process. Keen to follow medical team advice and to delegate responsibility for decision making.	Dialysis start initially in hospital but finally settled into regular dialysis slot at preferred dialysis centre.	

Figure 7.6: Variations in the evolution of treatment burden during KRT

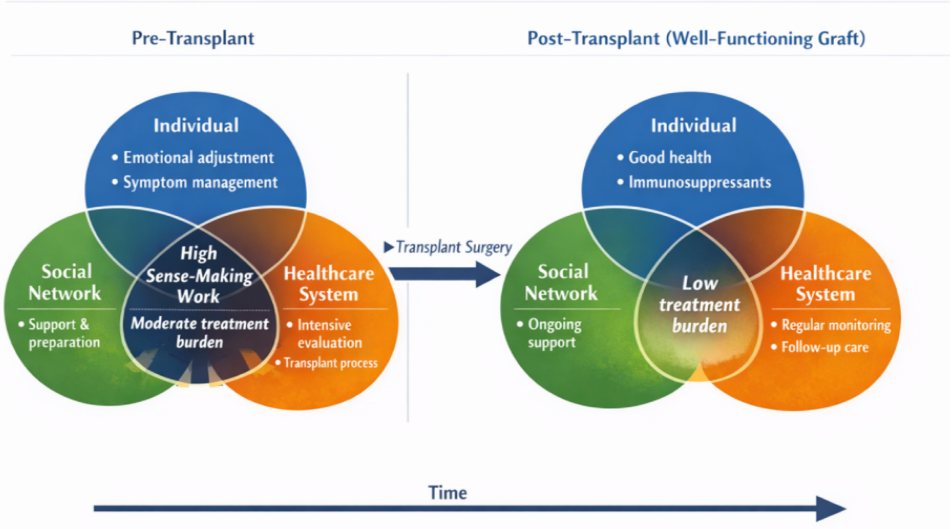
a) Reducing treatment burden over time as KRT workload becomes normalised



b) Increasing and sustained treatment burden in the context of complications or modality change



c) Reducing treatment burden in context of successful transplantation



7.6 Discussion

7.6.1 Summary of findings

In this work we have explored how treatment burdens are experienced through engaging personal and social resources to navigate KRT transition, creating the ability to meet the challenges of transition, preparing to enact the healthcare workload and undertaking KRT transition related workload, and how this evolves over time. This provides a comprehensive and novel understanding of treatment burden during KRT transition.

The study of the evolution of burden over time in this work is novel and has not been explored in other work. We identified three main treatment burden patterns over time (figure 6). Firstly, the general trend is for healthcare workload and treatment burden to increase rapidly during the period immediately preceding KRT initiation, peak at the time of initiation, and subsequently reduce as the workload becomes normalised and the burden subsides. The nature of the workload also evolves, transitioning from initially sense-making and preparatory co-ordinating work before starting, to more task based enacting and co-ordinating work at the time of initiation, and eventually to more refining and reflexive work when established on KRT. Secondly, for some patients, treatment burden remains high and they do not experience the transition to greater stability and lower burden. This is predominantly driven by instability through complications, modality changes, and poor systemic processes. This instability means that participants could not progress to the refining and reflecting stage as they were perpetually required to understand and make decisions about new treatment avenues and co-ordinate their social network to enact new tasks in response to events, leading to sustained high burden. Thirdly, successful transplantation can have a transformative effect on burden, with a much lower healthcare workload and increased capacity due to improved physical health.

A key finding in our study is the importance of the accessibility and responsiveness of healthcare systems. In our study three key areas emerged where poor system functioning increased treatment burden: lack of continuity of care within renal services, poor interface between different system components, and divergence between expectations of care and lived experiences. Participants' relational network was key to enhancing capacity in our study, with friends and family providing support and assistance at all stages of the transition journey. What is also clear in our study is that starting KRT has a

profound impact on families, with a large amount of new work required of a participants' loved ones without much support to help them adapt.

7.6.2 How it fits with other work

Other work supports the finding that kidney failure simultaneously reduces physical and cognitive capacity whilst increasing workload leaving patients highly vulnerable to becoming overburdened, and that a patient's social network is a vital enhancer of agency resulting in patients with a weak network being vulnerable to harm[145,146,148].

Studies of the impact of biographical disruption on experiences of kidney disease align with our findings that the impact of the loss of role, physical abilities, expectations of life and social functioning can be profound and impair a patient's capacity to engage in healthcare workload[96,147]. Studies of the impact of KRT transition on families found that family members of KRT patients reported negative experiences in becoming a carer for the patient, dealing with adverse psychological responses including sadness and anxiety, burden from treatment delivery and logistics, and burden from dealing with increased symptoms in the patient[423,424].

Health system issue including continuity of care and frequency of healthcare encounters have been identified in other work as the most important source of treatment burden in advanced CKD[393]. The concept of minimally disruptive medicine recognises that a substantial burden is modifiable and results from how healthcare is organised and delivered, and that non-compliance should be understood not as poor patient behaviour but as a symptom of poor system delivery[4,420,425–427].

There is a large body of evidence that health related quality of life improves after transplantation[428,429]. Health related quality of life is different to treatment burden in that it mostly captures the effect of illness rather than the effect of treatment, however there is considerable overlap between improving symptomatology and the physical, cognitive and psychological health domains of patient capacity and possible reduction in health related workload.

Little work has been done studying patient capacity in the context of advanced CKD but studies of patient activation, defined as a patient's knowledge, skill and ability to manage their own health, in advanced CKD have shown that patients with higher levels of

activation were more able to engage with shared decision making and adhere to treatment [179,430], and lower activation is associated with worse health related quality of life[177]. There is some evidence that interventions aimed at improving patient activation can improve self-management and self-efficacy in advanced CKD[431]. Patient activation is a narrower, more individualistic concept than capacity but there is significant overlap between the two concepts and it would be reasonable to assume that activation is a proxy for some domains of capacity.

7.6.3 Implications for clinical practice, policy and further research

Our findings suggest that improving the access to transplantation for those who are potentially eligible may represent the most potent intervention to reduce burden at the level of the individual. This adds to the body of evidence that kidney transplantation is associated with both an improvement in quality of life from pre-transplant and a superior quality of life to HD or PD, and that seeking to achieve early transplantation offers the best outcomes for suitable patients[208,428,429]. There are significant systemic limitations to this as there is a national shortage of deceased donor organs and not all patients have potential live donors[432]. Improving both rates of transplantation and access to pre-emptive transplant would require local and national work. On a national level, efforts to increase donor organ availability and utilisation could increase the availability of decreased donor transplant and reduce the waiting time. On a local level, improving accessibility to transplant assessment could improve access to transplant especially in driving forward the requisite investigations to facilitate listing. Prioritising timely pre-emptive vascular access and focusing on improving procedure selection could also significantly reduce the workload experienced by patients. This is wholly compatible with the Kidney Disease Outcomes Quality Initiative (KDOQI) 'right patient, right procedure, right time' approach to dialysis vascular access[43].

Whilst treatment burden is multifactorial and influenced by many factors relating to the patient, their social network, and the healthcare system, understanding the impact of health system function on burden is important as it is a potentially modifiable factor that clinicians and policy makers can directly impact, whereas other factors that are the product of the wider socioeconomic functioning of society are more intractable. KRT involves a significant disruption in patients' lives, however prioritising innovations that facilitate better continuity of care with key clinicians and the fostering of lasting doctor-

patient relationships; ensuring seamless communication between different components of the system; and building capacity that would facilitate the system to be flexible around the needs of the patient rather than requiring the patient to be flexible around the needs of the system could significantly reduce burden.

It has been hypothesised that capacity could be assessed and coached by clinicians by using a structured discussion aid to explore the different domains of capacity and identify areas that could be improved[433,434]. Whether a KRT specific capacity discussion aid could help clinicians to identify areas of low capacity and tailor interventions to help is a potential avenue of further research. Interventions could be developed to bolster KRT patients' peer-to-peer network with other KRT patients, with formal peer-to-peer support groups found to improve patient engagement with care, treatment adherence, and self-efficacy in patients with kidney failure [435]. Interventions could also be developed that improve the support offered to care-givers and the wider relational network and could therefore reduce the treatment burden experienced by patients by enhancing the capacity of their social network.

7.6.4 Limitations

Our study had several limitations. Firstly, it is a single centre study conducted in the West of Scotland which limits its transferability to other cultural contexts. We were unable to offer translation services due to financial constraints and therefore were only able to recruit those whose English was sufficient to conduct interviews without support. This is a significant limitation as it does not capture the treatment burden generated by navigating a healthcare service with limited proficiency in the dominant local language. Language barriers could represent a major direct and indirect source of treatment burden, and this has not been addressed by this work. The ethnic diversity in the study population (90% White, 10% Asian) is representative of the ethnic diversity of the wider patient population served by the unit, but is not representative of the ethnic diversity of the renal population in the UK more widely which again limits the transferability of the study.

The heterogeneity of the study population represents both a strength and a weakness. The study population represents different modalities and 8 out of 30 participants experience a modality change. This could be seen as a strength as it reflects the real life experiences of KRT transition: patients rarely fit into neat fixed categories but experience

complications, delays, successful transplantations, and many other changes to their clinical and life circumstance and this range of experiences are reflected in the data. However, the heterogeneity of the population has meant that some subgroups are small and therefore caution should be exercised in drawing too definitive a conclusion from the findings . There was some loss to follow up, with only 20 of the 30 participants completing all three interviews and 4 only undertaking one. The most common reason for incomplete follow-up was slower than expected progression of CKD in those who's intended first KRT modality was HD, resulting in either not starting KRT at all or starting with insufficient time for the third interview to be completed within the study period. Failing to fully capture the experiences of those with a more indolent illness course may mean that especially in our HD population we have disproportionately captured the experiences of those who have had a more rapid progression of their illness and quicker starts, and therefore different experiences of burden.

7.7 Conclusion

Transition onto KRT is a time of profound change, with a rapid and substantial increase in healthcare workload at a time when their capacity to do the work can be severely reduced. Most patients experience high levels of treatment burden. This paper provides a detailed and novel exploration of the drivers of treatment burden during KRT transition and how it evolves over time. A key finding is that healthcare system processes are a prominent contributor to the experience of burden, and represent a potentially modifiable driver of treatment burden in this population. Developing treatment burden informed care for KRT transition could represent a potent way to reduce the burden experienced by patients. Secondly, for eligible patients, successful kidney transplantation represents the treatment pathway that offers the lowest workload and burden, and interventions that improve access to transplantation are key to reducing treatment burden.

Chapter 8 Discussion

8.1 Introduction

8.1.1 Aims

This chapter has four key aims. Firstly, to integrate findings from the systematic review, cohort study, and longitudinal qualitative study to conceptually model treatment burden during KRT transition. Secondly, to generate hypotheses about ways that the healthcare system and wider health policy and practices could be changed to lessen treatment burden during KRT transition. Thirdly, to discuss the strengths and limitations of this thesis. Fourthly, to discuss how the findings align with current knowledge and to suggest future research requirements.

8.1.2 Rationale

This thesis aimed to explore the relationship between healthcare workload, patient capacity, and treatment burden during transition onto KRT. The four core objectives were:

1. To systematically review the published literature to create a taxonomy of healthcare workload and a taxonomy of patient capacity during KRT Transition.
2. To describe patterns in treatment related workload during the six months before and the first three years following initiation of KRT, and explore the association between different demographic and clinical characteristics and workload.
3. To explore patients' experiences of treatment burden and workload-capacity imbalance during the year of KRT transition and describe how they evolve over time.
4. To conceptually model treatment burden in KRT transition and identify possible areas for intervention.

The first three objectives have been fulfilled in previous chapters, which provide a rich description and exploration of the patient experience of workload, capacity, and treatment burden during transition onto KRT. In Chapter 5, through a systematic review of the literature two taxonomies were developed: a taxonomy of workload associated with KRT transition (Table 5.4) and a taxonomy of patient capacity during KRT transition (Table 5.5).

Four broad categories of workload were described: making sense of KRT; working out what to do, and how to do it; working with their social network and the healthcare system to meet the challenges of KRT; and reflecting on and evaluating the work done. There were many examples of the influence of patient capacity on experiences of KRT transition across the five domains of Biography, Resources, Environment, Realisation of work, and Social functioning.

In Chapter 6, in a retrospective cohort study of healthcare workload during KRT transition we found that there was considerable variation in healthcare workload across different KRT modalities and that workload patterns changed over time. Workload for all was highest at the point of KRT initiation, and subsequently the workload settled to a lower baseline average. Healthcare workload was highest for those on HD, and markedly lower for those who were pre-emptively transplanted especially when more than six months post initiation of KRT. Increased workload was associated with several clinical and demographic factors such as female sex, polypharmacy of greater than 15 medications, late referral, older age, modality change, and failed transplant.

In Chapter 7, through a longitudinal qualitative study, five themes that described the processes through which treatment burden was experienced by participants during KRT transition were delineated: engaging personal and social resources to navigate KRT transition; being able to meet the challenges of KRT transition; preparing to meet the healthcare workload of KRT transition; enacting KRT transition work; and evolution of burden over time. Key findings showed that poor system functioning increased treatment burden especially in the context of lack of continuity of care within renal services, poor interface between different system components, and divergence between expectations of care and lived experience. A novel aspect of the work in this chapter was a qualitative examination of the evolution of treatment burden over time. There was a rapid increase in perceived burden leading up to KRT initiation which peaked at the point of KRT commencement, with most subsequently reporting reducing burden as KRT became a more normalised part of everyday life. Some participants reported high levels of ongoing burden due to complications, modality changes, and poor systemic processes. Transplantation was found to considerably reduce perceived burden.

In this chapter two conceptual models of treatment burden during KRT transition are described: one conceptualising how healthcare workload, patient capacity, and healthcare

system processes interact to generate treatment burden, and one conceptualising how treatment burden evolves over time. These models were created by careful examination of the findings of Chapters 5-7 to describe key mechanisms for the generation of treatment burden over time during the KRT transition process, and the relationship between these mechanisms. The development of the models followed a process of theoretical triangulation and narrative integration. Findings from all three studies were compared iteratively to identify areas of convergence, complementarity, and divergence. Methodology is described in detail in Chapter 4. The models are presented below, along with discussion of potential areas of intervention that could lessen treatment burden in KRT transition and placing these recommendations in the context of previous research. This includes a discussion about changes to the structures and processes of healthcare delivery to minimise treatment burden during KRT transition, potential strategies for supporting caregivers, enhancing the social network, and maximising access to kidney transplantation. Subsequently the strengths and limitations of the thesis are discussed and potential future avenues for research are suggested.

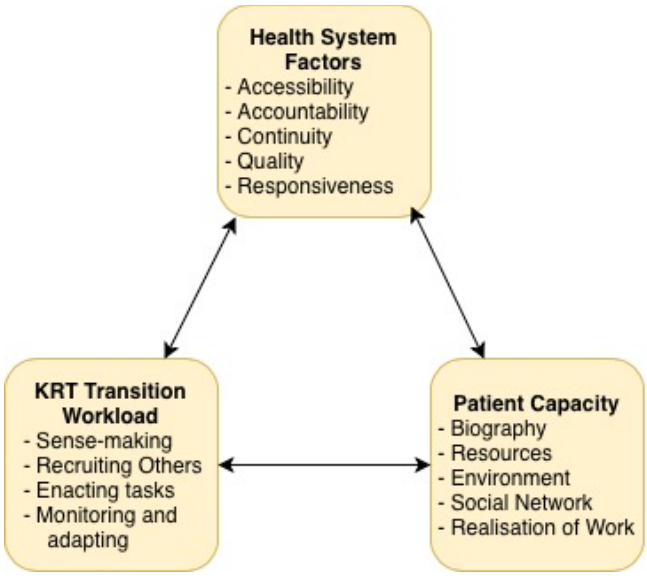
8.2 Conceptual Model of Treatment Burden During KRT Transition

In keeping with previous research on treatment burden in other long-term conditions, the results from Chapters 5-7 showed that treatment burden during KRT transition is the product of the interaction between healthcare workload, patient capacity, and the healthcare system and wider social context within which the healthcare work is enacted[394]. Examination of the taxonomies of workload and capacity described in Chapter 5, the quantitative description of workload patterns over the KRT transition period in Chapter 6, and the exploration of treatment burden over time offered in Chapter 7 have identified several mechanisms and processes through which treatment burden is propagated which are described below.

Treatment burden in KRT transition arises through interaction between healthcare workload, patient capacity, and the system (Figure 8.1). Workload that exceeds the patient's capacity to meet it or workload that is unsupported or inadequately supported by the healthcare system manifests itself as treatment burden. As KRT transition is a complex process that unfolds over time, the resulting treatment burdens are also complex and dynamic, and interact with each other. For example, patients that start the process

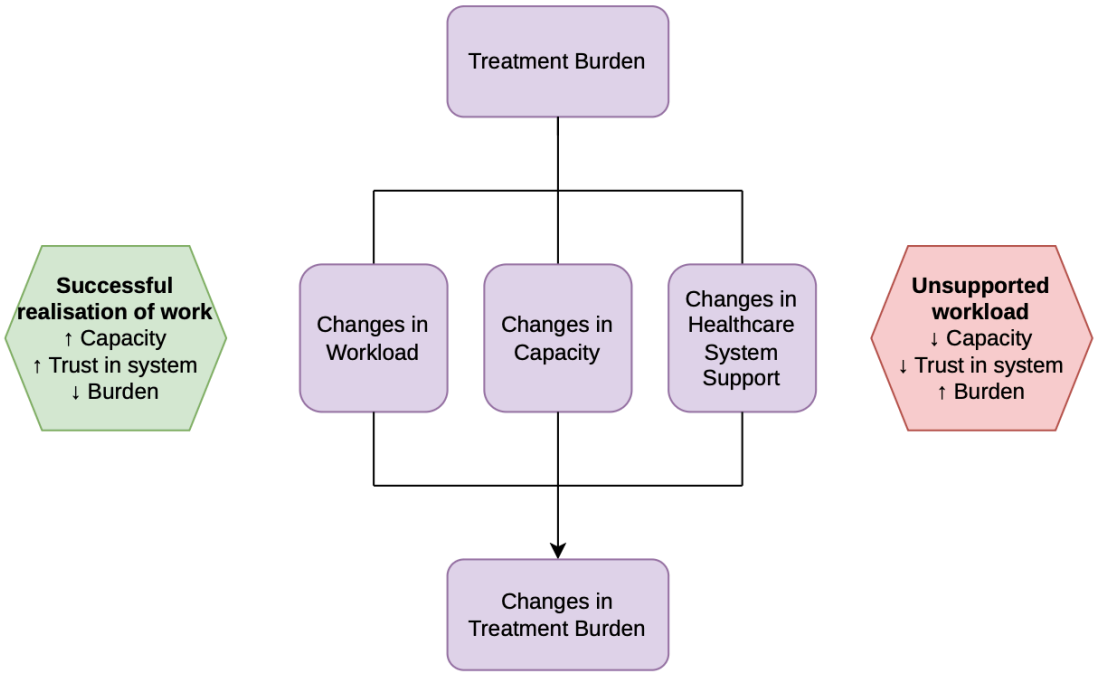
well informed and have confidence in their decisions as they initiate KRT may have increasing confidence in their ability to undertake the work and find treatment less burdensome over time. On the other hand, some patients get increasingly burdened as their workload becomes unsustainable and their capacity to meet it is diminished. For example, a patient who started KRT on PD as a bridge to transplantation might develop PD peritonitis and require an unplanned change to in-centre HD. This requires a great deal of new sense-making work on top of all the new healthcare tasks to enact whilst having diminished capacity because of the symptoms of the complication, biographical disruption due to loss of freedom and autonomy, as well as potential financial consequences due to loss of employment. This can be compounded by a loss of confidence in their ability to realise work, as well as a loss of confidence in clinicians and the healthcare system resulting from the complication. Especially when considering the concurrent additional ongoing workload of preparing for a transplant, these patients can become considerably overburdened.

Figure 8.1: Conceptual model of the interaction between workload, patient capacity and the healthcare system in the generation of treatment burden during KRT transition



The structures, resources, and processes of the healthcare system have a significant influence on treatment burden and can both relieve and exacerbate the burden experienced by patients. The relationship between these factors over time on the experience of treatment burden is demonstrated in the conceptual model below (Figure 8.2). This model has been used to identify areas that are potential targets for interventions to reduce treatment burden, which is discussed below.

Figure 8.2 Conceptual model of the evolution of treatment burden over time during KRT transition



8.3 Areas for intervention to reduce treatment burden in KRT transition

This thesis has explored the complex relationship between the person, their lifeworld, the healthcare system, and the treatment burden experienced during KRT transition. Kidney failure and facing the need for KRT is inherently difficult. It is important to recognise that a person with the highest degree of capacity across all domains accessing care in a perfect healthcare system would still encounter a life-altering volume of healthcare workload that could be difficult, intrusive, time-consuming, and potentially burdensome whilst transitioning onto KRT. However, as demonstrated in this thesis there is considerable variation in the nature, volume, and extent of burdens experienced during KRT transition. Some of these burdens are difficult to change, but many are amenable to be ameliorated

if not eliminated. This could involve making changes at any level from governmental whole system policy to small changes in individual consultations.

Four broad areas for intervention for reducing treatment burden during KRT transition are proposed in this thesis: improving healthcare system processes, supporting caregivers, enhancing the social network, and improving access to transplantation.

There is a clear thread throughout the work presented in this thesis that the functioning of the healthcare system is a key influence on the experience of KRT-specific treatment burden. There is also clear evidence that burdens are not experienced in isolation but interact with one another and are influenced by each other over time. Therefore, although the healthcare system is by no means the only driver of treatment burden in KRT transition and there are likely to be many other notable contributors to treatment burden outwith the healthcare system, intervention within healthcare delivery could be a potent and fruitful avenue to reduce treatment burden during KRT transition as it is the area that clinicians and policy makers have the greatest ability to directly influence. It is also possible that as different burdens interact with one another, by addressing the burdens that are most directly influenced by healthcare system structure and function one could indirectly influence the burdens that are caused by factors that are not directly under the influence of the healthcare system. For example, having continuity of care and a meaningful trusting relationship with key clinicians and accessible and responsive care might mean that a patient opts for PD where they otherwise would have opted for in-centre HD which is less disruptive to their daily life, which in turn might allow them to continue in full time employment which eases the financial burdens placed upon them and their family and might reduce the biographical disruption encountered, which over time might contribute to lower levels of burden and greater structural resilience to meet whatever challenge might arise.

8.3.1 Potential interventions for the healthcare system

How healthcare is structured and delivered during KRT transition had a profound impact on the burden experienced. Key aspects of healthcare system delivery that modify the experience of treatment burden in KRT transition are outlined below.

8.3.1.1 Continuity of care

A key finding in our study is that the relationships that patients build with clinicians, especially with nephrologists and specialist nurses, have a profound impact on experiences of treatment burden. Trusted clinicians can be recruited into a patient's mobilizable social network and enhance their capacity. They can be a source of reliable information, and they can support, and advocate and navigate on behalf of the patient within the system. This is especially important for patients with a weaker social network. This was a common finding in both the systematic review and the longitudinal qualitative study which identified patient-clinician relationship as an important modifier of burden and found that having a positive trusting relationship with healthcare staff was protective.

It was clear that when patients described continuity of care, they did not necessarily expect to see the exact same person every time but valued seeing the same small team and having consistency in how things were approached. There were some contexts where continuity of care was already achieved. The Home HD and PD teams are small, and these patients would see the same dedicated team of nephrologists and specialist nurses who would train them up intensively to perform home therapies and support them on an ongoing basis. Once in-centre HD patients were established in a regular dialysis slot they would often get to know the dialysis nurses that worked those shifts well, and they would often be their first port of call with any issues and concerns and provide considerable assistance: they would become part of the patients' mobilizable social network that enhanced their capacity to navigate the system. This was especially notable in the smaller units, but was reported in the larger units as well. Pre-KRT patients who attended satellite nephrology clinics in the smaller outlying hospitals would often describe seeing the same nephrologists and developing a meaningful and capacity-enhancing patient-clinician relationship with them. Continuity was also valued with ancillary and auxiliary staff such as clinic receptionists and healthcare assistants, with participants especially in the smaller units describing feeling familiar and supported in their local unit. The patients who were served by the much larger central hospitals had a more variable and often more impersonal experience, with some raising concerns that they didn't have any real continuity with their nephrology team. Transplant services had little continuity either before or after transplant. Typically, in the pre-transplant period patients remain under the care of their base nephrology team and receive their regular care either in the low

clearance clinic if pre-KRT, or through their HD or PD unit. Transplant surgeons see patients in the Transplant Assessment clinic to consider transplant listing. Transplant Co-ordinators, who are Specialist Nurses expert in transplant care, co-ordinate the process from referral to transplantation. Different Transplant Co-ordinators co-ordinate the living donor and the deceased donor pathways, and within the living donor pathway the donor and the recipient are cared for by separate teams in order to protect the rights and needs of the donor. Participants described varying experiences with the pre-transplant process. If the transplant work-up process went smoothly and they had good continuity with their base nephrologist then the lack of continuity from transplant was not described as burdensome. However if the pre-transplant process had any complications or hold ups, especially in the context of living donor work-up, then the lack of clear continuity within transplant care was described as burdensome. Typically, post-transplant patients are followed up for 12 months in the centralised acute transplant clinic which is staffed by a wide range of nephrology and transplant surgery consultants and registrars, and therefore continuity was rare. Most participants didn't find the lack of continuity problematic immediately post-transplant as they were seen so often, however several expressed a strong preference for transferring their care as early as possible back to their base units especially if they were progressing well and had significant commutes to the central hospital.

Three targets for intervention to improve continuity of care are proposed: continuity of location, continuity of main nephrologist, and greater resourcing of the live donor transplant co-ordinator role.

Continuity of location means that systems processes should be structured to deliver as much care as possible in the patient's closest hospital. There are some services such as in-patient acute transplant care that must be delivered in a centralised tertiary location, but this is not true for many services. The recognition that travelling out of area to unfamiliar sites is not a cost-free request for patients and their families should be centred in service design considerations. The question should be asked of all tertiary services if it is necessary that they are delivered centrally or if alternative models such as outreach clinics or expanded capacity in secondary care nephrology services would be feasible. For KRT transition care, this could mean developing an outreach model for transplant assessment clinics or vascular access and expanding capacity in secondary care

nephrology to facilitate post-transplant patients to be transferred back to their base unit significantly earlier than 12 months. There is significant evidence for the negative effects of long travel times on experiences and outcomes in KRT. Travel time to dialysis has been identified as an independent predictor of poorer HRQoL and higher mortality[436,437]. Living further away from transplant centres is associated with reduced access to transplant listing[438], deceased donor transplant and increased risk of post-transplant death[439]. A qualitative study of rural and remote kidney transplant recipients in Australia reported significant barriers to transplantation throughout their transplant journey due to rurality, with considerable logistic, financial, and psychosocial challenges arising from living far from the kidney transplant services[440]. Evidence for the effects of interventions that improve continuity of location and bring care closer to home is limited. The strongest evidence base is for tele-medicine interventions in kidney transplant, where remote follow up appointments were found to reduce the time and financial burden associated with travelling to appointments[441], and are well received by patients[442].

Continuity of main nephrologist would mean that from the point of referral to a low clearance clinic patients should have one named nephrologist who takes overall responsibility for their care and who they see for most nephrology clinic consultations. Reviews of the effect of continuity of care more generally have found that greater continuity is associated with lower mortality rates[443]; increased patient satisfaction and decreased hospitalisations and emergency department visits[444]; chronic disease management, patient experience, and quality of life[445]. However, an American study into the effect of continuity of primary nephrologist on the quality of dialysis starts found that the quality of the nephrologist's primary facility had a significant impact on the quality of dialysis start, with significantly higher hospitalisation rates associated with low quality facilities [446]. It also found that Black patients were more likely to be cared for by nephrologists attached to low quality institutions, and were therefore more likely to experience lower quality dialysis starts. This provides important nuance when considering the benefit of continuity: continuity will only provide benefit if it facilitates the continuity of high-quality care and therefore quality assurance of both staff and facilities is vital. Mandating continuity in lower quality institutions rather than transferring out could exacerbate inequalities.

Greater resourcing of the living donor transplant co-ordinator role would augment the specialist nursing support offered to patients navigating the process. Adequate resourcing and departmental ethos- especially if co-ordinators had an individual named patient workload and were able to get to know patients and their circumstances- would facilitate the live donor transplant process pro-actively identifying needs and driving forward the process rather than being more reactive to patient demands. This would transfer workload from the patient and their social network back into the system, ease the patient experience, and reduce the inequity introduced by having processes where access to care can be modified by the agency of the patient rather than clinical need.

8.3.1.2 Improving the integration between different components of the healthcare system

A common source of burden for participants in the longitudinal qualitative study was dysfunction between different components of the healthcare system which resulted in the patient and their family needing to perform significant additional work co-ordinating between the different services. The most common area of dysfunction was ensuring the timely and accurate dispensing of medications. Patients would attend secondary or tertiary nephrology or transplant clinics and have alterations to their medication regimen advised there. This in turn would require their GP to prescribe these medications on an ongoing basis and for a community pharmacy to dispense them. This process is highly vulnerable to failure, especially the process of communicating prescription alterations between secondary care and primary care, and communication between the prescribing clinician and the dispensing pharmacy. An added complicating factor in this was the mandatory introduction of digital systems in some primary care practices to request medications or to triage appointments instead of using a reception team as first contact which participants, especially those with disabilities or reduced digital literacy, regarded as impeding rather than ameliorating their ability to navigate the system and co-ordinate their care. The medication in question would often be either immunosuppressant medication or anticoagulants, which carry a high potential for adverse outcomes from a short period of missed doses and therefore required an emergency prescription if routine ordering processes had failed. The risks involved with missed doses further increased the concern felt by the patient and their family, and further undermined their trust in the system. This meant that even when the process worked seamlessly, previous poor

experiences meant patients could not trust it and they devoted considerable effort in double checking and developing contingencies in case the system failed again.

In the longitudinal study, some participants reported processes being unreliable especially when navigating between community-delivered and hospital-delivered services. This was particularly consequential in the context of patients experiencing complications or deterioration in their health in the community and trying to access specialist hospital-based services, but could also be experienced when transferring from hospital back to a community setting, especially following an inpatient stay.

Improving the integration between different components of the system and their dependability could be an important mechanism to reduce treatment burden. Service must function in a way that is predictable and logical to patients, caregivers, and clinicians. No service can be everything to everyone all the time, but it is demonstrated in both the systematic review and longitudinal qualitative study that there's profound difference in the workload and burden caused by gaps in provision that are known and plannable around and services that unexpectedly fail. If we tell patients that they can rely on hospital transport then it must be reliable. Referral criteria and pathways must be predictable and coherent for both patients and clinicians, lest they expend unnecessary energy seeking access to services that they do not meet the criteria for or are denied access to interventions from which they might benefit. If a patient is told that a process is likely to take 6 months and to plan accordingly, that must bear resemblance to reality. For patients with high level of hospital-based healthcare contact such as dialysis or acute transplant patients, it may be worth considering service restructuring that would permit routine prescribing and dispensing of chronic medications from secondary care.

Dependability is also a key consideration when introducing new technology into services. There is great interest and optimism surrounding the potential role for artificial intelligence (AI), new digital platforms, wearable technology, and many other digital innovations in KRT patient care. There is clear evidence presented in our work that the introduction of bad technology can increase complexity and fragmentation, and reduce the dependability of system processes such as when digital medication ordering processes fail or when patients are asked to use digital platforms that they lack the technology, dexterity, and digital literacy to easily utilise. New innovations have great potential for

improving care, but must be introduced with careful consideration of unintended consequences, unsupported transfer of work, and unforeseen gaps in functionality.

8.3.1.3 Accessibility, navigatability, and responsiveness in KRT care

In the longitudinal study, difficulty accessing information regarding progress in the live donor transplant work up process made planning very difficult for participants and exacerbated feelings of helplessness and disempowerment. The responsiveness and adaptability of the live donor work-up process to life events and the needs of both recipient and donor was also criticised by some participants. Several described great difficulty trying to get dates for requisite investigations for both recipient and donor, and finding out information regarding potential dates for transplant in order to co-ordinate with employers, families and friends. Several described themselves or their donor needing to contact the live donor service to chase appointments and self-advocate to drive the process forward, which potentially introduced inequity into the system by providing a mechanism for those with higher social capital and cognitive authority to achieve better access to treatment. The live donor transplant process was less captured in the systematic review, but difficulty in accessing information and systematic inflexibility was also identified as a source of burden.

Reynolds defined the concept of devitalisation, when structural processes result in institutional indifference, bureaucratic demands, or rigid pathways that diminish a patients' and their social networks' energy, effectiveness, and agency as they navigate care in a system that exhausts rather than supports them[133]. Reducing the devitalisation that occur due to systemic processes in KRT could be a valuable target for intervention to reduce burden.

User experience, sometimes abbreviated as UX, is a concept from industry that analyses and seeks to improve a person's perceptions and responses that result from the use or anticipated use of a product, system, or service. It is not solely limited to usability and accessibility, but is conceptualised as human-centred design as it also includes the emotional, cognitive, and contextual aspects of interacting with the service[447]. UX concepts can be applied to healthcare service designs, and could be used to redesign care pathways and improve both the service performance and the patient experience[448,449].

KRT transition care could be improved by developing a detailed understanding of the flow of work from the system to the patient and from the patient to the system across different pathways in order to identify processes that are excessively complex and experiences that exacerbate the burden felt by patients. Designing processes that maximise the availability of information, demystify processes, and augments the ability of patients to advocate for their needs and express autonomy could be potent targets for intervention to reduce burden.

8.3.1.4 Civility in KRT Services

The ability to access services that function in a way that is respectful of patients was an important factor in reducing treatment burden.

The systematic review identified more areas than the qualitative study where the clinician-patient relationship was negatively influenced by stigma, discrimination, and dismissiveness and how this in turn increased experiences of treatment burden such as stigmatising care leading to patients feeling unable to disclose illiteracy or financial hardship, and consultations that felt too hurried and paternalistic to ask questions or meaningfully participate in shared decision making. In the longitudinal qualitative study, when participants discussed examples of when the clinician-patient relationship had increased their burden they reported lack of continuity rather than any stigma or discrimination. There are two potential reasons for this divergence between the findings of the systematic review in Chapter 5 and the longitudinal qualitative study in Chapter 7. Firstly, there are papers included in the systematic review that have deliberately sought out to capture the experiences of marginalised communities such as the Māori[276] and undocumented Latinx in the USA[373], and may have therefore captured socio-cultural contexts that generated higher levels of perceived stigma and discrimination that are not generalisable to the experiences of KRT patients accessing NHS delivered KRT care in Glasgow. Secondly, as the interviews in Chapter 7 were conducted by a researcher with professional links to the Renal Unit participants may not have felt able to disclose experiences of stigma or discrimination.

A key finding in the systematic review was the importance of culturally coherent care in relieving burden. In order to operate in a manner that is respectful of patients and affirms their ability to participate in care KRT services need to understand the population that

they serve and the diversity within it, understand how different cultures and communities may differ in their interaction with KRT services, and understand what additional support might be required to fully and equitably participate in care. Three of the studies included in the systematic review were conducted in New Zealand, where the importance of understanding and accommodating Māori culture in care and the resultant reduction in burden by delivering culturally coherent care was clearly described[276,371,376]. A systematic and narrative review of cultural safety in kidney care within indigenous communities suggested three key solutions to improve the care delivered to these communities[450]. Firstly, relationality, engagement, and healthcare self-determination should be encouraged with incorporation of translators, traditional approaches, engaging Elders, individualised education, and incorporation of indigenous art and culture into care. Secondly, systemic barriers to access and other systemic issues must be addressed with recognition of the importance of land and place of origin to communities and the practical and spiritual burden placed if required to travel for kidney care. Thirdly, healthcare providers should address the legacies of colonialism and enter a self-reflective journey on potential harmful assumptions and stereotyping minorities communities are subjected to and how it might alter their care. Studies of the experiences of migrant and refugee populations also reflect the need and importance of culturally coherent care, with a need to understand and accommodate their particular social, emotional, and spiritual needs [451]. Furthermore, practical assistance is required with access to translation services and culturally appropriate dietary advice[452].

8.3.2 Supporting Caregivers during KRT transition

It is clear in both the systematic review and the longitudinal qualitative study that KRT transition is a process that involves the patient's whole social network, and caregivers are confronted with life-changing changes and considerable workload. Caregiver burden, defined as the strain borne by individuals caring for chronically ill family members[453], is often overlooked in research and system design. Patients who have a rich social network with financial, educational, emotional, physical, cognitive, and social capital resources that can be mobilised to meet the healthcare workload of KRT experience less burden. The burden experienced by the social network is also dynamic and influenced by experiences of realising work: manageable and normalizable work achieving noticeable positive results enhances capacity and reduces burden over time, whereas unsustainable

and unsupported workload and complications diminish capacity. Therefore, supporting caregivers could lead to lower treatment burden for the patient by enhancing the capacity within their social network. Providing interventions that support the patient's social network has been identified in other work as a potential target for intervention[90].

The argument can be made that the most important way of reducing caregiver burden is to have a well-functioning, well-resourced, cohesive healthcare system that avoids inappropriate transfer of workload onto the patient and their family, as described above. Whilst this is true, even in a highly-functioning treatment burden-informed system the nature of KRT means that there will always be considerable healthcare workload that the patient and their family are required to meet, and therefore supporting caregivers is an important target for intervention to minimise treatment burden.

A systematic review studying the effectiveness of psychosocial interventions for informal caregivers of haemodialysis patients found that caregiver education, psychological support, and family-centred empowerment were effective at reducing caregiver burden[454]. A peer mentoring for caregivers of patients with CKD intervention which involved regular face-to-face or online meetings with trained volunteer mentors who were themselves adult caregivers of CKD patients was found to improve caregiver burden[455]. Enhanced psychosocial support from specialist nurses and social workers was found to reduce caregiver burden in the context of CCM for KFRT[456]. Peer support groups were also found to be effective at reducing caregiver burden in CKD[457]. Family focused interventions have been found to increase access to and acceptability of live donor kidney transplant[458].

8.3.3 Enhancing the Social Network

Another potential avenue for intervention is to develop interventions that help to enhance the social network of patients wider than the primary caregiver. In both the systematic review and the longitudinal qualitative study patients derived benefit and support from building relationships with other people with advanced kidney disease. They could be the source of informal knowledge about living on KRT with a different emphasis and content to that shared by clinicians, and patients often conferred great legitimacy to the recommendations of other KRT patients. Other patients could be the source of practical advice such as how to arrange holidays when on KRT and how to manage dietary restrictions. Seeing other patients successfully negotiate life on KRT and learning how

they managed could be the source of great comfort and hope, and the camaraderie with other patients on dialysis units and in clinics offered a new and valuable source of joy and sustenance when their social world in other parts of life contracted. Younger participants reported that connecting online with other young people on KRT helped to reduce the social isolation and biographical disruption associated with developing advanced kidney disease earlier in life.

Peer support is defined as the provision of emotional, appraisal, and informational assistance by person with experiential knowledge of a particular stressor or context and similar characteristics to the target population in order to aid a health-related issue of a potentially stressed or actually stressed focal person[459]. Potential forms of peer support in KRT care that have been identified include informal groups, online groups, trained volunteer mentors within formal programmes, and peer support groups[460].

A systematic review of peer support interventions for patients undergoing KRT found that there is some evidence that peer support can improve engagement with care, psychological wellbeing, self-efficacy, and treatment adherence although the evidence was of limited quality due to small sample sizes and non- randomised non-controlled study designs[461]. A further scoping review on peer support interventions for people with CKD had similar findings, supporting a conclusion that peer support interventions are associated with improvements in psychological health but that the evidence for their use is of low quality and with notable gaps such as the role of peer support in home therapies or in navigating the transplant process[462].

8.3.4 Maximising access to Kidney Transplantation

It is clear across the work presented in this thesis that KRT modalities are not equal in the workload and burden that they entail: kidney transplantation, and especially pre-emptive kidney transplantation, is associated with much lower workload and burden. As demonstrated in Chapter 6, once out of the immediate peri-transplant period patients who had a pre-emptive transplant had a relative workload that had an IRR of 0.04 [CI 0.03-0.05] compared to haemodialysis patients: they had 4% of the HD population's workload in terms of time spent on hospital based clinical work. A striking finding in the qualitative study described in Chapter 7 that for participants who had a potential live donor but did not get transplanted pre-emptively and needed to start KRT by HD or PD,

the process of starting KRT by an alternative modality was highly burdensome and attritional to their capacity. This cohort of non-pre-emptive live donor transplant recipients especially when post KRT initiation, pre transplant were often the most burdened by their treatment of all the participants interviewed. Participants described profound biographical disruption, financial hardship, losing trust in clinicians and the system, and a very high workload managing both transition to HD or PD and the workload of live donor transplant. Although their burden reduced considerably post-transplant, they entered the live donor transplant process battle-scarred in a way that wasn't true for those who had been transplanted pre-emptively.

As outlined in Chapter 1, because of the discrepancy between the average wait time on the transplant list for a deceased donor kidney (12-36 months) and the time prior to anticipated KRT start that patients are eligible to be active on the waitlist (6 months), most pre-emptive transplants are live donor transplants. Therefore, one of the most effective ways renal services could reduce the burden encountered by their patients is to concentrate resources and streamline processes to maximise the access to live donor transplantation for eligible patients and maximise the efficiency in the system so that patients and their potential donors can be assessed, listed, and transplanted in a timely manner (preferably pre-emptively).

As outlined in Chapter 1, socioeconomically disadvantaged patients are less likely to receive a LDTx[81], which may be as a result of greater passivity and disempowerment in their relationship with clinicians and a lack of social support[82]. A systematic review of randomized controlled trials into interventions that aid patient access to kidney transplantation found that educational interventions, especially home-based interventions, were associated improved rates of inquiry regarding transplant, transplant evaluation, and actual transplant events[463]. Although the review compared and combined the effects of heterogenous interventions and did not distinguish between LDTx and DDTx, it does provide an evidence base that providing home-based interventions above and beyond standard care may improve access to transplantation and is therefore a potential avenue of further research and innovation.

Other potential avenues to increase access to LDTx is to enhance the package of support offered to potential donors. There are strong moral and ethical reasons why donation should be altruistic and that it is imperative that potential donors are not excessively

financially incentivised into donation. Currently in the UK, donors can be reimbursed for lost earnings and travel costs usually to a maximum of £5000[464]. However, some argue that the current support package offered in the UK mean that some, especially those that are in more unstable employment, are disincentivised and disadvantaged by the process of donation and enhancing the support available would increase the acceptability of live donation[465]. It has been shown that reimbursement programmes are associated with higher living donation rates[466], and it is a worthwhile exploring whether the current reimbursement structure has struck the right balance between fair and comprehensive donor compensation and not trading in organs.

Fundamentally the most potent way to reduce treatment burden is to enhance access to transplantation, and the most potent way to enhance access to transplantation is to increase the availability of donor organs. Several methods have been used to attempt to increase the availability. Public awareness campaigns using advertisements have been held to improve population awareness and acceptability of organ donation. There is evidence that public information campaigns and positive stories regarding donation are associated with higher donation rates, but that negative or false stories can negatively impact the acceptability of organ donation[467]. This may become an increasingly important dynamic in the current deregulated and increasingly conspiratorial and sceptical media environment. Targeted interventions have been developed to engage with communities with historically low levels of organ donation in order to work with religious and community leaders to improve the acceptability of organ donation within that community. A systematic review of these interventions found that there is very limited evidence for their use in the UK, but in American contexts community educational interventions especially those delivered by appropriately trained lay individuals from their own community were effective at increasing organ donor registration[468]. The law around organ donation after death has been changed from an ‘opt-in’ to a soft ‘opt-out’ model, where the presumption has changed towards donation, although the evidence for the efficacy of this approach in increasing donation rates is limited[469]. Other interventions to increase the availability of organs include extending the eligibility criteria for donation, meaning that higher risk kidney such as those from older or more co-morbid donors or those with some infectious diseases such as Hepatitis C that would have historically been rejected are now transplanted[470]. Further innovations that are being developed include using machine

perfusion for enhanced viability assessment[471] and potentially organ reconditioning[472], which would further augment the pool of available organs.

8.4 Strengths and Limitations

As the strength and limitations of different individual components of this work (Chapter 5-7) and the methodological approaches used (Chapter 4) have been discussed in detail elsewhere, the aim of this section is to discuss the strengths and limitations of the mixed methods approach utilised in this discussion. As discussed in Chapter 4, some argue that qualitative and quantitative work should not be integrated as they have incompatible epistemological and ontological assumptions[249]. It can also be argued that integrating different qualitative work such as the systematic review and longitudinal qualitative study is also methodologically flawed, as each study has a different construction of reality. However, this thesis was underpinned by a pragmatic critical realist stance, which holds that objective reality and socially constructed knowledge are not mutually exclusive concepts but different approaches to understanding different types of knowledge. This epistemological stance permits the integration of methodologically diverse work, and holds that integration and triangulation of the findings can lead to a more comprehensive and multi-faceted understanding as well as increasing the credibility of the result.

This thesis benefited from robust theoretical underpinnings and an iterative approach, with the methods being informed by three core middle range theories- NPT, TPC, and BoTT, and iteratively by findings that arose as the research progressed. This was described in greater detail in Chapter 4. The use of the taxonomy of workload and taxonomy of capacity described in Chapter 5 and the findings of the cohort study in Chapter 6 to inform the topic guides and the initial coding framework for the longitudinal qualitative study in Chapter 7 allowed for comparison and triangulation between the three bodies of work.

Despite the selection of intentionally complementary approaches, there were some challenges triangulating findings across studies with substantially different epistemological assumptions, methodologies, and units of analysis. The qualitative systematic review explored subjective experiences of treatment burden through framework synthesis, whereas the retrospective cohort study quantified healthcare workload using routinely collected data. The longitudinal qualitative study subsequently

examined the dynamic interaction between workload, capacity, and health system factors over time. Each study conceptualised and operationalised 'treatment burden' differently, which made triangulating more challenging.

There are inherent limitations in attempting to triangulate objective markers of healthcare workload with subjective experiences of burden. High measurable objective healthcare workload does not necessarily correlate with high perceived treatment burden, as experiences are influenced by patient capacity factors, social network support, and healthcare system responsiveness. Conversely, some patients may experience significant and overwhelming burden despite comparatively low measurable workload. This reflects the complexity of treatment burden as a multidimensional construct, and the caution required when using objective measures as proxy for subjective experiences.

There were also temporal and contextual limitations to triangulation. The retrospective cohort study provided a broad overview of healthcare interactions during transition onto KRT with a sizeable study population, while the qualitative work captured a detailed exploration of evolving burden albeit with a much smaller number of participants and a shorter data collection period. Furthermore, the studies were conducted sequentially rather than as a fully integrated mixed-methods design with prospective linking of participants and outcomes. This limited the extent to which quantitative findings could be directly explained by qualitative experiences at the individual patient level, although the data was all collected within the same unit during a time frame when clinical processes were similar. Instead, triangulation primarily occurred at the conceptual and thematic level. This still strengthened the overall interpretation of treatment burden during KRT transition, and granted greater confidence to key findings that were matched in both qualitative and quantitative data such as that burden is worst at the point of initiation and subsequently reduces and that kidney transplant is associated with substantially lower burden. However, it is important to acknowledge that the findings are complementary rather than fully integrated.

Finally, researcher interpretation inevitably influenced the process of triangulation. Integrating qualitative and quantitative findings required subjective judgement regarding where findings converged, diverged, or expanded upon one another. Although the interpretative process was informed by theoretical frameworks including BoTT, NPT and TPC, alternative interpretations of how the datasets relate to one another are possible.

Another limitation of this thesis is that all the primary data presented was collected in one unit, which limits the generalisability and transferability of the data. Incomplete recording of ethnicity data in the quantitative arm and the inability to provide translation services in the qualitative arm has meant that the study of the potential impact of ethnicity, being part of a minoritized community, and other vulnerabilities such as recent migration is limited in this work.

Being a clinician as well as a researcher has influenced my approach to this thesis in many ways. The direct influences of my role as a surgical trainee on the conduct of the interviews is discussed in detail in Chapter 4, however my wider experiences working as a clinician in the NHS has undoubtedly indirectly influenced my understanding of this work, of the theories that underpin it, and the arguments I present in this discussion. I became interested in treatment burden because I thought it was an interesting concept that appeared to accurately reflect challenges that I saw my patients confront. I have always had an interest in sociology, health policy and health inequalities and have read widely in the field since medical school: I was not a blank sheet at the start of this PhD, I already had views and biases. My prior healthcare experiences greatly assisted my understanding of the participants illnesses and their journey. However, the aim of this work was to explore the patients' perspective of workload, capacity, and treatment burden and care was required at all times to ensure that the findings were grounded in the data to ensure the credibility of the results.

8.5 How the findings relate to current knowledge

As outlined in Chapter 2, the hypotheses and research questions that underpin this work and the understanding and assumptions made about the interplay of healthcare workload, patient capacity, and the provision and structure of healthcare services were heavily influenced by the theoretical work and collaborations of Prof Carl May, especially Normalisation Process Theory[107] and the Burden of Treatment Theory[1]. The work of Kasey Boehmer, especially the Theory of Patient Capacity[6], and Shippee et al with the Cumulative Complexity Model[7], was also heavily influential.

In comparison to the work of other research groups applying BoTT to other conditions including heart failure, stroke, diabetes, cancer, and multimorbidity, there were some notable similarities and differences in the treatment burdens described. Common drivers

of treatment burdens identified were: 1) the nature and meaning of the tasks imposed on patients and their families; 2) structural challenges, such as access to healthcare resources and poor co-ordination between care providers; 3) personal, situational, and financial factors that impair access to resources that can facilitate the completion of the work; 4) the consequence of unmet needs and excessive burden such as poor adherence[425]. However, several key differences were noted in work comparing the burdens of KRT transition to other conditions, reflecting the differences in the onset, trajectory, and treatment of these chronic conditions. Due to the range of choices in terms of modalities and the complexity of the treatments required, KRT had more prominent sense-making work compared to congestive heart failure and stroke[321,322]. The intrusion of KRT treatment work rather than disease related symptoms into daily life also differed, with the intensity of the healthcare contact involved in in-centre dialysis or the complexity of home-based treatment work involved in PD unmatched by studies in other conditions. The emotional burdens involved with kidney transplant was also specific to KRT. This illustrates the importance of developing disease and context specific understanding of treatment burden.

As outlined in Chapter 3, there is some pre-existing literature applying BoTT in kidney disease and KRT. This work shares several common findings with the work of Roberti et al, namely that being a person with kidney failure requiring replacement therapy involves high burden, time-consuming, invasive, and exhausting tasks that impact on all aspects of patients' and caregivers' lives[148]. What this work contributes in addition to pre-existing work is its focus on understanding KRT transition and understanding how burden evolves over time.

The core recommendation of this thesis is that the structure and processes of the healthcare service are the main modifiable drivers of treatment burden in KRT, and therefore the most practical and fruitful target for interventions to minimise burden is to improve the processes of the healthcare service to reduce the burden they cause. This aligns with the concept of minimally disruptive medicine (MDM), which promotes changes in clinical behaviour and restructuring of clinical services that take patient values, preferences, goals, and priorities into account and seeks to minimise the iatrogenic burdens that the healthcare system generates[5,425,426]. The importance of understanding and ameliorating systemic trajectories, and implementing policy and practice

interventions to improve access to diagnostic and specialist services, improve the quality of interactions with clinicians and supportive gatekeepers, and to better understand and target information needs of service users and caregivers was identified in a large systematic evidence synthesis on the lived experiences of illness trajectories and burdens of treatment[90].

8.6 Future research requirements

As discussed in Chapter 3, with the exception of one transplant specific measure (PETS-KT), there are no validated measures of either treatment burden or patient capacity that have being designed for use in the general KRT population, and none that have been developed to capture the specific needs and context of KRT transition. A potential avenue of further research would be to take the taxonomies of workload and capacity developed in this thesis and the insights gained from the longitudinal qualitative study to develop a patient-reported measure of treatment burden during KRT transition. This would facilitate the routine measurement of burden and would allow for the objective tracking of burden over time, and facilitate comparison studies between the burden generated by different treatment approaches. In turn, this could provide an evidence base that could better inform patient choice, contribute to health economic evaluations, and help identify patients at risk of becoming overburdened facilitating targeted support.

However, caution is required not to overestimate the potential benefits or applications of a quantitative measure. Despite the development and application of numerous measures, there is little evidence that the use of PREMs and other such measures leads to meaningful change in the quality of care delivered to patients[473]. Questionnaire burden or respondent burden is a valid concern in vulnerable patient populations. Questionnaires that are too long, too complex, or are presented too frequently may overburden patients resulting in poor completion rates, missing data, and introduce bias into findings by over-representing higher capacity patients [474]. Therefore, caution is required when designing and introducing new measures, and the assumptions that having a comprehensive measure would necessarily lead to good data collection or that the collection of treatment burden data by itself is likely to deliver change are deserving of critical interrogation.

A striking finding in the evaluation of the development of a PREM for kidney care in the UK was that an overwhelming proportion of the explained variance in PREM scores was

driven by centre-level factors rather than patient-level factors. This poses an interesting question, which is whether the individual is the right unit of analysis or intervention for treatment burden, or would evaluating burden at a system level lead to more actionable findings[217]. A potential avenue for further research would be to develop an evidence-based structured service evaluation measure to assess how system processes contribute to generating treatment burden during KRT transition and facilitate the identification of targets for intervention.

In this thesis a detailed exploration of treatment burden during KRT transition is presented. However, as discussed in the limitations section, the primary quantitative and qualitative data presented were all collected in a single centre. In order to develop generalisable tools, further work would be required studying treatment burden during KRT transition and defining treatment burden reducing care in different contexts especially capturing populations with greater ethnic and cultural diversity, different geographic catchment areas, and different socio-economic profiles than Glasgow.

8.7 Conclusion

This work has used qualitative and quantitative methods to explore the treatment burdens experienced during transition onto kidney replacement therapy. We identified that during KRT transition, patients experience a high volume of difficult, intrusive, and time-consuming healthcare workload at a time where their identity, physical health, finances, and psychological wellbeing are significantly challenged. These experiences are heavily influenced by the quality and configuration of the healthcare system's structures and processes. Taxonomies of healthcare workload and patient capacity during KRT transition have been created, and a detailed exploration of how these interact to influence treatment burden and how burdens evolve over time has been presented. Scrutiny of these has led to identification of potential areas for improvement, and the identification of potential avenues for further research. Further research into the development of healthcare system level evaluation tools could facilitate the evaluation of KRT services to identify processes and gaps in provision that drive treatment burden. Reducing treatment burden in KRT transition could improve patient experience, quality of life, adherence to treatment, and health outcomes for KRT patients.

Appendix 1

Search Strategy for Systematic Review

Database: Ovid MEDLINE(R) ALL <1946 to May 10, 2023>

Search Strategy:

1 Renal Replacement Therapy/ (6872)

2 ((renal or kidney) adj replacement therapy).tw. (17015)

3 ((kidney or renal or pre?emptive) adj transplant*).tw. (87626)

4 exp Renal Dialysis/ (125686)

5 dialysis.tw. (120584)

6 (hemodialysis or haemodialysis).tw. (86642)

7 (endstage kidney or endstage renal or end stage kidney or end stage renal).tw. (49690)

8 (ESKD or ESKF or ESRD or ESRF).tw. (21845)

9 (kidney adj failure).tw. (9828)

10 (renal adj (insufficiency or care)).tw. (23722)

11 (hemofiltration or haemofiltration).tw. (4614)

12 ultrafiltration.tw. (17666)

13 vascular access.tw. (11277)

14 peritoneal dialysis.tw. (28030)

15 or/1-14 (341440)

16 ((Treatment* or (disease* adj3 management) or interven* or medicat* or therap* or medicin* or (patient* adj3 care) or selfcare or self-care or (health adj3 program$)) adj3 workload*).tw. (574)

17 ((Treatment* or (disease* adj3 management) or interven* or medicat* or therap* or medicin* or (patient* adj3 care) or selfcare or self-care or (health adj3 program$)) adj3 impact*).tw. (59056)

18 ((drug* or treat* or illness or procedure? or interven* or medicat* or therap* or medicin* or (patient* adj3 care) or selfcare or self-care or (health adj3 program*)) adj3 burden*).tw. (14994)

19 exp Quality of Life/ (265284)

20 exp Patient-Centered Care/ (23997)

21 (minimally disruptive medicine or patient-cent* care or chronic care or lived experience? or psycho?social experience? or decisions or BoT or QoL or HRQoL or TB).tw. (345478)

22 or/16-21 (634335)

23 Workload/ (23844)

24 Self-Management/ (5268)

25 disease management/ (42964)

26 Work/ (20245)

27 (work or workload or utili?ation review or process assess* or analys* or efficien* or task performance or task analys* or health?care contacts or health?care events or self-management or disease management or training or complex* or CuCoM).tw. (9507147)

28 or/23-27 (9555324)

29 coping.mp. or physician-patient relations/ or communicat*.mp. or partnership.mp. or socioeconomic*.mp. or psychosocial*.mp. or attitude*.mp. or acceptance of health care/ or acceptance.mp. or denial.mp. or choice*.mp. or resilien*.mp. or mobiliz*.mp. or mobilis*.mp. or "social conflict*".mp. or "physical status".mp. or "physical function*".mp. (2050821)

30 ("quality of life" or "well-being" or dysfunction* or community* or work or intimacy or intimate or emotion* or mood* or unmet or preference* or participat* or "side effect*" or emotion*).mp. (4273067)

31 (multimorbid* or comorbid* or morbidities).mp. (333483)

32 (multiple adj3 (chronic or illness* or morbid* or disease* or condition*)).mp. (50801)

33 ((multi or co) adj morbid*).mp. (34153)

34 "more chronic".mp. (3896)

35 or/29-34 (5913229)

36 Qualitative Research/ (80936)

37 Nursing Methodology Research/ (16407)

38 Questionnaires/ (559486)

39 exp Attitude/ (634914)

40 Focus Groups/ (35613)

41 discourse analysis.mp. (2512)

42 content analysis.mp. (42299)

43 ethnographic research.mp. (1230)

44 ethnological research.mp. (8)

45 ethnonursing research.mp. (42)

46 constant comparative method.mp. (1928)

47 qualitative validity.mp. (23)

48 purposive sample.mp. (4547)

49 observational method$.mp. (976)

50 field stud$.mp. (18168)

51 theoretical sampl$.mp. (909)

52 phenomenology/ (0)

53 phenomenological research.mp. (669)

54 life experience$.mp. (7532)

55 cluster sampl$.mp. (9432)

56 ethnonursing.af. (127)

57 ethnograph$.mp. (13823)

58 phenomenol$.af. (33855)

59 grounded theory.mp. (15101)

60 (grounded adj (theor$ or study or studies or research or analys?s)).af. (15333)

61 (life stor$ or women's stor$).af. (1702)

62 (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw. (30223)

63 (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp. (619938)

64 (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.

(5641)

65 (humanistic or existential or experiential or paradigm$).mp. (192076)

66 (field adj (study or studies or research)).tw. (19508)

67 human science.tw. (265)

68 biographical method.tw. (21)

69 qualitative validity.af. (23)

70 purposive sampl$.af. (12054)

71 theoretical sampl$.af. (909)

72 ((purpos$ adj4 sampl$) or (focus adj group$)).af. (89137)

73 (account or accounts or unstructured or open-ended or open ended or text$ or narrative$).mp. (811101)

74 (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp. (17744)

75 lived experience$.tw. (10855)

76 life experience$.mp. (7532)

77 cluster sampl$.mp. (9432)

78 (theme$ or thematic).mp. (165879)

79 categor$.mp. (474419)

80 observational method$.af. (977)

81 field stud$.mp. (18168)

82 focus group$.af. (69038)

83 questionnaire$.mp. (940099)

84 content analysis.af. (42318)

85 thematic analysis.af. (37874)

86 constant comparative.af. (3915)

87 discourse analys?s.af. (2559)

88 ((discourse$ or discurs$) adj3 analys?s).tw. (2982)

89 (constant adj (comparative or comparison)).af. (5950)

90 narrative analys?s.af. (1854)

91 heidegger$.tw. (769)

92 colaizzi$.tw. (1118)

93 speigelberg$.tw. (2)

94 (van adj manen$).tw. (529)

95 (van adj kaam$).tw. (44)

96 (merleau adj ponty$).tw. (260)

97 husserl$.tw. (308)

98 giorgi$.tw. (858)

99 foucault$.tw. (953)

100 (corbin$ adj2 strauss$).tw. (439)

101 (strauss$ adj2 corbin$).tw. (439)

102 (glaser$ adj2 strauss$).tw. (119)

103 glaser$.tw. (1084)

104 findings.af. (2561355)

105 interview$.af. or Interviews/ (483317)

106 qualitative.af. (340078)

107 or/36-106 (5767911)

108 22 or 28 or 35 (12733572)

109 15 and 107 and 108 (30202)

110 " 'Beats the alternative but it messes up your life': aboriginal people's experience of haemodialysis in rural Australia ".ti. (1)

111 " African American kidney transplant patients' perspectives on challenges in the living donation process ".ti. (1)

112 " Compartmentalising time and space: a phenomenological interpretation of the temporal experience of commencing haemodialysis ".ti. (1)

113 " Dialysis modality decision-making for older adults with chronic kidney disease ".ti. (1)

114 " Engagement in decision-making and patient satisfaction: a qualitative study of older patients'

perceptions of dialysis initiation and modality decisions ".ti. (1)

115 " Experiences of patients undergoing dialysis who are from ethnic and racial minorities ".ti. (1)

116 " The perspectives of Aboriginal patients and their health care providers on improving the quality of hemodialysis services: a qualitative study ".ti. (1)

117 " Patient perspectives on the optimal start of renal replacement therapy ".ti. (1)

118 " Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study ".ti. (1)

119 " Patient experience after kidney transplant: a conceptual framework of treatment burden ".ti. (1)

120 " Patient experiences of training and transition to home haemodialysis: A mixed-methods study ".ti. (1)

121 " You know your own fistula, it becomes a part of you --Patient perspectives on vascular access: A semistructured interview study ".ti. (1)

122 " The psychosocial experience of patients with end-stage renal disease and its impact on quality of life: findings from a needs assessment to shape a service ".ti. (1)

123 " Waiting for a kidney transplant: the experience of patients with end-stage renal disease in South Korea ".ti. (1)

124 " Working to establish 'normality' post-transplant: a qualitative study of kidney transplant patients ".ti. (1)

125 or/110-124 (15)

126 109 and 125 (15)

127 limit 109 to yr="2012 -Current" (18115)

Appendix 2

Data Extraction Form for the Systematic Review

Data Extraction Form

1. Title
2. Journal
3. Authors
4. Year of Publication
5. Country
6. Number of participants
7. Description of population
8. Date of data collection
9. Healthcare funding
    - **a.** Government funded/Universal healthcare
    - **b.** Medicaid/ State based Insurance/ Co-pay
    - **c.** Private/ Self funded
    - d. Mixed
    - e. Other
    - f. Not stated
10. Number of sites:
    - **a.** 1
    - **b.** 2-3
    - **c.** 4-5
    - **d.** 5+
    - **e.** Not stated
11. KRT modality:
    - **a.** PD
    - **b.** HD
    - **c.** KTx
    - **d.** Mixed
12. What methodological orientation was stated to underpin the study?
    - a. Grounded theory
    - b. Discourse analysis
    - c. Ethnography
    - d. Phenomenology
    - e. Content analysis
    - f. Other
13. How were patients selected?
    - a. Purposive
    - b. Convenience
    - c. Consecutive
    - d. Snowball
    - e. Other
    - f. Not stated

14. How was the data collected?
    - a. Key Informant Interviews

   b. Focus groups
   c. Observation
   d. Mixed
   e. Others
15. Were repeat interviews carried out?
   a. Yes
   b. No
16. What aspects of transition were covered?
   a. Decision making on modality
   b. Experiences of procedures
   c. Physical adaptation
   d. Lifestyle adaptation
   e. Emotional adaptation
   f. Biographical disruption
   g. Impact on family/social life
   h. Financial/economic
   i. Other

Joanna Briggs Quality Screen

17. Is there congruity between the stated philosophical perspective and the research methodology?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
18. Is there congruity between the research methodology and the research question or objectives?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
19. Is there congruity between the research methodology and the methods used to collect data?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
20. Is there congruity between the research methodology and the representation and analysis of data?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
21. Is there congruity between the research methodology and the interpretation of results?
   a. Yes

   b. No
   c. Unclear
   d. Not applicable
22. Is there a statement locating the researcher culturally or theoretically?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
23. Is the influence of the researcher on the research, and vice versa, addressed?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
24. Are participants and their voices adequately represented?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
25. Is the research ethical according to current criteria or is there evidence of ethical approval by an appropriate body?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable
26. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?
   a. Yes
   b. No
   c. Unclear
   d. Not applicable

Subjective global assessment

27. As a whole, how would you appraise the quality of this study?
   a. High quality
   b. Mostly high quality but some aspects lower quality/absent
   c. Low quality
28. Additional comments

Appendix 3

Coding Framework for the Systematic Review

Workload

Coherence Building

- Differentiation
- Communal Specification
- Individual Specification
- Internalisation

Cognitive Participation

- Initiation
- Enrolment
- Legitimisation
- Activation

Collective Action

- Interactional Workability
- Relational Integration
- Skillset Workability
- Contextual Integration

Reflexive Monitoring

- Systematisation
- Communal Appraisal
- Individual Appraisal
- Reconfiguration

Capacity

Biography

- Biographical adaptation
    - Finding a new role in life
    - Reframing future expectations
- Biographical disruption
    - Fear of future suffering
    - Loss of a meaningful life
    - Loss of future dreams, hopes and aspirations
    - Loss of role

Resources

- Financial
- Literacy
- Medical knowledge
- Paid support services
- Physical abilities
- Physical energy
- Physical health
- Psychological resilience
- Self-efficacy
- Time
- Transport

Environment

- Capacity building environment
- Experiences of person-centred care
- Negative experiences

Realisation of Work

- Realisation of work affecting capacity

Social Functioning

- Ability of their social network to accept condition and effects
- Personal ability to socialise
- Provision of instrumental support
- Social relationship with their healthcare teams

Other

- Cultural differences
- Experiences of procedures
- Recommendations for improvement
- Trauma

Appendix 4

COREQ Checklist for Chapter 7

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Pg7 Line 138-140
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Pg7 Line 140
3. Occupation	What was their occupation at the time of the study?	Pg7 Line 140-141
4. Gender	Was the researcher male or female?	Pg7 Line 138
5. Experience and training	What experience or training did the researcher have?	Pg7 Line 139-140
Relationship with participants		

6. Relationship established	Was a relationship established prior to study commencement?	Pg7 Line 142
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Pg7 Line 142-143
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg 7 143 to Pg8-160
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 5 line 83
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Pg 5 line 85-87
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Pg 5 line 88-90
12. Sample size	How many participants were in the study?	Pg 5 line 101

13. Non-participation	How many people refused to participate or dropped out? Reasons?	Pg 8 162-165
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Pg 6 line 103-104
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Pg 6 line 113-116
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Pg 9 Table 2
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Pg 6 line 108-110
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	Pg 6 line 104-108
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Pg 6 line 111-112
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Pg 6 line 112-113
21. Duration	What was the duration of the inter views or focus group?	Pg 6 line 103
22. Data saturation	Was data saturation discussed: information power	Pg 5 line 91-93

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Pg 6 line 113
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Pg 7 line 122-123
25. Description of the coding tree	Did authors provide a description of the coding tree?	Pg 7 line 123-126
26. Derivation of themes	Were themes identified in advance or derived from the data?	Pg 7 line 122-136
27. Software	What software, if applicable, was used to manage the data?	Pg 6 line 118
28. Participant checking	Did participants provide feedback on the findings?	Pg 6 line 113-114
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Pg 13-27
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pg 13-27

31. Clarity of major themes	Were major themes clearly presented in the findings?	Pg 13-27
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pg 13-27

Glossary

Chronic Kidney Disease	Chronic kidney disease is a sustained reduction in kidney function or evidence of structural damage such as proteinuria that persists for more than 3 months. It results in the irreversible loss of the kidneys ability to filter waste and excess fluids.
Cohort Study	A longitudinal observational study that follows a cohort over time.
Conceptual Model	A simplified representation of how different concepts, factors, or processes are related.
Framework analysis	A structured method for analysing qualitative data which utilises a matrix to sort data into themes or categories.
Framework synthesis	Framework synthesis is a method of qualitative evidence synthesis that uses an existing framework to organise and analyse data from multiple studies, while allowing new themes to emerge from the evidence.
Haemodialysis	A form of kidney replacement therapy that removes waste product and excess fluid from the blood when kidney function is severely reduced or absent.
Healthcare Workload	The tasks and demands associated with managing health and healthcare.
Illness Burden	The impact of a disease or health condition on a person's physical, emotional, social, and financial wellbeing.

Kidney Failure requiring Replacement Therapy	Advanced kidney disease, where native kidney function is insufficient to sustain life without replacement therapy.
Kidney Replacement Therapy	A medical treatment to replace the function of failing kidneys. Three main types: haemodialysis, peritoneal dialysis, kidney transplant
Kidney Transplant	A surgical procedure in which a healthy kidney from a living or deceased donor is placed in a person with kidney failure in order to replace their renal function.
Multimorbidity	The presence of two or more long term health conditions
Non-adherence	Deviation from medical advice
Patient Capacity	The physical, psychological, cognitive, social, financial, and environmental resources available to an individual to manage their health, healthcare, and daily life.
Peritoneal Dialysis	A form of kidney replacement therapy that uses the exchange of dialysis fluid within the abdominal cavity and the movement of solutes across lining of the abdomen to replace renal function.
Polypharmacy	The concurrent use of multiple medications by a single individual.
Self-efficacy	An individual's belief in their ability to successfully perform behaviours or tasks required to achieve specific goals or outcomes.

Taxonomy	A systematic classification system for different phenomena.
Thematic analysis	Qualitative research methodology that is used to identify, analyse, and interpret patterns (themes) within a dataset
Treatment Burden	The impact of undertaking healthcare workload has on a person's daily life and wellbeing.

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