CHIEF SCIENTIST OFFICE

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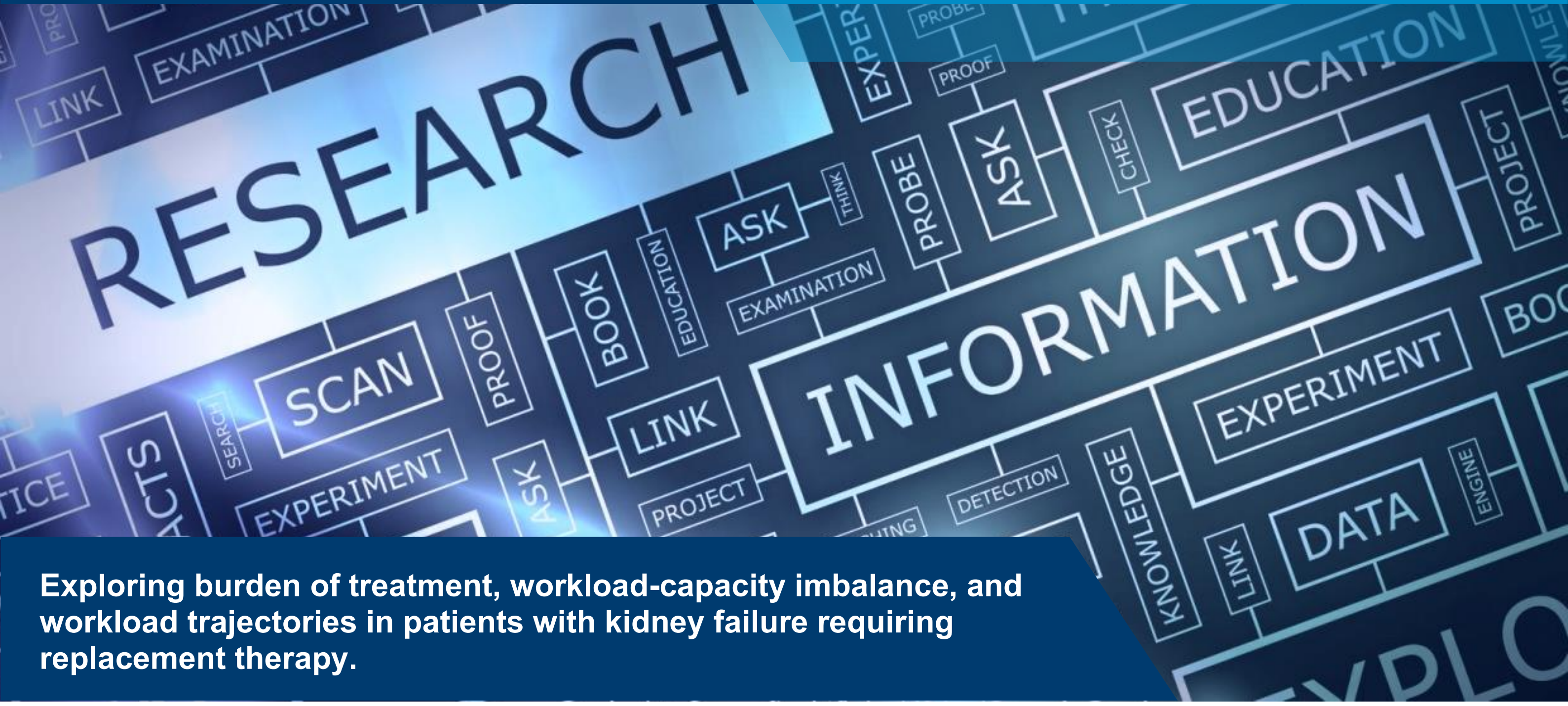
RESEARCH PROJECT BRIEFING



Exploring burden of treatment, workload-capacity imbalance, and workload trajectories in patients with kidney failure requiring replacement therapy.

AIMS

- ‘Healthcare workload’ is what we call the work people are required to do to manage their health conditions. This encompasses everything from understanding what their condition is and what their treatment options are, recruiting others to help them, enacting complex management plans at home including taking medications and sticking to tight dietary and fluid regimes, attending clinic appointments and procedures, and evaluating their choices and adapting to ongoing changes.
- ‘Capacity’ is what we call the ability to undertake this work. It is influenced by many things, including the financial resources, prior medical knowledge, access to transport, physical and mental health and the ability of family, friends and the wider community to help.
- ‘Treatment Burden’ is the impact healthcare workload has on wellbeing. If someone’s workload outstrips their capacity, they could become overburdened which can lead to worse outcomes.
- When patients experience kidney failure and need to start kidney replacement therapy (KRT)- either haemodialysis, peritoneal dialysis or a kidney transplant- they are faced with life changing treatment that can be completely overwhelming. 615 people in Scotland started KRT during 2024, and almost 6000 people receive KRT long term in Scotland.
- The aim of this study is to understand patients’ experiences of treatment burden during transition onto kidney replacement therapy in order to understand how we could improve the care of patients transitioning onto KRT.

KEY FINDINGS

- The process of transitioning onto KRT is very onerous for patients and there are a wide variety of healthcare workloads and ways that patient capacity can affect experiences of starting KRT described in the academic studies included in the systematic review.
- Older patients, patients with a higher medication burden (>15 medications), patients who start KRT on haemodialysis, late referral to renal services and changing KRT modality (for example changing from peritoneal dialysis to haemodialysis) and having a transplant that failed were all associated with higher average workload. Patients who started KRT with a pre-emptive transplant had much lower average workload compared to patients who started KRT on haemodialysis or peritoneal dialysis.
- Treatment burden evolves over time. Almost all find the immediate period of transitioning onto KRT burdensome and difficult, however some participants described their burden reducing over time and some described ongoing high burden.
- The factors that determined participants' experience of burden was a combination of their individual healthcare workload, their capacity to meet this workload and their experiences of interacting with the healthcare system. Over time, healthcare system experiences had a pronounced impact on treatment burden regardless of individual workload and capacity factors with those who had experiences of smooth, well-coordinated care much less burdened than those with experiences of significant gaps and difficulty accessing the required services. This is a key modifiable factor.

WHAT DID THE STUDY INVOLVE?

This project had three parts:

1. A large systematic review looking at what had already been published on treatment burden during transition onto kidney replacement therapy
2. A study looking at how much time per month kidney replacement therapy patients spent doing healthcare work in the six month before they started and the 3 years afterwards, and what were the features that placed patients at risk of higher workload
3. An interview study where participants were interviewed once before they started kidney replacement therapy and up to three times in the first year after start to see what they're experiences of treatment burden were and how it changed over time

A Patient Public Involvement and Engagement (PPIE) group was involved with the design of every aspect of the study. The PPIE group consisted of up to six longstanding renal patients with experiences of reviewing research proposals. The group met every three months at the design stages and provided input on both overarching conceptual elements of the research question, study design and overall acceptability, and specific elements such as the acceptability of recruitment

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

- We found that patients had a very high workload during transition onto kidney replacement therapy, and their capacity had a large impact on how burdensome they found the work.
- Some patients had much higher burdens and some patients had much lower burdens. Although patients who underwent kidney transplant often were burdened at the time of the operation, when interviewed more than 6 months after the operation these patients had a noticeably lower burden than patients on haemodialysis or peritoneal dialysis. This highlights how beneficial kidney transplant is, and the importance of innovations both to increase the availability of organs and to help renal patients remain well enough to be eligible for transplant.
- Patients who had a weak social network for support, younger patients who were missing out on 'normal' life, disabled patients, patients who needed to start kidney replacement therapy at very short notice, and patients who experienced complications or setbacks in their expected plans (for example a potential transplant falling through) had high levels of burden. This highlights how some patient groups are at a higher risk of being overburdened and could benefit from targeted support.
- How the system operated had a big impact on patients' experiences of treatment burden. Difficulty accessing or co-ordinating care had a great impact on experiences of burden regardless of individual workload and capacity factors. Continuity of care was very important to patients, and the ability to build long-term trusting relationship with a small number of clinicians rather than seeing someone different every time was highlighted often. Communication between primary and secondary care was also very important, with patients describing difficulty in getting medications prescribed in hospital dispensed in the community causing considerable burden. The need to travel great distances to access specialist services was often described as burdensome by rural participants.

- Healthcare system experiences are a key modifiable factor in treatment burden. As clinicians, it can be very difficult to meaningfully impact some of the societal factors such as poor housing, poverty or social isolation that may curtail patient capacity or reduce the necessary healthcare workload required in managing a life-threatening chronic condition such as kidney failure but we can alter the way we deliver services to provide treatment burden informed care. This work provides an important insight into how services might be reconfigured to best meet the needs of patients by highlighting the healthcare system factors that have the greatest impact on treatment burden.

WHAT IMPACT COULD THE FINDINGS HAVE?

- For patients, this is a study that captures the patient experience and could inform interventions to reduce the burden of treatment.
- For policy, this study highlights how some innovations in service delivery such as greater centralisation and reduced continuity can contribute to increased treatment burden. It reinforces that treatment burden is a vitally important consideration especially as complex new developments such as incorporating new digital infrastructures and AI into service delivery, workforce development or reconfiguring the service for multimorbidity are proposed.
- For practice, this study reinforces that we should actively consider our patients workload and capacity and try to deliver care in ways that minimises excessive workload and increases capacity.

HOW WILL THE OUTCOMES BE DISSEMINATED?

- Outputs from this project have been presented in a wide range of academic conferences including British Transplant Society, Vascular Access Society of Great Britain and Ireland, UK Kidney Week, European Society of Organ Transplantation, Association of Surgeons of Great Britain and Ireland and the World Transplant Congress.
- The systematic review is already published in BMC Medicine, and the healthcare workload study and the interview study have been written up and are in the process of being submitted to academic journals for publication.

- This work has been presented extensively at local level and at national level to the Scottish Live Donor Network, a joint meeting of the Edinburgh and Glasgow Transplant Unit, and CSO Renal and Diabetes research day where it might help inform decisions about service development.
- We are working with the PPIE group to find the best way to disseminate the results to patients. Options under consideration include posters, leaflets and short videos, and reaching out to dialysis units, clinics and patient groups.

CONCLUSION

Treatment burden is a valid and important consideration in the care of patients transitioning onto kidney replacement therapy. There are three key questions that front line clinicians and politicians, civil servants and health service managers who make decisions about how services are structured should ask:

1) Are there ways of reducing patients' healthcare workload and making it as easy as possible to fulfil?
2) How can we best support and build patients' capacity?
3) How can we deliver treatment burden informed care and design our services and processes to generate as little burden as possible?

This work provides some answers and important insights for renal care and could provide an important evidence base for improving the care we offer Scotland's renal patients.

RESEARCH TEAM & CONTACT

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Additional Information

CAF/23/03. Grant completed 31/07/2025. PhD to be submitted by April 2026.