

CAF/23/03 - Exploring burden of treatment, workload-capacity imbalance and workload trajectories in patients with kidney failure requiring replacement therapy.

Being a patient with kidney failure is hard work. Not only do patients need to deal with the burden of the illness itself with its numerous symptoms that tax their energy and quality of life, but also meet the work that comes with its' treatment. This work can include numerous hospital visits, complex medication regimes, a range of operations and procedures to create and maintain dialysis access, attending dialysis, dietary and fluid restrictions and all the work involved with being prepared for and having a kidney transplant. None of this happens in isolation: people with kidney failure still have roles and responsibilities to cope with on top of dealing logistically and emotionally with their kidney disease. They may have families to care for, bills to pay, careers, friendships, responsibilities in the community and on top of that, many people with kidney disease also have other medical conditions that come with their own symptoms and treatment workload to cope with. We name the ability that a person has to cope with this workload their 'capacity'.

Some people with kidney failure become overwhelmed by all they have to deal with. This can start a vicious cycle where they can't do what is being asked of them, and therefore start omitting important parts of their treatment such as attending hospital appointments or taking vital medication. This can lead to their health further deteriorating, and then they have even more to cope with and even less resources to cope with all that's going on. We hope to better understand which patients are most at risk of becoming overwhelmed and at which points in their kidney failure treatment journey this is most likely to happen, and what are the protective features that can stop people from becoming overwhelmed. We will do this by looking in detail at work already published about the burden of treatment at the time of moving onto kidney replacement therapy, looking at patterns in treatment workload in patients treated in a large kidney centre, and by conducting a series of interviews with patients and their caregivers over the first year of needing kidney replacement therapy. The hope is that by understanding this we will be able to develop ways to identify these patients early and put in place interventions and approaches to treatment that will support them and improve their ability to meet the demands of their illness and their treatment, and improve both their clinical outcomes and their overall quality of life.