# The role of self-regulation in managing chronic kidney disease

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# Abstract

Self-regulation, which involves planning, initiating, monitoring, and evaluating behaviour to achieve goals, is essential for optimising health outcomes among patients on dialysis. However, many patients struggle with this, and the factors influencing effective self-regulation remain unclear. This thesis aimed to identify factors contributing to successful self-management of chronic kidney disease across three empirical chapters. Chapter 2 revealed that 46 randomised control interventions using techniques like goal setting and monitoring produced moderate to large effects on behavioural and physiological outcomes. Few studies assessed psychological targets, but significant effects were observed for knowledge and quality of life. Moderation showed that interventions including social support enhanced self-efficacy. Chapters 3 and 4 qualitatively examined patients' experiences and attitudes towards self-regulation, identifying differences between high and low adherence groups. Both groups used similar self-regulatory strategies, but their frequency and effectiveness varied. Patients with low adherence employed a broader range of strategies (e.g., more habitual behaviours, drink substitutions, and thirst management strategies, along with increased self-monitoring of behavioural outcomes) compared to those with high adherence. They also encountered more challenges, frequently reporting negative impacts from competing life demands and feeling less supported. Chapter 5 demonstrated a strong positive relationship between regulatory support and fluid management, with family support being particularly influential. Further, self-efficacy and commitment emerged as crucial mechanisms in this relationship. The quality of support and patients' geographical location significantly influenced outcomes. Overall, the findings highlight the significant impact of psychosocial and environmental factors on disease management. This work has several theoretical and methodological implications for understanding self-regulation and offers a nuanced perspective on processes supporting effective self-management.

# Author's notes

Three empirical chapters of this thesis (2 through 4) were written as individual manuscripts to facilitate submission of the work to peer-reviewed journals for publication. Although each report on independent studies, some content in the introductions of these chapter may overlap with each other, the General introduction (Chapter 1) and General discussion (Chapter 6) of the thesis. To ensure thematic organisation and smooth progression between chapters, all empirical chapters have been slightly modified for this thesis. Additionally, to enhance readability and cohesion, references for each chapter have been consolidated and are presented collectively at the end of the thesis. At time of submission, the results of two studies in this thesis have been submitted for publication in peer-reviewed journals, as listed below. The author collected data for all reported studies. All studies were pre-registered and received ethical approval from the University of Essex and the NHS Research Ethics Committee and Health Research Authority.

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# List of abbreviations and acronyms

| | |
|---|---|
| ANOVA | Analysis of Variance |
| BCT | Behaviour Change Taxonomy |
| CKD | Chronic Kidney Disease |
| CBT | Cognitive Behavioural Therapy |
| COREQ | Consolidated Criteria for Reporting Qualitative Research |
| CSM-SR | Common-Sense Model of Self-Regulation |
| CT | Control Theory |
| eGFR | estimated Glomerular Filtration Rate |
| ESRD | End-Stage Renal Disease |
| HADS | Hospital Anxiety and Depression Scale |
| HBM | Health Belief Model |
| IDWG | Interdialytic Weight Gain |
| KRT | Kidney Replacement Therapy |
| MEMS | Medication Event Monitoring System |
| NHS | National Health Services |
| OSF | Open Science Framework |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| QoL | Quality of Life |
| RES | Regulatory Effectiveness of Support |
| RS | Regulatory Support |
| SCT | Social Cognitive Theory |
| SDT | Self-Determination Theory |
| SSS | Social Support and Strain |
| TPB | Theory of Reasoned Action/Planned Behaviour |
| TTM | Transtheoretical Model |
| UK | United Kingdom |

# Chapter 1

# General introduction

The primary aim of this thesis was to gain insight into the specific factors that influence successful self-management in chronic kidney disease (CKD). In order to understand the relationship between self-regulation and adherence in chronic disease, the General Introduction is organised as follows. Firstly, I will acquaint the reader with a concise overview of chronic illness, including its management and various implications such as economic, social, and psychological impacts. Secondly, a detailed look at CKD will be presented, starting with an introduction to its epidemiology and risk factors. Thirdly, the focus will shift to the conceptualisation of self-management and the role of patients in this process. Fourthly, I will undertake a systematic exploration of the theoretical underpinnings of behaviour change, with a specific emphasis on their capacity to elucidate the psychological mechanisms or constructs involved in initiating and maintaining behaviours related to disease management. Fifthly, I will delineate some of the shortcomings of existing theories and models in explaining and predicting health behaviour change, recognising that a holistic understanding of successful self-management may necessitate incorporating processes drawn from various theoretical frameworks. Finally, the General introduction will conclude with an overview of the thesis, accompanied by a description of the objectives of the studies conducted in each subsequent chapter.

## Chronic illness

Chronic illnesses, characterised by their long-term progression and incurable nature, represent a significant global health challenge (NHS England, 2018; World Health Organization, 2021). In 2021, chronic diseases such as cardiovascular, respiratory, cancers, and diabetes accounted for 71% of all deaths worldwide, with 15 million deaths occurring prematurely between ages 30 and 69 (World Health Organization, 2021). These conditions not only impose a substantial public health burden but results in significant losses in workforce productivity, hindering economic and social growth.

In the United Kingdom (UK), chronic illnesses affect an estimated 26 million people, with 10 million managing two or more conditions. These individuals account for a substantial portion of healthcare utilisation, with 50% of GP appointments, 64% of hospital outpatient visits, and 70% of hospital bed occupancy attributed to them (NHS England, 2018). Moreover, chronic illnesses necessitate ongoing management, leading to increased reliance on health services and substantial healthcare expenditures.

Living with chronic illness has profound physical, social, and psychological impacts. Optimal management involves individuals taking an active role in self-management, encompassing lifestyle changes, medication adherence, and symptom monitoring. However, this management is complex, demanding, and disruptive to daily life, often requiring support from close others (e.g., family, friends). Such dependence can lead to changes in social roles, economic challenges, and psychological distress, impacting both the affected individual and their close others. As chronic illnesses progress, the burden on close others increases, impacting their quality of life and mental wellbeing which may influence their capacity to appropriately respond to the situation (Gilliss et al., 2019; Juntunen et al., 2018). For affected individuals, dependence on others can lead to distressing emotions (e.g., guilt, anger, and helplessness) and threaten their autonomy, causing uncertainties about the future. These challenges contribute to poor psychological health, with a significant portion of individuals with chronic illness experiencing mental health conditions such as depression and anxiety (e.g., Battalio et al., 2018; Lim et al., 2017). At least 30% of individuals with chronic illness have a mental health condition (Cimpean & Drake, 2011), directly impacting the severity of their primary chronic illness and the presence of secondary illnesses such as pain, fatigue, and general functioning (Battalio et al., 2018, 2019; Wood et al., 2013).

Addressing the challenges of chronic illness requires a comprehensive approach focused on tertiary prevention where individuals are assisted in optimally managing their condition (e.g., teaching coping strategies, support groups, multidisciplinary management programmes, follow ups to ensure adherence to treatment, symptom/condition monitoring). Such an approach can soften the impact of chronic illness, reduce disability, improve quality of life, and life expectancy for affected individuals and their close others.

The research reported in this thesis will focus upon self-management in the context of one chronic illness: chronic kidney disease.

## Chronic kidney disease

I start by providing an overview of the epidemiology and risk factors related to CKD. Following this, I delve into the process through which patients typically discover their CKD diagnosis, the difficulties inherent in managing CKD, and the crucial role patients play in self-managing their illness.

### *What is CKD and how common is it?*

Chronic Kidney Disease is a loss of kidney function that poses a substantial global health challenge due to its high incidence and prevalence (Jager & Fraser, 2017; Naghavi et al., 2017), driven by an aging population and increasing levels of diabetes, hypertension, and obesity. Approximately 1 in 8 adults worldwide suffer from CKD (Hill et al., 2016), with 697.5 million cases of CKD recorded in 2017, and a global prevalence of 9.1% (Bikbov et al., 2020; Saran et al., 2018). CKD is closely associated with diminished quality of life (Abdel-Kader et al., 2009; Makris & Spanou, 2016), reduced physical function (Hiraki et al., 2013), increased risk of cardiovascular disease and increased mortality (Astor et al., 2011; Levey & Coresh, 2012; MacKinnon et al., 2018).

In 2017, CKD contributed to approximately 1.2 million deaths globally, with mortality rates rising by 41.5% between 1990 and 2017 (Bikbov et al., 2020). Moreover, increased risk of cardiovascular diseases, resulted in an estimated additional 1.4 million deaths in 2017 (Bikbov et al., 2020). These mortality rates translate into substantial disability-adjusted life years lost, highlighting the profound impact of CKD on global health. Consequently, kidney diseases are ranked as the 8th cause of mortality, the 10th cause of years of life lost, and the 10th cause of disability-adjusted life years (PAHO, 2021). Beyond its health implications, CKD also imposes significant social and economic costs. In the UK, the management of CKD accounts for 3.2% of National Health Services (NHS) expenditure costing approximately £7 billion, with £6.4 billion related to direct NHS annual cost (Kidney Research UK, 2023). For patients on dialysis in particular, non-adherence results in acute hospital admissions with complications such as high plasma potassium concentrations and fluid overload, over and above the increased risk of cardiovascular disease. This places a considerable financial burden on both healthcare systems and individuals, affecting tax revenue and increasing reliance on welfare support. Moreover, CKD decreases the quality of life of patients and their close others, leading to social, financial, and psychological challenges. Patients often must give up work and activities, relying on others for assistance (Christensen & Ehlers, 2002; Untas et al., 2011), which can contribute to feelings of helplessness, disappointment, and low self-esteem, exacerbating anxiety and depression (Yucens et al., 2019).

### ***What causes CKD?***

The primary causes of CKD are hypertension (high blood pressure) and diabetes, which collectively contribute to 30-50% of all CKD cases (Atkins, 2005; Jha et al., 2013; Webster et al., 2017). Diabetes affects approximately 285 million adults globally, with a prevalence of 6.9%, projected to rise to 7.7% (439 million) by 2030 (Cho et al., 2018; Whiting et al., 2011). Similarly, hypertension is both a cause and consequence of CKD, with up to 90% of CKD patients also experiencing hypertension (Kearney et al., 2005; Muntner et al., 2010).

Age 60 years and over is associated with increasing incidence of CKD, the ageing population worldwide therefore driving an increase in the prevalence of CKD. Similarly, increasing rates of obesity results in increased prevalence of diabetes, hypertension, and cardiovascular diseases which are additional contributors to CKD development (Fuchs & Whelton, 2020; Lu et al., 2013).

### ***How is CKD detected?***

Kidney disease is often asymptomatic, with symptoms rarely prompting individuals to seek medical attention. Instead, it is typically identified incidentally through routine screenings of urine and serum chemistry profiles. Symptoms such as foamy urine, flank pain, and decreased urine output may occur infrequently, with symptoms such as nausea, oedema, and fatigue emerging as CKD progresses (Janmaat et al., 2021; Skorecki et al., 2012). Complications such as anaemia, mineral bone disease, and cardiovascular issues further compound the burden of care for patients (Kalantar-Zadeh et al., 2021). Chronic kidney disease is defined by abnormalities in kidney structure or function that last over three months, including decreased eGFR (a test that measures the level of kidney function and determines the stage of kidney disease), albuminuria or proteinuria (measured using albumin to creatinine ratio or protein to creatinine ratio), imaging indicating kidney damage or renal tubular disorders (Levey et al., 2015; Levin et al., 2013). Chronic kidney disease is classified into five stages, with stage 3 subdivided into 3a and 3b. As CKD progresses from stage 3 to 5, the associated cardiovascular risk also increases (Levin et al., 2013) – see Table 1.

**Table 1**
*Classification of Chronic Kidney Disease using eGFR*

| Stages of CKD | Estimated glomerular filtration rate (eGFR) | What it means |
|---|---|---|
| Stage 1 | 90 or higher | Kidney damage with normal kidney function |
| Stage 2 | 60-89 | Mild loss of kidney function |
| Stage 3A | 45-59 | Mild to moderate loss of kidney function |
| Stage 3B | 30-44 | Moderate to severe loss of kidney function |
| Stage 4 | 15-29 | Severe loss of kidney function |
| Stage 5 | Less than 15 | Kidney failure/ End stage renal disease |

*Note.* eGFR is a measurement of kidney function level and as the number decreases, kidney function worsens.

### *How is CKD managed?*

Upon diagnosis of CKD, patients and their care teams collaboratively determine treatment strategies, particularly focusing on managing hypertension, diabetes and associated complications to mitigate cardiovascular risk. A significant aspect of CKD management, from early stages through to when dialysis is needed, relies on patient self-management. For stages 3-5 this focuses on slowing progression of the kidney disease, minimising cardiovascular risk and preventing specific complications including renal bone disease. When CKD progresses to the point where the level of kidney function is no longer adequate to sustain a healthy existence, dialysis or transplantation (often called kidney replacement therapy [KRT]) become necessary. Adherence to medication regimens and attendance at clinic continue to be essential for all KRT patients. For patients on dialysis self-management remains particularly important to prevent the complications associated with high plasma potassium concentrations and fluid overload. Effective self-management necessitates patients taking responsibility for their health and working closely with clinicians to devise and adhere to treatment plans (Garnett et al., 2018). Research has shown that implementing these lifestyle changes can slow CKD progression, delay the need for dialysis or transplantation, and decrease premature mortality rates (Gutierrez et al., 2014; Rysz et al., 2017; Snelson et al., 2017). Nonetheless, self-management poses significant challenges for many patients, as they must be well-informed about medication usage, symptom identification and when to seek medical assistance. Moreover, they must develop coping strategies to manage the psychosocial effects of their illness and actively engage with healthcare services. Consequently, adherence levels may suffer due to the substantial effort required for effective self-management.

In summary, CKD is a progressive condition categorised into five stages based on declining kidney function, often diagnosed incidentally due to its asymptomatic nature. It’s high prevalence and associated complications contribute to significant social and economic burdens, particularly among individuals with diabetes, hypertension, and advanced age.

### Kidney replacement therapy.

***Kidney transplant.*** Kidney transplantation is the preferred option for most patients with end-stage renal disease (ESRD) due to its potential to improve survival and quality of life. However, the transplantation process is challenging. Patients must meet strict eligibility criteria, demonstrate treatment adherence (e.g., dietary and fluid restrictions) and commit to lifelong post-transplant care, including taking anti-rejection medications and attending regular check-ups. In the UK, patients face an average wait of three years for a kidney transplant, with demand surpassing availability. As of March 2021, 3,525 patients awaited transplantation, while the number of deceased donors decreased from 1,481 in 2019-2020 to 1,106 in 2020-2021, resulting in fewer kidney transplants being performed (NHS Blood and Transplant, 2022). Despite being the optimal treatment for ESRD, many patients are thus unlikely to receive a kidney transplant.

***Dialysis.*** Dialysis is a critical component of treatment for many patients with kidney disease, as it removes waste products and excess fluid from the body when the kidneys are no longer functioning properly. In the UK, approximately 30,000 people rely on dialysis (UK Renal Registry, 2021). There are two primary types of dialysis: haemodialysis and peritoneal dialysis. Haemodialysis involves using a machine to filter the blood, typically requiring three sessions per week lasting 4 hours each. Peritoneal dialysis uses the peritoneal lining of the abdomen as a filter and is typically performed at home with daily sessions lasting 40 minutes each and being necessary up to 4 times each day.  Dialysis imposes significant burdens on patients, including frequent visits to healthcare facilities, which may disrupt employment. Patients may also experience various physical and psychosocial challenges, such as sleep disturbances, pain, fatigue, abdominal discomfort, fluctuations in blood pressure, and emotional issues like anxiety and depression (Benetou et al., 2020; Lambourg et al., 2021; Pereira et al., 2017). Moreover, dialysis is only partially effective and will continue indefinitely unless patients receive a kidney transplant or choose palliative care. Without a transplant, many patients will remain on dialysis until death, highlighting the importance of self-management through dietary and fluid restrictions, lifestyle modifications, and medication adherence to optimise outcomes.

**The self-management of diet and fluid intake.** The diet individuals consume, and normal metabolic processes produce the waste products that the kidneys filter. As kidney function declines, waste products and water accumulate in the body due to the kidneys' reduced ability to filter them effectively. Dietary restrictions attempt to alleviate the kidneys' workload helping maintain a safe biochemical state (Nazar, 2013).

***Diet restrictions.*** Diets high in potassium and phosphate can exacerbate health issues in CKD patients, leading to complications such as hyperkalaemia (high potassium) and hyperphosphatemia (high phosphorus), which are associated with increased mortality and cardiovascular risks (Brunelli et al., 2017; Kovesdy et al., 2007; Luo et al., 2016; Noori et al., 2010; Torlen et al., 2012; Kalantar-Zadeh, 2013; Snelson et al., 2017). Adhering to recommended dietary changes, can mitigate these risks, and improve outcomes, including delaying the need for dialysis or kidney transplantation, reducing mortality and hospitalisations, and preventing CKD-related complications (Rysz et al., 2017; Goraya & Wesson, 2016; Kang, Chang & Park, 2017; Saran et al., 2003; Goraya et al., 2014; Isakova et al., 2013).

There is no fixed renal diet as dietary recommendations vary based on factors such as renal treatment type, comorbidities, body weight, and CKD stage. Early CKD patients may need to adjust protein and sodium intake, while those with ESRD require more extensive modifications, including fluid and protein intake adjustments, as well as vitamin and mineral supplementation (Ash et al., 2014; Lambert, Mullan & Mansfield, 2017; Ikizler et al., 2020; Snelson et al., 2017). Treatment changes, such as transitioning from peritoneal to haemodialysis, also necessitate dietary adjustments, such as potassium restrictions (Molina et al., 2021; Saran et al., 2003). Initial treatment often involves dietary restrictions and supplements to manage electrolyte imbalances and mineral disorders (Inker et al., 2014; Isakova et al., 2017; NICE, 2021; Wheeler et al., 2017).

***Fluid restriction.*** The kidney needs a minimal urine volume to filter and excrete waste products from the blood and any excess water in the body is excreted also. Healthy kidneys can regulate this with minimal effort. When the kidneys fail, alongside the ability to excrete waste products, the kidneys' ability to control the volume of water excreted fails also. This most often manifests as insufficient capacity to excrete water, resulting in fluid accumulation, which can result in life threatening complications such as pulmonary oedema. This fluid overload increases the risk of cardiovascular injuries contributing to hypertension, artery stiffness and left ventricular hypertrophy (Akdam et al., 2014; Mitsides et al., 2017; Tsai et al., 2015). Adherence to a restricted fluid intake is therefore essential as it minimises cardiovascular complications and promotes haemodynamic stability.

In summary, despite the importance of self-managing fluid and diet to delay progression and prevent complications of kidney disease, patients struggle to adhere to required regimens. Additionally, some of these alterations contradict regular healthy diet recommendations, due to restrictions on dairy, fruits, vegetables and fluid intake to control phosphate, potassium and fluid levels. Furthermore, there is a lack of theoretical and empirically informed self-management techniques within the NHS, hindering patients' ability to effectively self-manage, adhere to treatment, and minimise complications and mortality.

## Theoretical underpinnings of health behaviour change

Traditional disease management approaches for chronic conditions like CKD have often focused solely on treating the disease through pharmacological interventions, with patients playing a passive role. Nevertheless, these approaches have fallen short of expectations and proven expensive, largely due to a combination of factors. These include patients struggling to come to terms psychologically with their diagnosis, as well as the interference of other life circumstances or concurrent health issues that impede effective self-management.

To address these limitations, there has been a shift towards a collaborative approach to managing chronic diseases. This approach emphasises a partnership between patients and healthcare providers, with patients taking a central and active role in managing their disease to optimise health outcomes (Allegrante et al., 2019; De Ridder et al., 2008; Grady & Gough, 2014; Holman & Lorig, 2000).

### *Conceptualisation of self-management*

A CKD diagnosis necessitates patient self-management, encompassing three distinct but connected processes: emotional management, role management and medical or behavioural management of the disease (Lorig & Holman, 2003). This suggests that self-management is an interactive, dynamic, and ongoing task that patients must engage in to manage their disease. Self-management involves adopting various roles and utilising behavioural (lifestyle and role changes), cognitive (e.g., decision making, planning), and emotional regulation strategies (e.g., stress management) to monitor (e.g., symptoms, complications, and dialysis treatment) and optimise disease management and quality of life. Patients on dialysis and their close others must navigate treatment complexities, including transportation logistics and treatment decisions such as duration and frequency of dialysis (Costantini et al., 2011; Curtin et al., 2005). Dialysis imposes significant burdens on patients and close others, leading to psychosocial challenges and low adherence to medication, diet, fluid management, and dialysis attendance (Chironda et al., 2015; Griva et al., 2014; Peng et al., 2019; Theofilou, 2013; Vijay & Kang, 2022).

### *Understanding behaviour and how to change it*

Understanding the challenges in patient self-management and implementing effective interventions to improve adherence and health outcomes requires a grasp of the theoretical foundations of behaviour change. When exposed to any situation, we have the options of engaging in various behaviours. Some of these behavioural options have a greater chance of being executed than others reflecting our current internal (e.g., habits, motivation) and external (e.g., financial, resources) influences. Behavioural interventions draw upon various theories and models to identify relevant constructs for testing and implementation. These theories aim to describe and predict behaviours and behaviour change, guiding intervention design. However, the numerous theories measuring the same constructs under different names (e.g., illness consequences in CSM-SR and perceptions of severity in HBM) complicate the identification of when and how each construct is most dominant. This can potentially lead to interventions overlooking crucial constructs, highlighting the need for a comprehensive understanding of behaviour change theories. Consequently, there is a need for a comprehensive understanding of behaviour change theories.

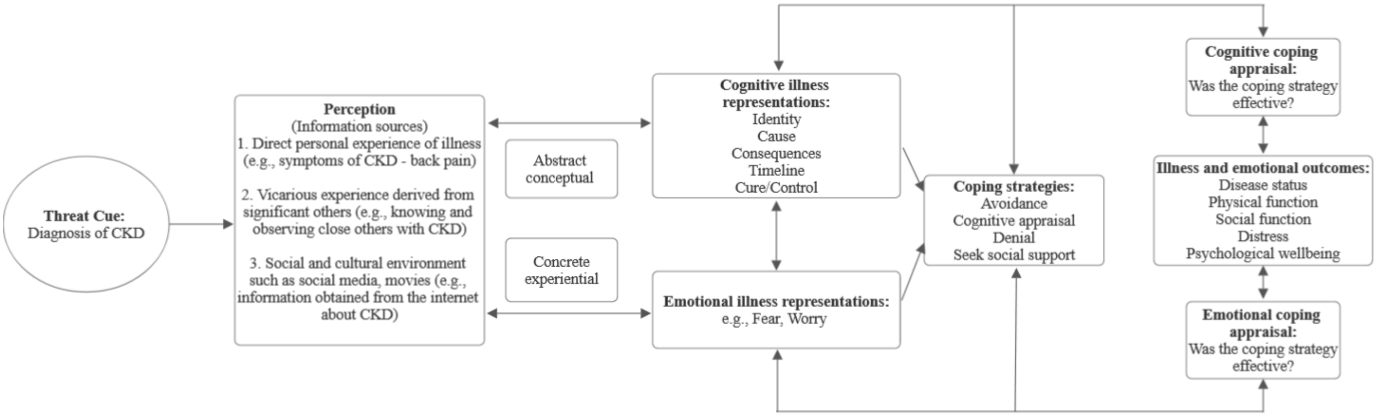
The most commonly used theories and models for understanding and predicting adherent behaviours include the Common-Sense Model of Self-Regulation (CSM-SR; Leventhal et al., 1980), Social Cognitive Theory (SCT; Bandura, 1986), Health Belief Model (HBM; Becker, 1974), Theory of Reasoned Action/Planned Behaviour (TPB; Ajzen, 1988, 1991; Ajzen & Fishbein, 1980), Transtheoretical Model (TTM; Prochaska & DiClemente, 1983), Control Theory (CT; Carver & Scheier, 1982), and Self-Determination Theory (SDT; Deci & Ryan, 1985). These theories aim to understand how patients perceive their illness and identify factors that influence or modify behaviour. While these theories differ in their specific approaches, they share several commonalities. Generally, they view individuals as rational beings whose health behaviours are influenced by how they appraise relevant information. This rational decision-making perspective is foundational across the various models. Moreover, these theories identify similar key constructs believed to be crucial in behaviour and behaviour change. Key constructs include intention, self-efficacy, attitudes and beliefs, and social factors, albeit using different terminology to describe similar constructs (Noar & Zimmerman, 2005; Sheeran et al., 2017). Furthermore, theories like SDT and SCT highlight the role of motivation in driving behaviour change. Cognitive processes are also recognised as significant across all these theories, underscoring their importance in decision-making and behaviour change. While most theories focus on mediating factors to understand behavioural engagement, three models stand out for their conceptualisation of behaviour change as a dynamic process unfolding in stages.. These are the Common-Sense Model of Self-Regulation (CSM-SR; Leventhal, Nerenz, & Steele, 1980), Control Theory (CT; Carver & Scheier, 1982), and Transtheoretical Model (TTM; Prochaska & DiClemente, 1983). It is important to note that these three theories are merely examples of stage-based models and are not necessarily endorsed over other approaches. These models propose that behaviour change is not a single event, but a progression through distinct phases, identifying the processes individuals go through when making behavioural changes.

While the theories share many similarities, they differ in their specific focus and have been applied to various health behaviours across different contexts. For instance, the HBM emphasises perceived threats and benefits, while SDT focuses more on intrinsic motivation. Equally, the CSM-SR has been used to understand how individuals manage chronic illnesses and adhere to treatment regimens (Muscat et al., 2021). The CT has been applied to health behaviours such as physical activity and dietary changes (Dombrowski et al., 2012; Michie et al., 2009). The TTM has been widely used in smoking cessation programs (Prochaska & Prochaska, 2019) and self-management in patients with diabetes (Dunkel et al., 2024; Ibrahim et al., 2015). The importance of self-regulation in behaviour change and adherence is emphasised in CSM-SR and CT, which will be discussed next. For the purposes of this thesis, examples illustrating the conceptualisation of these behavioural change theories and models will be made specific to CKD.

CSM-SR (Leventhal et al., 1980) posits that individuals, upon receiving a medical diagnosis (e.g., CKD), employ their beliefs to make sense of and cope with their condition. Patients' use their illness symptoms to create emotional (e.g., fear, anger) and cognitive (e.g., illness duration) representations that guide their management behaviours. These illness beliefs are based on three information sources: direct experience, vicarious experience from significant others, and social/cultural influences like media. Direct experience involves using past illness and coping strategies to manage current symptoms. Vicarious experience comes from observing friends and family handle illness. Social and cultural sources include interactions and media, shaping labels and strategies for illness management. The interaction between these sources influences patients' self-regulation decisions and behaviours.

The CSM-SR model is dynamic, allowing for the integration of new information, such as updates on CKD status or observations of others with CKD, which patients use to reassess their illness representations. This process forms a jigsaw-like representation where relevant information is retained, and irrelevant information discarded. Patients continuous monitoring of their condition provides additional data for reassessment. The emotional and cognitive representations that patients create incorporates their beliefs or actual labels of kidney symptoms (e.g., changes in urine), the cause of their CKD (e.g., diabetes; *cause*), duration of their CKD (e.g., lifetime; *timeline*), health outcomes (e.g., premature mortality; *consequences*), and CKD treatment effects and their level of their capacity to manage (*cure/control*). A schematic representation of the model can be seen in Figure 1.

**Figure 1**
*An outline of the Common-Sense Model of Self-Regulation Model (Leventhal, Nerenz & Steele, 1984)*



*Note.* The Abstract conceptual are the cognitive beliefs or perceptions describing the health threat (e.g., premature death associated with CKD). The concrete experiential are the actual experiences of having CKD (e.g., shortness of breath, back pain etc) or a memory of these experiences.

Similarly, control theory (Carver & Scheier, 1982) suggests that behaviour changes continuously to maintain perceived aspects of the self and the world close to desired reference values, such as personal goals or standards (e.g., avoiding high-potassium foods). The theory emphasises goal setting, feedback, self-regulation, and adaptive behaviour adjustments in the process of behaviour change. Patient-set goals serve as reference points, guiding behaviour, while continuous monitoring of progress through internal or external feedback informs patients of their performance relative to these goals. Based on this feedback, patients adjust their behaviour to align with their desired outcomes. Self-regulation involves patients actively monitoring their behaviour, setting goals (e.g., avoiding high-potassium foods), implementing strategies (e.g., seeking support), and adjusting their efforts to ensure goal achievement (e.g., refraining from purchasing high-potassium foods) see Figure 2.

**Figure 2**

*A concrete behavioural illustration of the five-level hierarchy of feedback systems (Carver & Scheier, 1981)*

*Note.* A five-level hierarchy of feedback systems in which the output of a superordinate system constitutes the resetting of reference values at the immediately subordinate level. At the lowest level, the output is behaviour with each level representing a comparator at that level. The behaviour described here is that of a patient becoming aware of food items that are high in potassium and phosphate whilst trying to get a kidney transplant.

Extensive research has demonstrated the significance of these theoretical factors in behaviour change across various health domains, including medication adherence, dietary modifications, physical activity, and health-related knowledge. This highlights their critical role as essential constructs for interventions: common sense model of self-regulation (e.g., Jansen et al., 2010; Muscat et al., 2021), social cognitive theory (e.g., Nguyen et al., 2019; Patterson et al., 2014), health belief model (e.g., Cengiz & Ozkan, 2022; Nooriani et al., 2019) theory of reasoned action/planned behaviour (e.g., Rich et al., 2015; Scannell et al., 2020), transtheoretical model (e.g., Mohebbi et al., 2021), control theory (e.g., Dombrowski et al., 2012; Michie et al., 2009), and self-determination theory (e.g., Sim et al., 2022; Wu et al., 2022).

In the context of CKD, a recent review of nine studies examined the link between illness perceptions, based on the CSM-SR, and treatment adherence. Six studies found associations between illness perceptions and treatment adherence. The strongest associations were found between adherence to dietary restrictions and emotional representations, consequences, acute timeline, and personal control. Additionally, IDWG was positively linked to patients' illness identity, their understanding of the illness's consequences and causes, and their perception of the illness timeline. Additionally, two studies combining various adherence measures into a composite score also revealed significant associations with illness perceptions (Oliveira et al., 2022). Similarly, supporting the principles of control theory, Chan et al., (2021) demonstrated that behaviour change interventions incorporating goal setting, monitoring, and feedback were linked to improved dietary adherence.

### ***Challenges of behaviour change theories***

While these commonly used models and theories have shown utility in various health behaviour contexts, they are not without limitations particularly in the context of chronic illnesses such as CKD. A more comprehensive examination of both their applications to health behaviours and their challenges and shortcomings will be presented in subsequent sections

**Generalisability and effectiveness.** While behavioural change theories aim for broad applicability across health behaviours and illnesses, empirical evidence reveals inconsistencies. For example, a review by Jones et al. (2014) assessing HBM interventions' effectiveness in improving adherence across various behaviours (e.g., medication uptake, use of sun cream, attending mammogram screening) found only moderate effect, especially in cancer patients but not substance abuse and bacterial vaginosis; suggesting that the HBM may be better at predicting some behaviours than others. Similarly, the Common-Sense Model (CSM) shows variability in predicting medication adherence across different clinical cases and populations. While some studies support associations between illness perceptions and adherence in conditions like stroke (e.g., Cheiloudaki & Alexopoulos, 2019; Ruksakulpiwat et al., 2020), diabetes (Kim et al., 2021), and CKD transplant recipients (Wang et al., 2022), others found no such predictive power, particularly in dialysis attendance among CKD patients (Dantas et al., 2020; Kim & Evangelista, 2010; O'Connor et al., 2008; Vélez-Vélez & Bosch, 2016). These inconsistencies suggest that these models may not universally apply across diverse populations and health conditions.

**Focus on behavioural initiation.** Many theories primarily concentrate on initialising behaviour rather than maintaining it which is crucial considering persistent engagement is necessary for optimal management of chronic diseases. The goal of health behaviour change is not only to initiate behaviour but also to ensure its maintenance over time by capturing the dynamic and ongoing nature of behaviour. Existing research regarding the maintained effect of theory-based interventions to promote adherence are conflicting (e.g., Carpenter et al., 2013; Chan et al., 2021; Dombrowski et al., 2010; 2014; Gourlan et al., 2016; Prestwich et al., 2014). For example, Chan et al. (2021) conducted a study to assess the impact of goal setting on enhancing diet quality in individuals with CKD. Findings demonstrated that patient-generated goal setting, particularly related to fruit and vegetable intake, significantly improved diet quality, vegetable intake, and fibre intake over a 3-month period. However, these effects were not observed at the 6 month follow up. In contrast, a review by Dombrowski et al. (2014) testing the effects of controlled trial interventions (e.g., dietary, pharmaceutical, exercise, behavioural therapy) on weight maintenance in obese adults revealed that these interventions effectively reduced weight regain post initial weight loss within 12 months. Furthermore, interventions incorporating a combination of strategies such as dietary adjustments, physical activity, behavioural techniques, and continuous support were linked to weight maintenance up to 24 months.

**Single behaviour focus.** These health behaviour theories have typically been used in studies testing a single behaviour and enhancing our understanding of that behaviour. Despite their insights, these theories offer limited guidance on tackling the complex, multifaceted challenges that individuals with chronic illnesses face in real-world situations. Specifically, they fall short in addressing how patients can manage the simultaneous implementation of multiple lifestyle changes often required for effective disease management. In the context of CKD patients must make several health behaviour changes (e.g., smoking cessation, alter their diet and fluid intake, dialysis, and medication adherence) to optimise their outcomes, an understanding of how to facilitate this would be more pertinent. An approach regarding the processes that underpin the magnitude of behaviours individuals with chronic illnesses must engage in will enable us to discover more general health factors associated with self-management but also the wider contexts in which these health behaviours operate (e.g., should behaviours be changed consecutively or concurrently, and which behaviours should be changed first). Additionally, this will allow the linkage of specific constructs from different health behaviour theories (e.g., CSM-SR, CT, SCT) such that we are able to develop a network of interrelated health beliefs and constructs that assists in the initiation and maintenance of behaviour change.

### Neglect of psychosocial factors.

Behavioural change theories, despite increased specificity, overlook the psychosocial and environmental factors crucial in managing chronic illnesses like CKD. Effective self-management involves navigating mood, home environment, social relationships, and resource access (Alexopoulou et al., 2016; Untas et al., 2011). While theories like TPB and CT assume stability in attitudes and internal controls, real-life circumstances and social influences challenge this stability. The need for self-management and the type of activities that a patient might engage in to manage their illness differs between individuals (and illnesses) and is not always consistent in the long term and can easily be influenced by interactions with their environment and others. Although the CSM-SR emphasises the role of illness representations being influenced by external environment, it fails to account for the role of social interactions in behaviour change and maintenance. In the case of CKD, patients encounter other patients, friends, families, charity organisations, healthcare professionals, transport support and are consequently interacting with so many people that could easily influence their behaviours. Studies highlight the significant impact of social support on treatment adherence and the adoption of healthy strategies among dialysis-dependent CKD patients (e.g., Alexopoulou et al., 2016; Damery et al., 2019; Kwasnicka et al., 2016). Quality support mitigates psychological distress and enhances quality of life, addressing prevalent issues like anxiety and depression (Davaridolatabadi & Abdeyazdan, 2016). Emotions play a significant role in influencing health behaviours (Ferrer & Mendes, 2018), emphasising the importance of emotional management in CKD adjustment and self-care.

Depression and anxiety are common among patients on dialysis, with prevalence rates ranging from 12% to 87% (Cohen et al., 2016; Cukor et al., 2008; Preljevic et al., 2011;

Rahman & Pradido, 2020). Studies show that up to one in five patients on dialysis experience depression, exceeding rates in other chronic illnesses and the general population. Depression is associated with poor psychosocial outcomes and increased mortality risk, with depressed patients having a relative risk of death 1.5 to 1.59 times greater than non-depressed patients (Palmer et al., 2013a; Waraich et al., 2004). Palmer et al. (2013a) found in a systematic review with 55,982 patients (46,505 receiving dialysis) that depression prevalence among patients on dialysis was 22.8% clinically diagnosed and 39.3% through self-reported measures. Depression in patients on dialysis is linked to poor psychosocial outcomes and negative health consequences (Cukor et al., 2013; Lee et al., 2013; Tsai et al., 2012; Belayev et al., 2015). Systematic reviews by Palmer et al. (2013b) and Farrokhi et al. (2014) reveal a heightened mortality risk associated with depression among patients on dialysis. Palmer et al. observed a relative risk of 1.59 for mortality in depressed patients, while Farrokhi et al. reported a mortality risk 1.5 times higher in depressed patients, with severity of depression correlating with increased mortality risk. Anxiety is also prevalent, with estimates ranging from 38% to 43% among patients on dialysis (Huang et al., 2021; Murtagh et al., 2007). Murtagh et al. (2007) found that approximately 38% of patients on dialysis experience anxiety, while a more recent review by Huang et al. (2021) estimated a prevalence of around 43% based on 61 observational studies. Lack of support or negative support, such as conflicts with close others, can worsen these mental health conditions and predict poor self-management (Davaridolatabadi & Abdeyazdan, 2016; Fisher et al., 1992; Gebrie & Ford, 2019; Goetz et al., 2012).

**Socioeconomic and cultural factors.** Structural and systemic factors like socioeconomic status, access to healthcare, and cultural differences significantly influence health behaviours and outcomes, leading to health disparities in managing chronic illnesses such as CKD. The oversimplification resulting from insufficient consideration of sociocultural determinants fails to address the impact of variables like poverty levels on successful self-management. The emphasis on individual agency and self-regulation in theories like SCT, CT, and SDT may overlook the influence of external factors and constraints. Cultural variations in values and socialisation, such as collectivism versus individualism (Triandis, 1993), may not be fully accounted for by promoting individual autonomy and intrinsic motivation.

In some countries (e.g., UK) CKD can be managed through universal health care funded by the government (National Health Service) whilst in others (e.g., United States) patients must rely on medical insurance or miss out on getting treatment and thus increasing their mortality risk if they have no insurance (Cervantes et al., 2018). Socioeconomic factors, such as poor living conditions and limited access to healthcare due to lack of insurance, contribute to accelerated progression and mortality in CKD patients (Fraser et al., 2013; Morton et al., 2016; Nicholas et al., 2013; Norris & Nissenson, 2008; Ricardo et al., 2014). Patients' socioeconomic status impacts their ability to self-manage effectively and access necessary care resources. Studies demonstrate strong associations between financial constraints and fragmented CKD care, increased emergency service utilisation, and reduced access to transplant treatment (Lipworth et al., 2012; Roberti et al., 2018). CKD patients with low socioeconomic status, especially those from ethnic minorities, experience delayed referrals, higher morbidity, mortality, and reduced access to transplant treatment compared to those with higher socioeconomic backgrounds (Alexander & Sehgal, 1998; Navaneethan et al., 2006; Patzer et al., 2012; Saunders et al., 2010; Weng et al., 2005). Additionally, socioeconomic status influences patients' perceptions, understanding (e.g., asking questions, making dietary changes, understanding health information), and ability to afford food items for effective self-management (Block et al., 2004). These theories fall short in encapsulating the full spectrum of influential factors beyond individual volition, highlighting the necessity for integrated models reflecting the compounding effects of psychology, biology, and sociopolitical milieu on CKD trajectories.

In summary, living with and managing CKD involves the self-regulation of cognitions, emotions, and behaviours. This includes tasks like monitoring fluid intake, adhering to dietary restrictions, taking prescribed medication, and attending medical appointments despite emotional challenges like uncertainty and depression. The complexity of managing CKD often overwhelms patients and their families, making effective self-management a struggle. However, receiving quality support from others and collaborating with healthcare providers can ease these challenges and encourage self-management. Moreover, considering emotional, environmental, and socioeconomic factors, as well as the structural context that patients exist in, can improve their access to care and provide resources to support healthy behaviour change and maintenance.

## The approach to understanding self-management in this research

This thesis takes a unique approach to understanding the complex processes that influence successful self-management in CKD by a departure from reliance on any singular theory or model. This shift is necessary due to the challenges posed by overlapping constructs in existing theories, which make it difficult to determine when and how these constructs are most influential in promoting adherence in CKD. Furthermore, the thesis recognises that self-management is a multifaceted concept, and while certain self-regulatory processes such as goal setting, self-monitoring, beliefs, appraisals, and adjustments have been delineated in past conceptualisations, their actual impact on behaviour, particularly from the perspective of individuals with chronic illness, remains inadequately understood.

The inadequacy of existing theoretical models further lies in their failure to comprehensively account for the role played by societal and cultural factors, as well as in providing a framework for conceptualising and operationalising them. Consequently, conducting research devoid of strict adherence to a single theory allows for a more exhaustive and flexible exploration of the multifaceted dimensions of self-management. This approach leads to a more nuanced understanding of the processes that foster effective self-management.

The thesis adopts a bottom-up logic, whereby constructs or processes emerge directly from the data collected in the studies conducted, thereby yielding a more accurate and contextually relevant comprehension of behaviour change with enhanced theoretical richness and greater predictive power. The significance of this approach is emphasised within the context of CKD, where effective self-management is an ongoing dynamic process requiring patients to possess an array of skills and to engage with numerous healthcare professionals. These skills include goal setting, problem solving, self-efficacy, intention, seeking support, and responsiveness to environmental cues. By taking this approach, this thesis seeks to contribute to our understanding of the self-management challenges faced by patients with CKD. By exploring these issues, the thesis hopes to offer insights that may inform more effective strategies for supporting patients in their day-to-day disease management.

## Thesis overview

It follows from the above literature review that through the identification and assessment of modifiable self-regulatory processes involved in the self-management of chronic disease, the processes that impact non-adherence amongst patients receiving dialysis will be feasible. The current thesis aimed to develop an understanding of the specific processes that impact upon successful self-management in CKD with four key research questions using a series of mixed methods: (1) How effective are controlled interventions aiming to improve self-regulation of psychological, behavioural, and physiological health outcomes amongst patients on dialysis? I also explored how and why these interventions were effective by conducting mediation and moderation analyses (2) What are the attitudes of patients on dialysis towards dietary and fluid restriction and the self-regulatory methods they use or find hard to use in daily life? (3) What are the contextual factors that influences how patients on dialysis self-regulate? and (4) What is the relationship between regulatory social support and inter dialytic weight gain (IDWG)?

This thesis contains 3 empirical studies presented across 4 chapters. All the studies focused on patients with CKD undergoing dialysis drawn from clinic settings or CKD support groups. All the studies were pre-registered with the specific aims/ hypotheses, analysis plan, and stopping rules for data collection for each study determined *a priori*. Sample sizes were determined by power analysis based on known effect sizes for all empirical studies.

The first study, presented in Chapter 2 evaluated the effectiveness of randomised controlled interventions that aimed to improve self-regulation of health outcomes amongst patients on dialysis. A systematic review and meta-analysis were conducted by computing effects on the psychological constructs targeted by the interventions, behavioural outcomes (dietary, fluid and medication adherence) and physiological outcomes (blood levels of potassium and phosphate, and IDWG). Additionally, an examination of *how* and *why* these interventions were effective was conducted by examining the direct and indirect relations between intervention effects on psychological constructs, behavioural and physiological outcomes. Finally, two categories of moderator analyses based on intervention contents derived from the behaviour change taxonomy (BCT: Michie et al., 2013), and intervention duration was conducted. The meta-analysis showed that the aggregated results of 46 varying and often multifaceted interventions drawing upon a range of techniques to modify a range of processes (e.g., goal setting or monitoring) did change behavioural and physiological outcomes with moderate to large effect sizes. However, few studies assessed psychological intervention targets, but large effects were obtained for knowledge change and quality of life.

Moderator analyses on the effect of BCTs on self-efficacy indicated that interventions that incorporate social support components were more successful in boosting patients' self-efficacy, which in turn led to improved treatment adherence. None of the papers explored the effects of social and environmental factors (e.g., cost of food products, who prepares the meals and food items kept in the home).

Studies 2 and 3 presented in Chapters 3 and 4 was a double-blind qualitative study of patients on dialysis experience of kidney disease. These studies expanded upon the meta-analysis results by exploring two key areas. First, they sought to identify the specific strategies that makes some patients better at self-management than others. Second, we investigated the broader biopsychosocial factors that impact self-management, including external influences that were not considered in the studies included in the meta-analysis. A qualitative approach was adopted for an in-depth exploration of the context within which patients engage in self-management. For example, their attitudes towards dietary and fluid restriction and the methods they use or find hard to use in daily life. Additionally, it plays a crucial role in understanding '*how*' and '*why*' a particular behaviour operates in a specific context enabling the identification of factors that influenced their behaviours and the motivations behind self-management.

The initial thematic analysis in Study 2 revealed four main themes: commitment to goals, planning, strategies for adhering to restrictions, and self-monitoring. While both high and low adherence groups used similar self-management approaches for their dietary and fluid restrictions, some key differences emerged. High adherence patients relied more on established routines rather than active planning, engaged in strategic planning when necessary, and allowed themselves occasional treats. In contrast, low adherence patients focused on drink substitutions and thirst management techniques, and actively monitored their behaviour outcomes. The results of the thematic analysis in Study 3 identified six themes (1) competing priorities (2) personalised support from healthcare team, (3) social support, (4) intrinsic and extrinsic motivation, (5) physiological feedback, and (6) outcome expectancies. Both high and low adherent patients expressed that social support, both instrumental and emotional, was vital in managing their kidney disease. However, of the few patients who noted the challenges associated with a lack of receiving support from others; half of the patients in the low adherent group reported feeling unsupported.

The final study (Study 4), presented in Chapter 5, built upon the meta-analysis findings on the role of social support in effective self-management. This was further supported by the qualitative study, where both patient adherence groups acknowledged the importance of social support for their self-management. The study further examined the importance of social support in disease outcomes by investigating whether social support targeting self-regulatory needs can affect self-reported IDWG among patients on dialysis. This study also addressed how self-regulatory strategies (e.g., self-efficacy, commitment, self-monitoring) mediated the relationship between regulatory support and IDWG. Results showed a significant positive relationship between regulatory support and fluid management, with family support having the strongest influence, followed by support from friends and neighbours. Mediation analyses revealed that self-efficacy and commitment to disease management, but not self-monitoring, significantly mediated the relationship between regulatory support and fluid management.

Chapter 6 provides a general discussion of the contribution of the work to the health behaviour change field and outlines the theoretical and practical implications of the findings from Studies 1 to 4.

This chapter was submitted for peer review publication and currently under review at Health Psychology Review.

# Chapter 2

# Promoting self-regulation in chronic disease: A systematic review and meta-analysis of behaviour change interventions

## Abstract

Given the importance of self-regulation for the effective self-management of kidney disease, researchers have developed interventions focused on improving self-regulation in patients on dialysis. The review and meta-analysis aimed to evaluate the efficacy of these interventions and identify the qualities of stronger interventions in this domain. A meta-analysis of randomised controlled interventions to promote self-management in patients on dialysis (K = 46, N= 4257) evaluated: effect of the interventions in changing psychological, behavioural and physiological outcomes; relations between changes in outcomes; moderation of outcomes by behaviour change techniques employed in the interventions, and intervention duration. The meta-analysis obtained moderate effect sizes demonstrating improvement in behavioural (*g* = 0.50-0.65) and physiological health outcomes (*g* = -0.32- -0.57). Fewer studies assessed psychological intervention targets, but large effects were obtained for knowledge change and quality of life (*g* = 0.65 & 1.17, respectively). Improved knowledge was positively associated with improved medication adherence, that in turn was associated with one physiological outcome. Interventions incorporating therapeutic techniques such as CBT or RET achieved superior physiological outcomes, particularly when used in isolation. Findings support the cautious interpretation that intervention strategies to enhance emotional self-regulation are effective in optimising outcomes for dialysis patients.

**Keywords:** Self-regulation, dialysis, meta-analysis, interventions, behaviour change, BCT, social support, self-efficacy, therapy.

# Introduction

Chronic disease accounts for two thirds of deaths worldwide (WHO, 2011) and the majority of patients receiving healthcare have a chronic illness. Whilst medical interventions are often available to manage disease progression and life quality, patient collaboration in care, for example, by maintaining physical activity, restricting food intake, attending hospital appointments, or adhering to medication is crucial to optimise outcomes. Understanding how to support and promote these behaviours via development of replicable interventions whose effective mechanisms are understood has the potential to improve health, reduce premature mortality and health care expenditures (Davidson & Scholz, 2020). A common oversight in behavioural change interventions is the lack of empirical testing of the specific mechanisms they purport to leverage (see French et al., 2012; Nielson et al., 2018; Sheeran, Klein Rothman, 2017).

The present review and meta-analysis focusses upon self-management of chronic kidney disease (CKD). CKD affects up to 840 million people worldwide with a global prevalence of 8-14% and is the third fastest growing cause of death worldwide (Hill et al., 2016; Bikbov et al., 2020). CKD typically progresses from stage G3 to G5 and then kidney failure requiring kidney replacement therapy (KRT), at which point kidney function is no longer sufficient to sustain life. Kidney replacement therapy can be provided by haemodialysis, peritoneal dialysis or kidney transplantation. The number of people receiving KRT worldwide is projected to reach 5.4 million by 2030 (Liyanage et al 2015). This study focuses on patients receiving dialysis; the most prevalent type of KRT worldwide. The cost of managing CKD is significant. Considering data from 31 countries, Jha et al. (2023) estimated the mean cost of kidney disease to be $3,060 USD per patient per year for stage

G3, increasing to $4,736 USD per patient per year for stage 5 and $57, 334 USD per patient per year for haemodialysis. Management of CKD accounts for 3.20% of National Health Services (NHS) expenditure costing approximately £6.4 billion on direct treatment (medication and kidney care) (Kidney Research UK, 2023).

Numerous interventions have been developed to enhance self-regulation among CKD patients undergoing dialysis. Nonetheless, there remains a lack of clarity regarding the effects of these interventions in changing key behaviours relevant to CKD management and outcomes or the specific active ingredients of these interventions.

## Self-management tasks in dialysis dependant CKD

Optimal medical care can reduce morbidity and mortality associated with dialysis. Patient collaboration, including maintaining physical activity, restricting specific dietary components and fluid intake, attending hospital appointments and dialysis sessions and adhering to medication is crucial to maximise outcomes. For dialysis patients it is particularly important to keep plasma potassium and phosphate concentrations within their respective target ranges and to avoid excessive fluid intake. These parameters are monitored closely for dialysis patients.

Dietary intake is an important determinant of plasma potassium concentration in dialysis patients. High levels of potassium are associated with increased all-cause mortality, hospitalisation, and cardiovascular injuries (Brunelli et al., 2017; Kovesdy et al., 2007; Luo et al., 2016; Noori et al., 2010). Similarly, excessive consumption of phosphorus-rich food contributes to increased plasma phosphate concentration which is a strong predictor of mortality and cardiovascular disease in dialysis patients. Maintenance of optimal plasma phosphate concentrations requires both restriction of dietary phosphate intake and adherence to medication reducing phosphate absorption from food (phosphate binders) (Gutierrez et al., 2014; Kalantar-Zadeh, 2013; Russo et al., 2015; Rysz et al., 2017; Snelson et al., 2017).

Adherence to these dietary restrictions reduces all-cause mortality (Hu et al., 2021; Morris et al., 2020). Finally, excess fluid intake, resulting in high weight gains between dialysis sessions (inter-dialytic weight gain [IDWG]), increases cardiovascular morbidity and mortality (Akdam et al., 2014; Mitsides et al., 2017; Tsai et al., 2015). Thus, self-management of diet and fluid intake is essential for dialysis patients. However, up to 18% of patients miss dialysis sessions; up to 80% are non-compliant with phosphate binder medication, 10-75% for fluid intake, and 2-81% for dietary restrictions (Durose et al., 2004; Ghimire et al., 2015; Hecking et al., 2004; Leggat et al., 1998; Schmid et al., 2009).

The self-regulation required of patients on dialysis is therefore considerable. Patients have to be willing and motivated to maintain appropriate behaviours concerning diet, fluid intake, and medication (take medication as prescribed) and possess the skills and opportunity to enact these behaviours. Consequently, researchers have developed and evaluated behaviour change interventions to improve self-management of CKD. The primary aim of the present review is to evaluate the outcomes of these interventions.

## Behaviour change interventions in CKD

Our search of the literature identified six previous reviews of behaviour change interventions in CKD dialysis patients published between the years 2010 and 2020 (Karavetian et al., 2014; Matteson & Russell, 2010, 2013; Milazi et al., 2017; Murali et al., 2019; Tao et al., 2020). However, previous reviews are limited by very small numbers of included studies, and the inclusion of non-controlled quasi-experimental studies (Matteson & Russell, 2010, 2013), non-randomised control studies (Karavetian et al., 2014; Milazi et al., 2017) or the inclusion of studies published predominantly in Chinese (Tao et al., 2020). Murali et al., (2019) identified 36 studies evaluating interventions to improve adherence to CKD treatment. Their meta-analysis demonstrated that phosphate levels ($g$ = -0.45, CI -0.66 to -0.21) and interdialytic weight gain [IDWG] ($g$ = -0.20. CI -0.32 to -0.08) significantly improved in intervention groups relative to controls. The authors were unable to compute effects of interventions on behaviour, such as dietary and fluid restriction or medication adherence due to small numbers of studies, and do not consider intervention effects on psychological targets presumed to underly behaviour change.

No previous meta-analytic review of randomised controlled trials of interventions to improve outcomes amongst patients on dialysis  has investigated change in psychological, behavioural and physiological targets simultaneously in the same study. The pre-post assessment of psychological and behavioural constructs targeted by interventions is important to identify mechanisms through which changes in behaviour or physiological outcomes might occur, to inform future intervention development. Further, no previous review has considered the content of the interventions nor evaluated the role of intervention content in moderating intervention outcomes.

### *Moderators of the impact of interventions on outcomes*

An additional aim of our review is to advance understanding beyond assessing outcome, to consider under what circumstances and how interventions might be more or less effective. Various factors could influence the observed effect of these interventions on psychological, behavioural, and physiological outcomes. In the current review we investigated two categories of moderator effects: first, intervention content as specified by the Behaviour Change Taxonomy (BCT) (Michie et al., 2013), and second, intervention duration.

Intervention content refers to the specific active ingredients used in the interventions. A BCT technique is an observable, replicable, and intricate component of an intervention developed to modify the causal processes that regulate behaviour, with the technique proposed to be an ‘active ingredient’ (Michie et al., 2013). A comprehensive BCT taxonomy was developed through an international consensus process by Michie et al. (2013). The resulting taxonomy, the Behaviour Change Techniques Taxonomy version 1, includes 93 distinct BCTs grouped within 16 categories with detailed definitions, labels, and examples of each. Examples of BCTs include goal setting, self-monitoring of behaviour, problem solving, social support and instructions on how to perform the behaviour. Identifying techniques used within interventions that target specific theory derived interpersonal and intrapersonal processes, and comparing interventions that include or do not include such techniques, enables researchers to test potential active ingredients of interventions that drive behaviour change and physiological outcomes. This approach to classifying intervention contents has been previously employed in meta-analyses of interventions in cardiovascular disease management (e.g., Suls et al., 2020), physical activity interventions amongst obese adults (Olander et al., 2013), medication adherence and diabetes management (e.g., Hennessy et al., 2020). However, no previous review of interventions to promote self-management in CKD has investigated the role of intervention components as a moderator of psychological, behavioural and physiological outcomes.

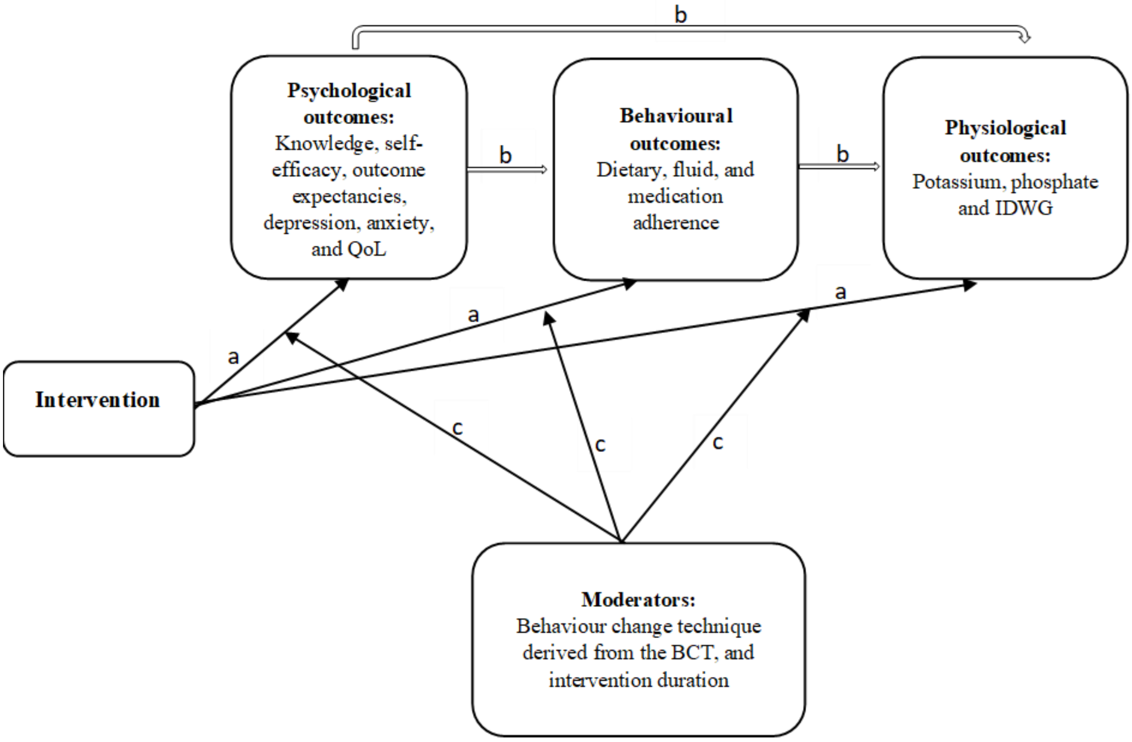
The second moderator variable considered is intervention duration. Intervention duration describes the period of time during which the intervention was delivered. For example, an intervention might comprise a single session taking place on one day or might involve repeated engagement with intervention delivery over weeks or months. We examined if intervention duration modified intervention effects on psychological, behavioural and physiological outcomes.

### ***Summary of aims of the present review***

A schematic representation of the research questions addressed by our review is provided in Figure 3. The primary aim of the review was to conduct an updated and extended meta-analysis of controlled interventions that aimed to improve self-management of health outcomes amongst dialysis patients. As illustrated by Figure 3 pathway (a) we extended previous reviews by computing effects on psychological constructs targeted by the interventions, behavioural targets in terms of dietary, fluid and medication adherence and downstream physiological outcomes determined by blood levels of potassium, phosphate, and IDWG. No previous review has considered all of these intervention targets. We extended previous research in two further important respects directed at furthering understanding beyond simply whether interventions in this field are effective, to how and why they are effective. Accordingly, our second aim, as illustrated by Figure 3 pathway (b), was to examine the relations between intervention effects on psychological, behavioural and physiological constructs to evaluate whether intervention effects on psychological or behavioural outcomes were associated with effects on physiological outcomes. Third, we examined moderation of outcomes. Two categories of moderator were included as shown in Figure 3 pathway (c). The first of these is intervention content. The intervention contents were classified according to the behaviour change taxonomy (Michie et al., 2013) and the moderating effects of intervention content on psychological, behavioural, and physiological outcomes evaluated. Intervention duration was examined as an additional moderator.

**Figure 3**

*Conceptual model of the relationships between the constructs and outcomes examined in the meta-analysis*



# Study 1

## Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and checklist was employed to structure this review. The review was registered at PROSPERO register of systematic reviews in May 2022 (Registration number: CRD42022333522). Our project page on the Open Science Framework includes a dataset containing the effect sizes for each individual study, along with information on the behaviour change taxonomy and intervention duration from all 46 studies reviewed: https://osf.io/ca3fm/?view_only=3bd898d91375404a95c6b57f60abfd60

### Search strategy

Electronic database searches were performed in the Cochrane central register of controlled trials, Embase, and PubMed/Medline for relevant articles using standard and MeSH search strategies. The search was expanded to include Web of Science, Google Scholar and Scopus to identify additional studies not indexed in PubMed/Medline. Searches were restricted to articles published in English.

We conducted Boolean and MeSH operations in our search strategy. Medical subject headings and search terms included combinations of 'dialysis', 'renal dialysis', 'haemodialysis', 'peritoneal dialysis', 'patient compliance', 'adherence', 'medication adherence', and text word searches using combinations of 'adheren*', 'non-adheren*', 'nonadheren*', 'complian*', 'non-complian*', 'noncomplian*', 'fluid', 'diet', 'diet*', 'medication', 'dialys*', 'inter-dialy*', 'interdialy*', 'haemodialys*', 'hemodialys*', 'peritoneal dialys*', and 'CAPD'. For example, we used the Boolean operator AND to combine terms such as 'haemodialysis AND adherence', ensuring both concepts were present in the search results. We also employed the OR operator to broaden our search, as in 'ESKD OR ESRD OR CKD', to capture various terminologies for kidney disease. Additional search terms included 'ESKD', 'ESRD', 'CKD', 'water', 'overload', 'overloading', 'hypervolemia', 'kidney dialysis', 'food', 'phosphate', 'potassium', 'IDWG', 'weight', and 'treatment'.

## Study selection criteria and characteristics

The criteria for study inclusion were: (i) randomised controlled trials (parallel, cluster randomization, crossover design or factorial design) or controlled studies using random allocation of participants to different groups that evaluated dialysis dependant patients (haemodialysis or peritoneal) aged 18 and over; (ii) assessed at least one intervention with the aim of primarily enhancing psychological, behavioural or physiological outcomes; (iii) reported at least one of these outcomes pre- and post-intervention using the same measure; and (iv) the measurement of outcomes included biochemical measures (e.g., monthly blood tests, interdialytic weight gain measurements) or self-reported measures. We excluded non-randomised intervention studies, observational, qualitative studies, studies published as reviews, letters to editors, commentaries, study protocols and abstracts. Titles and abstracts of search results were examined by the first three authors ensuring inter-rater agreement to identify studies that randomly allocated dialysis dependant participants to a treatment condition intended to improve at least one psychological, behavioural, or physiological outcome. Any disagreement was resolved by discussion.

## Data extraction

Data extraction was carried out independently by the lead author and verified for accuracy by the second and third authors using a pre-specified standard checklist created by the authors. The checklist was used to extract significant features of each study such as the first author’s name, publication year, study design, sample size, country location of intervention, intervention, behaviour change techniques employed by the interventions according to the behaviour change technique taxonomy (Michie et al., 2013), and the reported psychological, behavioural, and physiological outcomes. Extracted data was compiled into a summary table (Table 2) to support results interpretation and synthesis.

## Quality assessment

The first three authors independently assessed the quality of the included studies using the Cochrane ROB 2.0 tool (Higgins et al., 2016). The Cochrane RoB 2.0 tool is a framework for considering the risk of bias in the findings of randomised studies comprising of five domains: (i) bias arising from randomisation process (containing 3 signalling questions); (ii) bias due to deviations from intended interventions (containing 6 signalling questions); (iii) bias due to missing outcome data (containing 3 signalling questions); (iv) bias in measurement of the outcome (containing 2 signalling questions); and (v) bias in selection of the reported result (containing 2 signalling questions). The response for each signalling questions were “yes”, “probably yes”, “probably no”, “no” and “no information”. The responses to the signalling questions provided the basis for domain-level judgements about the risk of bias with one of three options (low risk, some concern and high risk of bias). Discrepancies between the three authors was resolved by discussions and consensus agreement. Kappa was calculated to assess domain specific inter-rater reliability.

## Statistical methods for meta-analysis

Statistical analyses were conducted using R Studio version 4. In relation to the meta-analysis, we used the R “metafor” and “metasens” package (Viechtbauer, 2010), and used the mean difference and standard deviation between intervention and control groups across psychological, behavioural, and physiological outcomes, and the sample size to calculate effect size. As we anticipated considerable between-study heterogeneity, a random-effects model was used to pool effect sizes. The Cochran's Q test was used to determine whether significant differences existed between the effect sizes of individual studies, essentially asking if the variability in results was greater than what we would expect by chance. The $I^2$

statistic quantified the proportion of observed variance in effect sizes attributable to real differences between studies rather than random error, expressed as a percentage. For instance, an $I^2$ of 75% would indicate that three-quarters of the observed variability is due to true heterogeneity. Finally, we used the restricted maximum likelihood estimator (REML) to calculate $\tau^2$ (tau-squared), which represents the between-study variance in effect sizes (Viechtbauer, 2005). A larger $\tau^2$ value indicates greater heterogeneity. Together, these measures provided a comprehensive assessment of heterogeneity, allowing us to determine not only its presence but also its magnitude and impact on our meta-analysis results. A value of 0% indicates no heterogeneity and higher values indicate higher heterogeneity. A heterogeneity of 25% is defined as the threshold for low, 50% for moderate and 75% for high heterogeneity (Ioannidis et al., 2007).

Knapp-Hartung adjustments (Knapp & Hartung, 2003) were used to calculate the confidence interval around the pooled effect and Hedges' g as a measure of effect size. Standard deviation values were primarily extracted from the papers. However, when this was not possible, standard deviation was computed using the t-statistic derived from the confidence intervals or p values cited in the papers (Fu et al., 2013). When probability values or confidence intervals were not cited in the papers, the standard deviation was derived using the arithmetic mean of the standard deviations of the mean difference in both the intervention and control groups.

Funnel plots were created to visualise publication bias with the expectation that when there is no publication bias, the data points on the plots would form a roughly symmetrical, upside-down funnel. Egger’s regression test (Egger et al., 1997) was used to quantify asymmetry in the funnel plots and assess potential publication bias.

Our analysis revealed evidence of publication bias for medication adherence ($p$ = 0.04). To address this, we employed Rucker's limit meta-analysis to estimate the true effect size after accounting for this bias (Rucker et al., 2011).

## Meta-regression analyses

Following the overall meta-analysis, we performed additional planned analyses as follows to evaluate the relationship between constructs (Figure 3 pathway (b)) and moderation of effects (Figure 3 pathway (c)). To ascertain whether intervention effects on psychological and behavioural outcomes were associated with intervention effects on behavioural and physiological outcomes, linear regressions were conducted using studies' individual standardised mean difference as the correlation value ($R$) where outcome data could be retrieved. Moderation effects were examined by random mixed-effects univariate and multivariate meta-regressions on BCT intervention content, and intervention duration to test their effects on psychological, behavioural, and physiological constructs. Moderator analyses were conducted only if significant heterogeneity was observed in the effect sizes across studies. While Card (2015) recommends a minimum of 10 studies for moderator analyses in meta-analyses, recent research suggests this threshold may be overly conservative in some cases. For example, recent meta-analyses on suicide and self-injury by Fox et al. (2020) and Huang et al. (2022) have demonstrated that conducting moderator analyses with fewer than 10 studies for some comparisons can be justified and informative. This approach is supported by recent simulation studies, which indicate that moderator analyses can achieve adequate statistical power with fewer than 10 studies, depending on factors such as effect size magnitude and between-study heterogeneity (Li, Dusseldorp & Meulman, 2019). Furthermore, in critical research areas like enhancing adherence in kidney treatment to reduce complications and premature death, exploring potential moderators, even with limited studies, can provide valuable insights to guide future interventions and research. We acknowledge the limitations of this approach with fewer studies and interpret the results cautiously, viewing them as hypothesis-generating rather than confirmatory. To conduct this analysis, psychological (e.g., self-efficacy, depression, anxiety, knowledge, outcome expectancies, quality of life), behavioural (dietary, fluid and medication adherence), and physiological (IDWG, potassium and phosphate serum levels) outcomes were aggregated by combining health outcomes into the above overarching constructs: psychological, behavioural, and physiological. Further, psychological construct was categorised into wellbeing (depression, anxiety, and Quality of Life (QoL)) and psychological construct excluding wellbeing (knowledge, self-efficacy, and outcome expectancies). Due to some studies measuring multiple health indices and contributing more than one effect size, study was treated as an additional level. Next, to determine the effects of intervention duration for differences in effect size between the different psychological, behavioural, and physiological outcomes, random mixed-effects meta-regression models were tested.

# Results

## Characteristics of studies

The PRISMA flow chart is provided in Figure 4. A total of 1,527 publications were identified after an initial search. After removal of duplicates, reviews and screening of titles and abstracts, 118 articles were reviewed in full. After secondary screening to remove papers reporting nonrandomised controlled studies, 46 randomised control studies were identified and included in the review. Thirteen studies were conducted in the United States, eight in the United Kingdom, five studies each in China and Iran, three studies in Korea, two each in Brazil, Lebanon and Switzerland, and one each in the United Arab Emirates, Singapore, Spain, Taiwan, India, and Philippines.

Characteristics of the included studies are summarised in Table 2. The total number of participants in the included studies was 4,257, with the intervention and control groups consisting of 2,470 and 1,787 participants respectively. Just over half of participants were male (58.02%), and the mean participant age was 53.7 years (*SD* = 7.16). Four studies comprised of patients undergoing peritoneal dialysis (Chen et al., 2021; Chen W, 2006; Hare et al., 2014; Wong et al., 2010) and the remaining 42 studies comprised of haemodialysis patients.

**Figure 4**

*PRISMA flow chart of systematic review process*

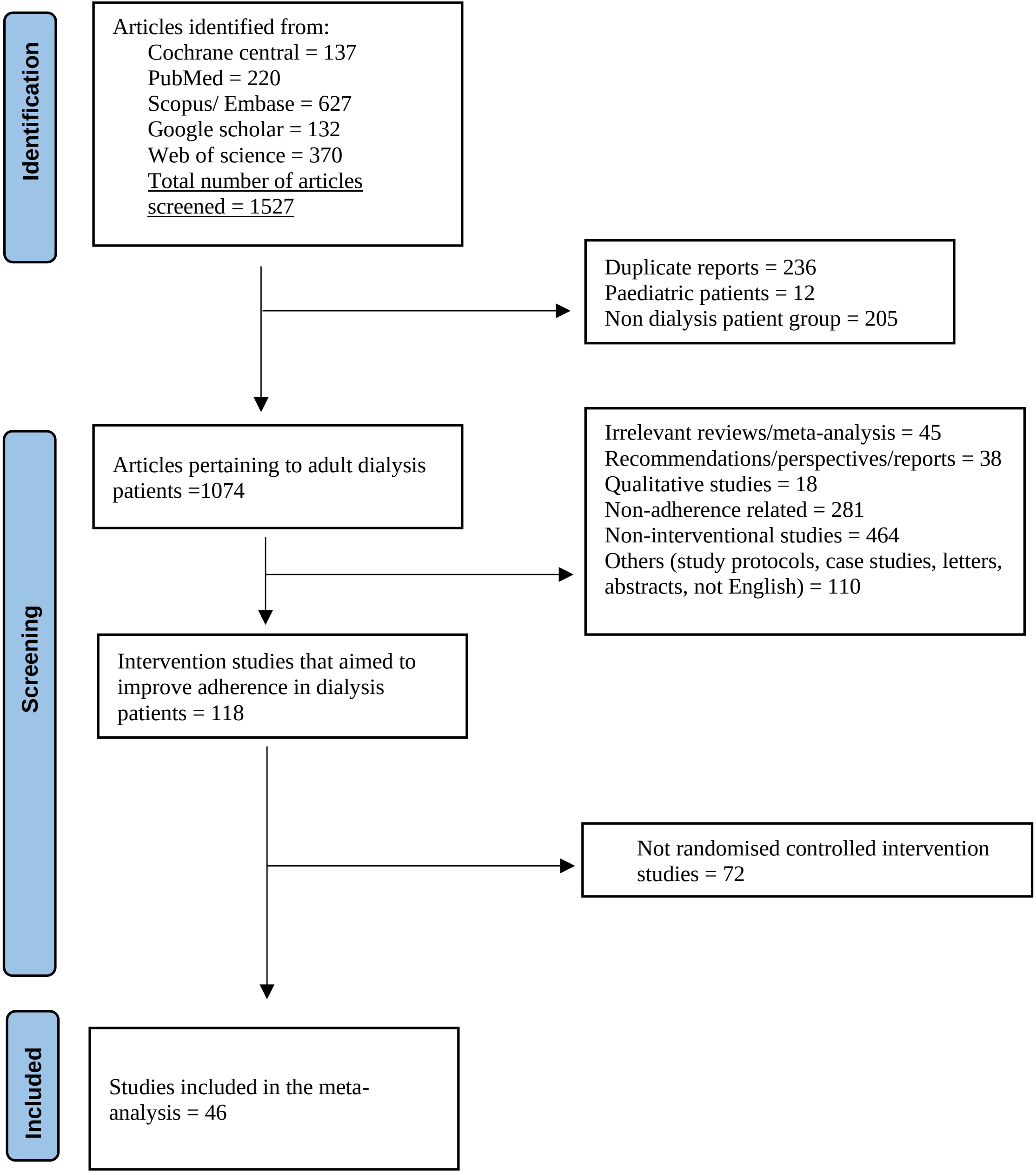


**Table 2**

*Characteristics of the (n = 46) randomised control trials included in the review*

| **Author**<br>**Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size**[1] | **Behavioural outcome measured and effect size**[2] | **Physiological outcome measured and effect size**[3] | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| Arad et al., (2021) Iran | Parallel group<br>66 (33/33) | 1.2 problem solving; 4.1 instruction on how to perform the behaviour 5.1 information about health consequences | | Dietary adherence (*g* = 0.70)<br>Fluid adherence (*g* = 0.61)<br>Medication adherence (*g* = 1.87) | Potassium serum (*g* = -1.16)<br>Phosphate serum (*g* = -0.80)<br>Data collected pre, post, 1 & 3 months after intervention | 1d /<br>3m |
| Ashurst & Dobbie, (2003) UK | Parallel group<br>58 (29/29) | 2.3 self-monitoring of behaviour; 2.5 monitoring outcome(s) of behaviour by others without feedback; 4.1 instruction on how to perform the behaviour; 5.1 information about health consequences | | | Phosphate serum (*g* = -0.46)<br>Data collected monthly for 6m | 1d /<br>6m |
| Baraz et al., (2010) Iran | Parallel group<br>63 (32/31) | 3.1 social support (unspecified); 4.1 instruction on how to perform the behaviour; 5.1 information about health consequences | | | IDWG (*g* = 0.01)<br>Potassium serum (*g* = -0.05)<br>Phosphate serum (*g* = -0.02)<br>Data collected at baseline, 2 & 4m | 1d /<br>4m |
| Brantley et al., (1990) USA | Cluster randomised<br>56 (14/14#/ 14#/ 14) | 4.1 instruction on how to perform the behaviour; 7.1 prompts/ cues; 10.1 material incentive; 10.10 reward (outcome) | | Vascular access cleansing<br>Data collected at baseline, post intervention, 1 & 12m | | 3d /<br>12m |
| Chang et al., (2021) Korea | Parallel group<br>84 (29/27#/28) | 1.2 problem solving; 1.3 goal setting (outcome); 1.7 review outcome goal (s); 1.8 behavioural contract; 2.3 self-monitoring of behaviour; 3.1 social support (unspecified); 3.2 social support (practical); 4.1 instruction on how to perform the behaviour; 5.1 information about health consequences | QoL (*g* = 1.07) | Fluid adherence (g = 1.06) | IDWG (*g* = -0.86)<br>data collected at baseline, after the intervention (6w), and 4m | 6d /<br>4m |
| Chen W et al., (2006) China | Parallel group<br>70 (35/35) | 2.3 self-monitoring of behaviour; 4.1 instruction on how to perform the behaviour; 5.1 information about health consequences; 8.2 behaviour substitution | | Dietary adherence (*g* = 0.28)<br>Data collected at baseline and 1m | Phosphate serum (*g* = -0.02)<br>Data collected at baseline and 1m | 1d /<br>1m |
| Chen et al., (2021) China | Parallel group<br>105 (35/35#/35) | 2.7 feedback on outcome of behaviour; 3.1 social support (unspecified); 3.2 social support (practical) | | Dietary adherence (*g* = 1.20) | Phosphate serum (*g* = -0.29) | 12d /<br>6m |

| **Author Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size[1]** | **Behavioural outcome measured and effect size[2]** | **Physiological outcome measured and effect size[3]** | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| Cho, (2013)<br>Korea | Parallel group<br>43 (21/22) | 1.1 goal setting (behaviour); 1.8 behavioural contracting; 2.3 self-monitoring of behaviour; 3.1 social support (unspecified); 4.1 instructions on how to perform the behaviour; 10 social reward | | Dietary adherence (*g* = 0.60)<br>Medication adherence (*g* = 0.09)<br>Data collected at baseline and 1m | IDWG (*g* = -0.52)<br>Potassium serum (*g* = -1.48)<br>Phosphate serum (*g* = -0.53)<br>Data collected at baseline and 1m | 4d /<br>1m |
| Cukor et al., (2014)<br>USA | Crossover randomised<br>59 (33/26) | 3.3 social support (emotional)- CBT; 13.2 framing/reframing | Depression (*g* = -3.49)<br>QoL (*g* = 3.03)<br>Data collected at baseline, 3 & 6m | | IDWG (*g* = -3.91)<br>Data collected at baseline, 3 & 6m | 12d /<br>6m |
| Cummings et al., 1981) USA | Parallel group<br>96 (24/19#/ 28#/ 25) | 1.1 goal setting (behaviour); 1.2 problem solving; 1.7 review outcome goal (s); 1.8 behaviour contract; 2.3 self-monitoring of behaviour; 3.2 social support (practical); 4.3 re-attribution; 5.1 information about health consequences; 10.10 reward (outcome) | | | IDWG (*g* = -0.27)<br>Potassium (*g* = -0.73)<br>Data collected at baseline, 6w & 3m | 6d /<br>3m |
| de Araujo et al., (2010)<br>Brazil | Parallel group<br>33 (16/17) | 4.1 instruction on how to perform the behaviour: 5.1 information about health consequences | Knowledge (*g* = 0.39)<br>Data collected at baseline, 1, 2 & 3m | | Phosphate (*g* = 0.40)<br>Data collected at baseline, 1, 2 & 3m | 6d /<br>3m |
| de Freitas et al., (2020)<br>Brazil | Parallel group<br>87 (47/40) | 1.1 goal setting (behaviour); 1.2 problem solving; 1.6 discrepancy between current behaviour and goal; 2.1 behaviour monitoring without feedback; 4.1 instructions on how to perform the behaviour 4.4 behavioural experiments | QoL (*g* = 0.03)<br>Data collected at baseline, 6 & 12m | Dietary adherence (*g* = 0.05)<br>Data collected at baseline, 3, 6 & 12m | | 1d /<br>12 m |
| Ford et al., (2004)<br>USA | Parallel group<br>70 (35/35) | 2.3 self-monitoring of behaviour; 2.4 self-monitoring outcomes; 4.1 Instruction on how to perform the behaviour; 5.1 information about health consequences | Knowledge (*g* = 1.48)<br>Data collected before and after intervention (6m) | | Phosphate (*g* = -0.52)<br>Data was collected for 6 consecutive months | 6d /<br>6m |
| Forni Ogna et al., (2013) Switzerland | Parallel group<br>41 (19/22) | 1.2 problem solving; 1.4 action planning; 2.7 feedback on outcome; 3.3 social support (emotional) motivational interviewing | | Medication adherence (*g* = 1.10)<br>Data was collected daily using an electronic device for 6m | | 4d /<br>9m |
| Griva et al., (2018)<br>Singapore | Cluster randomised<br>235 (101/134) | 1.1 goal setting (behaviour); 1.2 problem solving; 3.1 social support (unspecified); 4.1 Instruction on how to perform the behaviour | Self-efficacy (g = 0.63)<br>Data collected at baseline, 1w, 3 & 9m post intervention | Dietary adherence (*g* = 0.20)<br>Fluid adherence (*g* = 0.22) | IDWG (*g* = -0.37)<br>Potassium serum (*g* = -0.37)<br>Phosphate serum (*g* = -0.37) | 4d /<br>9m |

| **Author Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size[1]** | **Behavioural outcome measured and effect size[2]** | **Physiological outcome measured and effect size[3]** | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| | | | | Medication adherence (*g* = 0.16)<br>Data collected at baseline, 1w, 3 & 9m post intervention | Data collected at baseline, 1w, 3 & 9m post intervention | |
| Hanifi et al., (2018) Iran | Parallel group<br>86 (43/43) | 1.2 problem solving, 1.4 action planning; 2.2 feedback on behaviour; 2.3 self-monitoring of behaviour | | | IDWG (%)<br>Potassium serum (%)<br>Phosphate serum (%)<br>Data collected at baseline, 1, 2 & 3m. | 2d /<br>3m |
| Hare et al., (2014) UK | Parallel group<br>15 (8/7) | 1.1 goal setting (behaviour); 2.3 self-monitoring of behaviour; 3.3 social support (emotional)- CBT; 4.1 Instruction on how to perform the behaviour; 4.2 information about antecedents; 4.3; re-attribution; 12.1 restructuring the physical environment; 13.2 framing/ reframing | Self-efficacy (*g* = 1.00)<br>Outcome expectancies (*g* = -0.16)<br>Depression (*g* = -0.20)<br>Anxiety (*g* = -1.67)<br>QoL (*g* = 2.13)<br>Data collected at baseline, 5 & 10w | | | 4d /<br>10w |
| Haq et al., (2014) UAE | Parallel group<br>23 (12/11) | 6.1 demonstration of the behaviour | | | Phosphate serum (*g* = -0.27)<br>Data was collected at pre-dialysis, 2, 3, 4, 5, 7, 9, & 11w | 15d /<br>4m |
| Hou et al., (2010) China | Parallel group<br>92 (48/44) | 3.3 social support (emotional) /rational emotive therapy (RET); 11.2 reduce negative emotions | | | IDWG (*g* = -0.62)<br>Data collected at baseline, 1, 2 & 3m | 12d/<br>3m |
| Howren et al., (2016) USA | Cluster randomised<br>119 (61/58) | 2.3 self-monitoring of behaviour 2.4 self-monitoring of outcome; 4.1 instruction on how to perform behaviour; 8.1 behavioural practice; 10.1 material incentive (behaviour); 10.9 self-reward | | | IDWG (*g* = 0.02)<br>Data was collected at baseline, 2, 12, 13th, 25th & 26th post-intervention | 7d /<br>8m |
| Karavetian et al., (2013), Lebanon | Cluster randomised<br>122 (41/41#/40) | 2.2 feedback on behaviour; 2.3 self-monitoring of behaviour, 2.7 feedback on outcome of behaviour; 5.1 information about health consequences | Knowledge (*g* = 0.31)<br>Data collected at baseline and 2m | Dietary adherence (*g* = 0.62)<br>Data collected at baseline and 2m | Phosphate serum (*g* = -0.52)<br>Data collected at baseline and 2m | 16d /<br>2 m |
| Karavetian et al., (2015) Lebanon | Cluster randomised<br>394 (88/ 201# /96) | 1.1 goal setting (behaviour); 1.2 problem solving; 1.4 action planning; 1.9 commitment; 3.1 social support (unspecified); 5.1 information about health consequences; 9.2 pros and cons; 14.2 punishment. | Knowledge (*g* = 1.91)<br>Data collected at baseline, 6 & 12m | Dietary adherence (*g* = 0.16)<br>Data collected at baseline, 6 & 12m | Phosphate serum (*g* = -0.36)<br>Data collected at baseline, 6 & 12m | 48d /<br>12m |

| **Author Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size[1]** | **Behavioural outcome measured and effect size[2]** | **Physiological outcome measured and effect size[3]** | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| Kauric-Klein et al., (2012) USA | Cluster randomised<br>118 (59/59) | 1.1 goal setting (behaviour); 1.2 problem solving; 2.3 self-monitoring of behaviour; 2.7 feedback on behaviour; 3.3 social support (emotional); 6.1 demonstration of behaviour; 10.4 social reward | Knowledge ($g = 0.26$)<br>Self-efficacy ($g = -0.22$)<br>Data collected at baseline and 12w | Medication adherence ($g = 0.16$)<br>Data collected at baseline and 12w | IDWG ($g = -0.05$)<br>Data collected at baseline and 12w | 2d /<br>4m |
| Lim et al., (2018) Korea | Parallel group<br>70 (48/22) | 4.1 Instruction on how to perform the behaviour: 5.1 information about health consequences | Knowledge ($g = 0.27$) | Medication adherence ($g = 0.12$) | Phosphate serum ($g = -0.04$)<br>Data collected at baseline, 1 & 3 months | 1d /<br>3m |
| Lou et al., (2012) Spain | Cluster randomised<br>80 (41/39) | 4.1 Instruction on how to perform the behaviour: 7.1 prompts/ cues | | | Phosphate serum ($g = -0.67$)<br>Data collected at baseline & 6m | 6d /<br>6m |
| Mateti et al., (2018) India | Parallel group<br>153 (78/75) | 2.7 feedback on outcome of behaviour; 4.1 Instruction on how to perform the behaviour; 5.1 information about health consequences | | Medication adherence ($g = 0.63^{a}$, $g = 0.85^{b}$, $g = 1.22^{c}$) | IDWG ($g = -0.84^{a}$, $g = -1.08^{b}$, $g = -2.37^{c}$)<br>Data collected at baseline, 6 & 12m | 6d /<br>12m |
| Mina et al., (2019) Philippines | Parallel group<br>23 (12/11) | 1 goals and planning; 2.3 self-monitoring of behaviour; 2.7 feedback on outcome of behaviour; 4.1 instructions on how to perform the behaviour; 5.1 information about health consequences | | Fluid adherence ($g = 0.90$)<br>Data collected baseline, post intervention (wk 1), 2, 3 and 4th wk | IDWG ($g = -0.57$)<br>Data collected baseline, post intervention (wk 1), 2, 3 and 4th wk | 2d /<br>4w |
| Molaison & Yadrick (2003) USA | Cluster randomised<br>316 (216/100) | 2.3 self-monitoring of behaviour; 2.7 feedback on outcome of behaviour; 4.1 instructions on how to perform the behaviour; 5.1 natural consequences; 7.3 reduce prompts/cues | Knowledge ($g = 0.26$)<br>Data collected at baseline, 6 & 12w | | IDWG ($g = 0.04$)<br>Data collected at 3w before baseline and 3w to the 6 & 12w fu | 12d /<br>3m |
| Morey et al., 2008) UK | Parallel group<br>67 (34/33) | 3.3 social support (emotional); 4.1 instruction on how to perform the behaviour; 7.1 prompts/ cues; 8.1 behavioural practice; 9.2 pros and cons; 10.4 social reward | | | Phosphate ($g = 0.19$)<br>Data collected baseline, 1, 2, 3, 4, 6 & 12m | 6d /<br>12m |
| Neumann et al., (2013) Switzerland | Parallel group<br>120 (60/60) | 2.3 self-monitoring of behaviour | | | IDWG ($g = -0.10$)<br>Data was collected pre and post dialysis for 3m | 1d /<br>3m |
| Pasyar et al., (2015) Iran | Parallel group<br>86 (43/43) | 11.2 reduce negative emotions- relaxation and breatheworks; 12.6 body changes | | | IDWG ($g = -0.36$)<br>Potassium serum ($g = 0.06$)<br>Phosphate serum ($g = -0.66$)<br>Data collected at baseline and 2m | 2d /<br>2m |

| **Author Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size[1]** | **Behavioural outcome measured and effect size[2]** | **Physiological outcome measured and effect size[3]** | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| Ramezani et al., (2018) Iran | Parallel group<br>70 (35/35) | 1.2 problem solving; 2.2 feedback on behaviour; 2.3 self-monitoring of behaviour; 4.1 instruction on how to perform the behaviour; 6.1 behavioural demonstration; 8.1 behavioural practice; 8.7 graded tasks | Knowledge (*g* = 0.78)<br>Data collected at baseline & 3m | Dietary adherence (*g* = 0.74)<br>Fluid adherence (*g* = 0.76)<br>Data collected at baseline & 3m | | 4d /<br>3m |
| Reese et al., (2015) USA | Parallel group<br>36 (12/12#/ 12) | 1.1 goal setting; 4.1 instruction on how to perform the behaviour; 4.2 information about antecedents; 7.1 prompts/cues; 10.1 material incentive (behaviour) | | | Phosphate serum (*g* = -0.18)<br>Data was collected every 2w (5x) | 1d /<br>10w |
| Sehgal et al., (2002) USA | Cluster randomised<br>169 (85/84) | 1.2 problem solving; 2.1 monitoring of behaviour without feedback; 4.1 instruction on how to perform the behaviour | | Dialysis adherence<br>Data collected pre (3m) and post intervention (4-6m) | | 6d /<br>6m |
| Sharp et al., (2005) UK | Cluster randomised<br>56 (29/27) | 1.1 goal setting; 1.2 problem solving; 1.4 action planning; 2.3 self-monitoring of behaviour; 3.3 social support (emotional)- CBT; 4.1 instruction on how to perform the behaviour; 5.1 information about health consequences; 7.3 reduce prompts/cues; 12.1 restructuring the physical environment; 12.6 body changes | Self-efficacy (*g* = 0.49)<br>Outcome expectancies (*g* = -0.00)<br>Depression (*g* = -0.09)<br>Anxiety (*g* = -0.22)<br>QoL (*g* = 0.74)<br>Data collected at baseline and 4w | | IDWG (*g* =-0.05)<br>Data collected pre and post-dialysis for 14w | 4d /<br>14w |
| Shi et al., (2013) China | Parallel group<br>80 (40/40) | 3.1 social support (unspecified); 4.1 instruction on how to perform the behaviour | Knowledge (*g* = 0.26)<br>Data collected at baseline, 3 & 6m after intervention | | Phosphate serum (*g* = -0.64)<br>Data collected at baseline, 3 & 6m after intervention | 54d /<br>6m |
| Skoutakis et al., (1978) USA | Parallel group<br>24 (12/12) | 2.2 feedback on behaviour; 4.1 instruction on how to perform the behaviour; 4.2 information about antecedents; 5.1 information about health consequences; 7.1 prompts/cues | Knowledge (*g* = 0.92)<br>Data collected at baseline, 4 & 8m | Medication adherence (*g* = 0.88)<br>Data collected at baseline, 4 & 8m | . | 12d /<br>8m |
| Sullivan et al., (2009) USA | Parallel group / Cluster randomised<br>279 (145/134) | 3.2 social support (practical); 4.1 instruction on how to perform the behaviour; 7.1 prompts/cues | Knowledge (*g* = 0.15)<br>Data collected at baseline and 3m | | Phosphate serum (*g* = -0.20)<br>Data collected at baseline and 3m | 1d /<br>3m |
| Tanner et al., (1998) USA | Parallel group<br>38 (28/10) | 1.3 goal setting (outcome); 1.4 action planning; 1.5 review behaviour goal; 1.7 review outcome goal; 1.8 behavioural contract; 2.7 feedback on outcomes; 4.1 instruction on how to perform the behaviour; 5.1 information about health | Knowledge (*g* = 1.00)<br>Self-efficacy (*g* = -0.24)<br>Outcome expectancies (g = 0.14)<br>Data collected baseline and end of intervention (6m) | | IDWG (*g* = -0.26)<br>Phosphate (*g* = 0.17)<br>Data collected baseline and end of intervention (6m) | 6d /<br>6m |

| **Author**<br>**Country** | **Study characteristics Trial design, Sample size (Intervention/ Control)** | **Contents of intervention as determined by taxonomy** | **Psychological outcome measured and effect size**[1] | **Behavioural outcome measured and effect size**[2] | **Physiological outcome measured and effect size**[3] | **Duration of intervention / Follow-up** |
|---|---|---|---|---|---|---|
| | | consequences; 10.4 social reward; 10.10 reward (outcome) | | | | |
| Tsay et al., (2003)<br>Taiwan | Parallel group<br>62 (31/31) | 1.1 goal setting; 2.2 feedback on behaviour; 2.3 self-monitoring of behaviour; 5.1 info consequences; 10.4 social reward; 12.6 body changes | | | IDWG (*g* = -0.31)<br>Data were collected at baseline, 1, 3 & 6m | 12d /<br>6m |
| Valsaraj et al., (2020)<br>India | Parallel group<br>67 (33/34) | 3.3 Social support (emotional)- CBT | Depression (*g* = -0.50)<br>Anxiety (*g* = -0.80) | Dietary adherence (*g* = 0.85)<br>Fluid adherence (*g* = 0.82)<br>Medication adherence (*g* = 0.67) | IDWG (*g* = -1.07)<br>Data collected baseline, 3m & 6m | 10d /<br>6m |
| Welch et al., (2013)<br>USA | Parallel group<br>44 (24/20) | 2.3 self-monitoring of behaviour; 5.2 salience of consequences | Self-efficacy (*g* = 0.02)<br>Data collected at baseline, 6 & 14w | | IDWG (*g* = -0.04)<br>Data collected at baseline, 6 & 14w | 3d /<br>14w |
| Wileman et al., (2014)<br>UK | Cluster randomised<br>112 (57/55) | 1.4 action planning; 4.1 instructions on how to perform the behaviour; 5.1 information about health consequences; 13.4 valued self-identity | | | Phosphate serum (*g* = -0.12)<br>Data collected at baseline, 1, 3, 6, 7, 9 and 12m post-intervention | 1d /<br>12m |
| Wileman et al., (2016)<br>UK | Cluster randomised<br>89 (49/40) | 4.1 instructions on how to perform the behaviour; 5.1 information about health consequences; 13.4 valued self-identity | | Fluid adherence (*g* = 0.26)<br>Data collected at baseline, 1 & 6m | IDWG (*g* = -0.41)<br>Data collected at baseline, 1, 5, 12,27, 40 & 52w | 1d /<br>12m |
| Wong et al., (2010)<br>China | Parallel group<br>98 (49/49) | 1.1 goal setting (behaviour); 1.2 problem solving; 1.5 review behaviour goals; 1.7 review outcome goals; 2.7 feedback on outcome of behaviour; 4.1 instructions on how to perform behaviour | QoL (*g* = 0.36)<br>Data was collected at baseline, 7w (a wk after intervention) and at 13 weeks | | | 6d /<br>3m |
| Yokum et al., (2008)<br>UK | Parallel group<br>34 (17/17) | 2.2 feedback on behaviour; 4.1 instructions on how to perform the behaviour; 7.1 prompts/cues | | | Phosphate serum (*g* = -0.79)<br>Data collected at baseline, 1, 2, 3 & 4m | 4d /<br>4m |

*Notes.* Abbreviations or symbols used in the table: *g* = Hedge's g, d = days, w = weeks, m = months, fu = follow up. Mateti et al., (2018) a = academic hospital, b = government hospital C = corporate hospital. Hanifi et al., (2018) % = data was presented as % and no raw data. 1 = psychological data reported post intervention was used in analyses, 2 & 3 = behavioural and physiological data reported at the last timepoint was used in analyses.

### *Outcome measures*

Across studies, 22 evaluated intervention effects on one or more psychological measure, 17 evaluated change in one or more behavioural outcome and 37 assessed effects of an intervention on one or more physiological outcome (Table 2). For the purposes of the meta-analysis, since psychological measures assess the validity of the intervention in changing target constructs, we computed effect sizes for the first available data point following completion of the intervention. For behavioural and physiological outcomes an effect size was computed for the last available data point post intervention for each study.

Psychological constructs targeted by the interventions were knowledge (12), self-efficacy (6), outcome expectancies (3), anxiety (3), depression (4), quality of life (6). All variables were assessed by questionnaire measures, generally self-administered. One study employed a clinician administered interview with verbal responses to assess knowledge (Skoutakis et al., 1978). Knowledge was conceptualised across studies as factual knowledge of correct and incorrect food items to consume, correct use of medications, symptomatic consequences of eating incorrect items or consuming excess fluid, and reasons for adhering to diet and fluid and medication regimes. Knowledge was most commonly assessed by multiple choice (e.g., Molaison & Yadrick, 2003; Karavetian et al., 2013, 2015; Shi et al. 2013) or true/false tests (e.g., Ramezani et al., 2018), with multiple items producing a single total score representing extent of correct knowledge. Self-efficacy, conceptualised as perceived ease or difficulty in enacting recommended dietary, fluid restriction and medication use were assessed via self-report questionnaire scales (e.g., Tanner et al., 1998), or a single question followed by a visual analogue scale (e.g., Sharp et al., 2005; Hare et al., 2014). Griva et al. (2018) report two measures of self-efficacy. The first, labelled disease self-efficacy was assessed by the self-efficacy for managing chronic disease questionnaire (Lorig et al., 2001). A second measure designed for the study assessed renal specific self-efficacy (fluid, diet, medication). For the meta-analysis, only scores from the renal specific self-efficacy measure were used. Outcome expectancies, or beliefs and attitudes were assessed in 3 studies, either by researcher developed questionnaires (Tanner et al., 1998) or visual analogue (Hare et al., 2014; Sharp et al., 2005). Anxiety and depression were assessed across studies by established validated instruments such as the Hospital Anxiety and Depression Scale (e.g., Sharp et al., 2005; Hare et al., 2014; Valsaraj et al., 2020), the PHQ-9 (Kauric-Klein et al., 2012) or the Beck Depression Inventory (e.g., Cukor et al., 2014). Quality of life was evaluated via established multi-item general life quality instruments such as the SF-36 (e.g., Sharp et al., 2005; Hare et al., 2014) or kidney specific instruments such as the Kidney Disease Quality of Life short form (e.g., Cukor et al., 2014; de Freitas et al., 2020; Wong et al., 2010). For the purpose of the meta-analysis, improvements in knowledge, self-efficacy, outcome expectancies and life quality are indicated by positive change, whereas improvements in anxiety and depression are indicated by negative change.

Behavioural outcomes included measures of adherence to dietary (10), fluid (7) and medication regimes (11) and for the purpose of the meta-analysis were coded so that higher scores indicated higher adherence. Dietary adherence was assessed across studies via multi-item questionnaires recording frequency of consuming food items on Likert scales (e.g., Arad et al., 2021; Cho, 2013; Griva et al., 2018; de Freitas et al., 2020; Ramezani et al., 2018). Karavetian et al. (2015) calculated phosphate and protein dietary intake based on the analysis of 24 hours recalls collected on 3 non-consecutive days from participants with higher scores reflecting higher adherence. Self-reported fluid adherence was assessed by single items (e.g., Wileman et al., 2016; During the past month how often have you stuck to your maximum recommend fluid intake?) or more commonly via multi-item questionnaires reporting fluid consumption. For example, Chang et al. (2021) used the 24-item Fluid Control in Haemodialysis Patient Scale by Cosar and Pakyuz (2016). Griva et al. (2018) used the Renal

Adherence Behaviour Questionnaire by Rushe and McGee (1998) to measure self-reported adherence to fluid restrictions. Some authors developed questionnaires for their studies (e.g., Ramezani et al., 2018; Valsaraj et al., 2020). Medication adherence was assessed either by self-reported multi-item scales such as the Morisky Medication Adherence- 8-item Scale (e.g., (Kauric- Klein et al., 2012; Griva et al., 2018; Lim et al., 2018; Mateti et al., 2018), pill box counts (e.g., Skoutakis et al.,1978), or electronic devices that detect pill box opening (Medication Event Monitoring System (MEMS); Forni Ogna et al., 2013). Some self-reports included frequency of buying medication as well as taking medication (e.g., Valsaraj et al., 2020).

Physiological outcomes, potassium (6), phosphate (22) and IDWG (22) were derived from clinical data in all studies. For all physiological measures, lower values post intervention are indicative of an improvement in adherence. Six studies (Cummings et al., 1981; Baraz et al., 2010; Cho, 2013; Pasyar et al., 2015; Griva et al., 2018, Arad et al., 2021) used laboratory results records to obtain values of serum potassium pre- and post-intervention. Lower serum potassium following the intervention suggests an improvement in adherence. Most but not all the studies (e.g., Ashurst & Dobbie, 2003; Baraz et al., 2010; Karavetian et al., 2013, 2015; Wileman et al., 2014; Chen et al., 2021) used laboratory records containing biochemical values of serum phosphate which were collected routinely to assess mean change of phosphate pre and post intervention. Reese et al. (2015) measured phosphate level every 2 weeks while Haq et al. (2014) measured serum phosphate at baseline and pre-dialysis on weeks 2, 3, 4, 5, 7, 9, 11. Twenty studies assessed change in inter-dialytic weight gain (fluid intake between dialysis sessions) in response to adherence interventions. All the studies (e.g., Cummings et al., 1981; Tanner et al., 1998; Sharp et al., 2003; Welch et al., 2013; Mateti et al., 2018, Valsaraj et al., 2020; Chang et al., 2021) assessed IDWG measured in kilograms by weighing participants pre- and post-dialysis during routine clinical care using an electronic scale. IDWG was calculated by subtracting the previous post-dialysis weight from the current pre-dialysis weight. Mateti et al. (2018) reported IDWG information for participants in three different hospitals (academic, government, and corporate hospitals). This means that outcome data was available for three independent samples and were all included in the meta-analysis. A reduction in IDWG post intervention reflects improved fluid adherence.

## Risk of bias assessment

Results of the risk of bias assessment for the 46 studies are summarised in Appendix A. Kappa assessment of inter-rater reliability across domains ranged from 0.7 to 1.0. The first domain is *bias arising from the randomisation process* which focuses on minimising bias through random allocation to groups through a specified method (e.g., computer generated random numbers, envelopes). Further, the schedule of random assignments must be concealed until participants were recruited and assigned to interventions. 20 studies were ‘low concern’, 20 were ‘some concern’ and six were judged as ‘high concern’. The second domain *bias due to deviations from intended interventions* relates to systematic differences when the care provided is different from what was intended. For example, planned care not being provided, additional care was provided, or participants were analysed in a different group. Such biases can be reduced or prevented by blinding (masking) intervention from participants and other study personnel. 14 studies were judged as ‘low concern’, 31 as ‘some concern’ and one as ‘high concern’. The third domain *bias due to missing outcome data* relates to issues around attrition, exclusions from analysis, participant distribution across groups, the reasons provided for the missing data and what has been done to address such issues in data analysis to minimise bias in the observed effect estimate. 19 studies rated as ‘low concern’, 24 as ‘some concern’ and three as ‘high concern’. The fourth domain *bias in measurement of the outcome* specifically addresses the blinding of intervention assignments to outcome assessors (including participants in self-reported outcomes). 31 studies were scored as ‘low concern’, 15 as ‘some concern’ and none as ‘high concern’. The final domain *bias in selection of the reported result* relates to outcome non-reporting whereby outcomes are partially or not reported due to the direction or statistical significance of results. This also includes where constructs were measured (e.g., self-efficacy) but no data were reported due to a lack of significance or where multiple measures were used for the same construct but not all measures were reported. 25 studies were rated as ‘low concern’, 20 as ‘some concern’ and one as ‘high concern’.

## Meta-analysis results

A summary of the results of the meta-analysis is shown in Table 3. The forest and funnel plots for each outcome are provided in Appendix B. Across outcomes, significant pooled intervention effect sizes ranging from $g = 0.32$ to $g = 1.17$ were observed and were associated with heterogeneity values ranging from $I^2 = 31.6\%$ to 90%. Egger’s test and funnel plots did not show evidence of publication bias across analyses.

### *Effect of interventions on psychological measures*

Psychological measures included in the studies were either of proposed mechanisms of action (knowledge, self-efficacy and outcome expectancy) or affective outcomes (anxiety, depression and quality of life). Significant pooled effects were observed for two of the psychological outcomes assessed, knowledge and quality of life. Meta-analytic synthesis of the 12 interventional studies targeting *knowledge* showed a medium effect ($g = 0.65$, $p < 0.01$). Knowledge about kidney disease (e.g., management) was significantly improved in intervention participants relative to controls. Six studies targeted self-reported *QoL* and showed a large significant effect ($g = 1.17$, $p = 0.05$), in the average score of self-reported QoL between participants in the intervention relative to control groups.

### *Effects of Interventions on Behavioural Outcomes*

Pooled estimates of mean differences in dietary, fluid and medication adherence showed significant improvements across all three behavioural constructs. The ten studies targeting *dietary adherence* behaviours showed a significant medium effect ($g = 0.50$, $p < 0.001$) with a significant improvement in dietary adherence in response to the intervention relative to controls. The seven studies that investigated *fluid restriction adherence* behaviours showed a medium effect ($g = 0.57$, $p < 0.01$) with significant improvements in fluid restriction in response to the intervention relative to controls. The eleven studies that targeted *medication adherence* behaviours showed a medium effect ($g = 0.65$, $p < 0.01$) and significant improvements in medication adherence in intervention participants relative to controls.

### *Effects of Interventions on Physiological Outcomes.*

Significant pooled effects were observed for change in phosphate and IDWG. In relation to physiological outcomes, it should be noted that a negative sign is indicative of improvement in outcome (lower phosphate, potassium and IDWG). The 22 studies that assessed reduction in *phosphate* levels showed a significant small effect ($g = - 0.32$, $p < 0.001$) with reduced levels of phosphate levels in response to the intervention. The 22 studies testing *IDWG* showed a significant moderate effect ($g = - 0.57$, $p = 0.004$) in the average IDWG between participants in the intervention and control groups in response to the adherence intervention. Six studies that examined intervention effect on *potassium* serum levels had moderate effect ($g = - 0.59$). However, change in potassium levels were not statistically different between participants in the intervention and the control groups ($p = 0.06$).

**Table 3**

*Weighted effect size of interventions on psychological, behavioural and physiological outcomes*

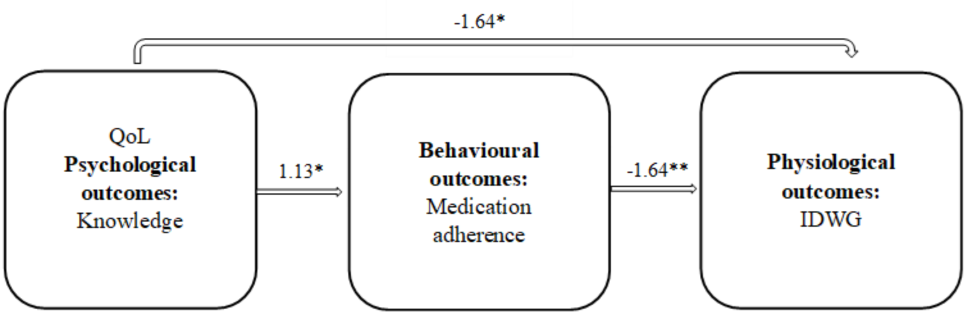
| | | Weighted effect sizes | | Heterogeneity | | |
|---|---|---|---|---|---|---|
| **Outcomes** | *k* | *g* (95% CI) | *p* | Q | *p* | $I^2$(%) |
| **Psychological outcomes** | | | | | | |
| Knowledge | 12 | 0.65 (0.28, 1.02 | 0.0026 | 94.08 | <0.001 | 88.3 |
| Self-efficacy | 6 | 0.24 (-0.24, 0.73) | 0.25 | 18.62 | 0.0023 | 73.1 |
| Outcome expectancies | 3 | 0.06 (-0.24, 0.35) | 0.48 | 0.35 | 0.84 | 0 |
| Depression | 4 | -1.06 (-3.64, 1.51) | 0.28 | 54.37 | <0.0001 | 94.5 |
| Anxiety | 4 | -0.74 (-2.33, 0.86) | 0.18 | 5.57 | 0.06 | 94.1 |
| Quality of life | 6 | 1.17 (-0.02, 2.36) | 0.05 | 55.64 | 0.0001 | 91 |
| **Behavioural outcomes** | | | | | | |
| Fluid | 7 | 0.59 (0.29, 0.90) | 0.0032 | 13.38 | 0.037 | 55.2 |
| Dietary | 10 | 0.50 (0.24, 0.76) | 0.0019 | 24.19 | 0.004 | 62.8 |
| Medication | 11 | 0.65 (0.28, 1.03) | 0.0031 | 43.27 | <0.0001 | 76.9 |
| **Physiological outcomes** | | | | | | |
| Potassium | 6 | -0.59 (-1.22, 0.04) | 0.06 | 25.16 | 0.0001 | 80.1 |
| Phosphate | 22 | -0.32 (-0.45, -0.19) | <0.001 | 30.7 | 0.07 | 31.6 |
| IDWG | 22 | -0.57 (-0.93, -0.20) | 0.004 | 117.62 | <0.0001 | 82.1 |

*Notes.* K number of studies; g hedges g test for overall effect; $T^2$ variance of the true effects; Q between study heterogeneity; $I^2$ between study heterogeneity expressed as a percentage of variation due to heterogeneity rather than chance.

## Relationship between outcomes

We tested whether the effect sizes obtained in the meta-analysis for psychological outcomes (knowledge, self-efficacy, outcome expectancies, depression, anxiety, and QoL) were associated with the effect sizes of behavioural outcomes (dietary, fluid and medication adherence) and physiological outcomes (potassium, phosphate and IDWG) (Figure 3, path (b)). As previously noted, the effect sizes for psychological outcomes were computed for the first available data point post intervention in each study, whilst the effect sizes for behavioural and physiological outcomes were computed for the last available data point post-intervention for each study. Figure 5 illustrates the significant pathways supported by the analyses.

**Figure 5**
*Linear model showing significant relational pathways between psychological constructs and behavioural and physiological outcomes*



*Note.* Unstandardised beta coefficients are presented (*$p \leq .05$; **$p \leq .01$)

A significant association was obtained between knowledge and medication adherence. The effect size for knowledge was significantly positively associated with that of medication adherence ($b = 1.13$, $SE = 0.07$, $t(4)= 16.65$, $p = 0.03$), showing that as knowledge improved as a function of the intervention received, medication adherence improved as well. The effect size of medication adherence behaviour was in turn significantly negatively associated with the effect size of IDWG ($b = -1.64$, $SE = 0.29$, $t(8)= -5.58$, $p = 0.002$). This finding indicates that as medication adherence increased as a function of the intervention received, IDWG decreased (e.g., patients successfully gained less weight between sessions). The effect obtained for QoL was significantly associated with the effect size of IDWG ($b = -1.64$, $SE = 0.11$, $t(4)= -14.98$, $p = 0.04$), showing that improvements in quality of life as a function of the intervention received were associated with decreases in IDWG.

## Moderation analysis results

Our third aim was to examine moderation of intervention effects. We analysed two categories of potential moderators: intervention content, and intervention duration (Figure 3, path (c)).

### *Moderation by intervention BCT content*

The BCT taxonomy (Michie et al., 2013) was used to code the intervention contents of the 46 studies, where at least one discrete BCT category could be identified and coded from the intervention descriptions (see Table 2). Agree function in R was used to calculate estimates of inter-rater agreement between authors 1 and 2.The overall estimated agreement was high (89.1%). The number of identifiable BCTs across studies ranged from one to seven (*M* = 4.23, *SD* = 2.35). A summary of techniques employed in the interventions is provided in Table 4. The most commonly employed BCT techniques were shaping knowledge, feedback and monitoring, natural consequences, goals and planning, and social support. Seven of the studies used established therapeutic techniques such as CBT, motivational interviewing, relaxation or rational emotive therapy (Cukor et al., 2014; Forni Ogna et al., 2013; Hare et al., 2014; Hou et al., 2010; Sharp et al., 2005; Pasyar et al., 2015; Valsaraj et al., 2020). Since these techniques are coded by the BCT as subcategories of 3.3 (Social support- emotional) it was decided to create a separate intervention technique category labelled as *therapy* for these techniques in subsequent analyses shown in Tables 4 and 5.

**Table 4**

*Number (%) of interventions including each BCT category (total N = 46 studies)*

| Moderator | N (%) | Details about BCT groupings |
|---|---|---|
| **1**. Goals and planning | **19 (41.3)** | **1.1** Behavioural goal setting: 11, **1.2** Problem solving: 13, **1.3** Outcome setting: 2, **1.4** Action planning: 6, **1.5** Review behaviour goal(s): 2, **1.6** Discrepancy between current behaviour and goal: 1, **1.7** Review outcome goal(s): 4, **1.8** Behaviour contract: 3, **1.9** Commitment: 1 |
| **2**. Feedback and monitoring | **24 (52.17)** | **2.1** Monitoring of behaviour by others without feedback: 2, **2.2** Feedback on behaviour: 6, **2.3** Self-monitoring of behaviour: 17, **2.4** Self-monitoring of outcome(s) of behaviour: 2, **2.5** Monitoring of outcome(s) of behaviour without feedback: 1, **2.6** Biofeedback: 0, **2.7** Feedback on outcome(s) of behaviour: 10 |
| **3**. Social support | **16 (34.78)** | **3.1** Social support (unspecified): 7, **3.2** Social support (practical): 4, **3.3** Social support (emotional): 8 |
| **4**. Shaping knowledge | **33 (71.74)** | **4.1** Instructions on how to perform the behaviour:30, **4.2** Information on antecedents: 3, **4.3** Re-attribution: 2, **4.4** Behavioural experiments: 1 |
| **5**. Natural consequences | **21 (45.65)** | **5.1** Information about health consequences: 20, **5.2** Salience of consequences: 1, **5.3** Information about social and environmental consequences: 0, **5.4** Monitoring of emotional consequences: 0, **5.5** Anticipated regret: 0, **5.6** Information about emotional consequences: 0 |
| **6**. Comparison of behaviour | **3 (6.52)** | **6.1** Behaviour demonstration:3, **6.2** Social comparison: 0, **6.3** Information about others' approval: 0 |

| | | |
|---|---|---|
| **7**. Associations | **9 (19.57)** | **7.1** Prompts/cues: 7, **7.2** Cue signalling reward: 0, **7.3** Reduce prompts/cues: 2, **7.4** Remove access to the reward: 0, **7.5** Remover aversive stimulus: 0, **7.6** Satiation: 0, **7.7** Exposure: 0, **7.8** Associative learning: 0 |
| **8**. Repetition and substitution | **4 (8.7)** | **8.1** Behavioural practice/rehearsal: 3, **8.2** Behaviour substitution: 0, **8.3** Habit formation: 0, **8.4** Habit reversal: 0, **8.5** Overcorrection: 0, **8.6** Generalisation of target behaviour: 0, **8.7** Graded tasks: 1 |
| **9**. Comparison of outcomes | **2 (4.35)** | **9.1** Credible source: 0, **9.2** Pros and Cons: 2, **9.3** Comparative imagining of future outcomes: 0 |
| **10**. Reward and threat | **9 (19.57)** | **10.1** Behaviour material incentive: 3, **10.2** Behaviour material reward: 0, **10.3** Non-specific reward: 0, **10.4** Social reward: 5 **10.5** Social incentive: 0, **10.6** Non-specific incentive: 0, **10.7** Self-incentive: 0, **10.8** Outcome incentive: 0, **10.9** Self-reward:1, **10.10** Outcome reward: 3, **10.11** Future punishment: 0 |
| **11**. Regulation | **2 (4.35)** | **11.1** Pharmacological support: 0, **11.2** Reduce negative emotions: 2, **11.3** Conserving mental resources: 0, **11.4** Paradoxical instructions: 0 |
| **12**. Antecedents | **4 (8.7)** | **12.1** Physical environment restructuring: 2, **12.2** Social environment restructuring: 0, **12.3** Avoidance/reducing exposure to cues for the behaviour: 0, **12.4** Distraction: 0, **12.5** Adding objects to the environment: 0, **12.6** Body changes: 2 |
| **13**. Identity | **4 (8.7)** | **13.1** Identification of self as role model: 0, **13.2** Framing/re-framing: 2, **13.3** Incompatible beliefs: 0, **13.4** Valued self-identity: 2, **13.5** Identity associated with changed behaviour: 0 |
| **14**. Scheduled consequences | **1 (2.17)** | **14.1** Behaviour cost: 0, **14.2** Punishment: 1, **14.3** Remove reward: 0, **14.4** Reward approximation: 0, **14.5** Reward completion: 0, **14.6** Situation-specific reward: 0, **14.7** Reward incompatible behaviour: 0, **14.8** Reward alternative behaviour: 0 **14.9** Reduce reward frequency: 0, **14.10** Remove punishment: 0 |
| **15**. Self-belief | **0** | **15.1** Verbal persuasion about capability: 0, **15.2** Mental rehearsal of successful performance: 0, **15.3** Focus on past success: 0, **15.4** Self-talk: 0 |
| **16**. Covert learning | **0** | **16.1** Imaginary punishment: 0, **16.2** Imaginary reward: 0, **16.3** Vicarious consequences: 0 |

Moderation analyses were conducted using meta-regression for combinations of BCT category and outcomes for which data from sufficient studies were available. In the first set of analyses summarised in Table 5, presence versus absence of single discrete BCT categories were regressed on intervention outcomes. These analyses investigated whether the presence of discrete BCT categories vs their absence moderated the effectiveness of the interventions on psychological, behavioural, and physiological outcomes. A positive beta value implies that the presence of the specific technique in the interventions was associated with an increased intervention effect on the relevant outcome. A negative beta value implies a decreased effect was observed when the intervention technique was present. We limit our discussion to instances where significant differences emerged.

**Table 5**

*Intervention content (behaviour change technique categories) meta-regressed on psychological, behavioural, and physiological outcomes of interventions*

| | Goals & planning | | Feedback & monitoring | | Social support | | Shaping knowledge | | Associations | | Natural consequences | | Reward & threat | | Therapy | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* |
| **Psychological outcomes** | | | | | | | | | | | | | | | | |
| Knowledge (k=12) | 0.52 | 0.14 | 0.22 | 0.53 | 0.16 | 0.68 | -0.62 | 0.16 | -0.37 | 0.36 | 0.36 | 0.36 | -0.08 | 0.86 | - | |
| Self-efficacy (k=6) | 0.27 | 0.67 | -0.52 | 0.25 | 0.80 | **0.00** | 0.27 | 0.67 | 0.30 | 0.60 | -0.68 | 0.06 | -0.78 | **0.01** | 0.55 | 0.23 |
| Outcome expectancies (k=3) | - | - | - | - | -0.17 | 0.30 | - | - | -0.09 | 0.69 | 0.23 | 0.47 | 0.17 | 0.30 | -0.17 | 0.30 |
| Depression (k=4) | 1.82 | 0.35 | 1.82 | 0.35 | - | - | 1.82 | 0.35 | 1.31 | 0.59 | 1.31 | 0.59 | - | | - | - |
| Anxiety (k=3) | -0.03 | 0.98 | -0.03 | 0.98 | - | - | -0.03 | 0.98 | 0.83 | 0.40 | 0.83 | 0.40 | - | | - | - |
| Quality of life (k=6) | -2.33 | **0.03** | -2.33 | **0.03** | 1.49 | 0.13 | -2.33 | **0.03** | -0.52 | 0.72 | -0.52 | 0.72 | - | | 1.44 | 0.13 |
| **Behavioural outcomes** | | | | | | | | | | | | | | | | |
| Dietary adherence (k=10) | -0.36 | 0.13 | 0.13 | 0.59 | 0.07 | 0.77 | -0.25 | 0.31 | - | - | -0.15 | 0.54 | 0.10 | 0.82 | 0.38 | 0.36 |
| Fluid adherence (k=7) | 0.01 | 0.97 | 0.44 | 0.14 | 0.04 | 0.89 | -0.26 | 0.52 | - | - | -0.13 | 0.64 | - | | -0.12 | 0.70 |
| Medication adherence (k=11) | -0.05 | 0.88 | -0.22 | 0.55 | -0.29 | 0.43 | -0.26 | 0.58 | 0.24 | 0.74 | 0.29 | 0.43 | -0.65 | 0.13 | 0.48 | 0.46 |
| **Physiological outcomes** | | | | | | | | | | | | | | | | |
| Potassium (k=6) | -0.87 | 0.07 | -0.72 | 0.21 | -0.09 | 0.88 | -0.78 | 0.26 | - | - | -0.10 | 0.87 | -0.72 | 0.21 | - | - |
| Phosphate (k=22) | -0.04 | 0.78 | -0.06 | 0.67 | 0.07 | 0.61 | 0.15 | 0.31 | 0.05 | 0.75 | 0.14 | 0.29 | 0.29 | 0.14 | 0.53 | 0.07 |
| IDWG (k=22) | 0.37 | 0.32 | 0.60 | 0.08 | -0.36 | 0.33 | 0.38 | 0.33 | - | - | 0.37 | 0.32 | 0.48 | 0.24 | -0.67 | 0.11 |

*Note.* Unstandardised beta coefficients and p values are reported in the table. Wellbeing denotes an aggregation of depression, anxiety and QoL. K denotes number of studies. Dash indicates that it was not meaningful to test the association between variables due to missing data. BCT categories were coded dichotomously: (present 1 v absent 0). Boldface indicates significant results.

As shown in Table 5, self-efficacy outcomes were larger when *social support* was present in the intervention ($b = 0.80$, $SE = 0.10$, $t(4) = 8.11$, $p = 0.001$), but smaller in interventions that included *reward and threat* ($b = -0.78$, $SE = 0.18$, $t(4) = -4.24$, $p = 0.013$). Interestingly, the presence of three of the eight BCT's (*goals and planning, feedback and monitoring, and shaping knowledge*) also led to significantly smaller intervention effects on QoL ($b = -2.34$, $SE = 0.77$, $t(4) = -3.04$, $p = 0.04$). We observed that the same six studies had these three BCT categories present, such that if they contained goals and planning, they also contained shaping knowledge and feedback and monitoring, resulting in identical beta values across these three BCT categories. These analyses revealed no significant moderation effects of BCT techniques on behavioural outcomes and marginal effects on physiological outcomes considered individually.

In order to increase available power, these analyses were re-run with outcomes aggregated into behavioural (dietary, fluid and medication adherence), physiological (IDWG, potassium and phosphate serum levels) and psychological (self-efficacy, knowledge, outcome expectancy, anxiety, depression and QoL) constructs. We also ran separate analyses for aggregated psychological outcomes denoting wellbeing (anxiety, depression, and QoL) and an aggregated psychological construct excluding wellbeing (self-efficacy, knowledge and outcome expectancy). The results of these analyses are shown in Table 6 and denoted by $^1$b. The presence of *shaping knowledge* ($^1b = -0.73$, $SE = 0.35$, $t(32) = -2.10$, $p = 0.04$) was significantly associated with a smaller intervention effect on the aggregate psychological construct.

Since interventions rarely employ a single BCT technique and techniques may be enhanced or diminished in their effects by their use in combination with other techniques, a second set of meta-regressions (Table 6) were conducted in which the effects of interventions on outcomes were regressed on the discrete BCT technique category after controlling for total number of techniques employed in the intervention (shown in the second row for each outcome and denoted $^{2}$ b), and on the interaction between the BCT category and the total number of techniques employed (shown in the third row for each outcome and denoted $^{3}$ b). In order to conduct these analyses, the effects on psychological, behavioural and physiological outcomes were analysed in aggregate. Results are summarised in Table 6.

As shown in Table 6, we observed significantly larger, positive, effects of the interventions on physiological outcomes when the presence of *therapy* was examined after controlling for additional techniques ($^{2}$*b* = 0.49, *SE* = 0.24, *t*(47) = 2.07 *p* = 0.043). Consistent with this observation, there was a significant interaction between the presence of therapy and number of BCT’s ($^{3}$*b* = -0.25, *SE* = 0.11, *t*(46) = -2.20, *p* = 0.03). Simple slopes analysis (Aiken & West, 1991) showed that the inclusion of therapy alone or with fewer other BCT’s in interventions was associated with significantly larger intervention effects on physiological outcomes (*b* = 0.88, *SE* = 0.29, *t*(46) = 3.02, *p* = 0.004) whereas the inclusion of therapy and a high number of other BCT techniques, was not significant (*b* = 0.14, *SE* = 0.27, *t*(46) = 0.52, *p* = 0.61). This suggests that to improve physiological outcomes, interventions that include therapy should be accompanied by fewer rather than multiple other BCT’s. No significant effects on aggregated behavioural outcomes were observed for any BCT technique alone, or in combination with other techniques.  The analyses shown in Table 6 also show distinctive effects of BCT techniques on the aggregate psychological construct excluding wellbeing (e.g., aggregated knowledge, self-efficacy and outcome expectancy). A significant interaction was observed between the presence of *feedback and monitoring* and the number of BCT’s employed in the interventions ($^{3}$ *b* = -0.59, *SE* = 0.16, *t*(17) = -3.69, *p* = 0.002). Simple slopes analysis showed that the inclusion of feedback and monitoring with a high number of additional BCT techniques was associated with significantly smaller intervention effects on these psychological measures (*b* = -1.77, *SE* = 0.48, *t*(17) = -3.71, *p* =

0.002), but there was no difference in effect size for studies with, compared to without feedback and monitoring in the intervention, when there were fewer BCTs present ($b = 0.32$, $SE = 0.26$, $t(17) = 1.20$, $p = 0.25$). This suggests that the presence of feedback and monitoring alone, and accompanied by additional BCTs was unhelpful in modifying these outcomes. A similar interaction was obtained for the effect of the presence of shaping knowledge, and the number of BCT techniques employed in interventions on this outcome ($^3b = -0.60$, $SE = 0.14$, $t(17) = 4.14$, $p = 0.0007$). Simple slopes analysis showed that the presence, relative to absence, of *shaping knowledge* and a high number of additional techniques led to significantly smaller intervention effects ($b = -2.11$, $SE = 0.44$, $t(17) = -4.80$, $p = 0.0002$). When the presence, relative to absence, of *shaping knowledge* was accompanied by a low number of other BCTs, there was no significant difference in intervention effects between the intervention and control conditions ($b = 0.01$, $SE = 0.27$, $t(17) = 0.03$, $p = 0.97$), suggesting that the addition of *shaping knowledge* and more BCT's can have undesirable effects on psychological outcomes excluding wellbeing, compared to when included with fewer other.

We also obtained significant interactions between three of the BCT categories (*goals and planning*, *feedback and monitoring*, and *shaping knowledge*)[1] and the number of BCT's in the interventions ($^3b = -2.52$, $SE = 0.76$, $t(9) = -3.30$, $p = 0.009$) on the aggregate wellbeing construct. Simple slopes analysis showed that in the studies that included, relative to those that did not include, *goals and planning*, *feedback and monitoring* and *shaping knowledge* in their intervention, the intervention effect was smaller both when accompanied by fewer other BCT's ($b = -2.57$, $SE = 0.68$, $t(9) = -3.77$, $p = 0.004$), and by more BCT's ($b = -14.44$, $SE =$

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[1] As previously noted, the same studies had these three BCT categories present, such that if they contained shaping knowledge, they also contained goals and planning, and feedback and monitoring, resulting in identical beta values across these three BCT categories.

3.88, $t(9) = -3.72$, $p = 0.005$), but the reduction of the effect size was even more pronounced in the presence of more BCTs, suggesting more BCTs per intervention is not always better.

**Table 6**

*Presence vs. absence of BCT categories in intervention ($^{1}$b), BCT categories whilst controlling for number of BCT ($^{2}$b), and their interaction ($^{3}$b) meta-regressed on aggregated psychological, behavioural, and physiological intervention outcomes*

| | Goals & planning | | Feedback & monitoring | | Social support | | Shaping knowledge | | Associations | | Natural consequences | | Reward & threat | | Therapy | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* | b | *p* |
| **Aggregated psychological outcomes (k=34)** | -0.05$^{1}$ | 0.88 | -0.28$^{1}$ | 0.39 | 0.54$^{1}$ | 0.08 | -0.73$^{1}$ | **0.04** | -0.39$^{1}$ | 0.35 | -0.21$^{1}$ | 0.51 | -0.44$^{1}$ | 0.41 | 0.62$^{1}$ | 0.09 |
| | -0.12$^{2}$ | 0.81 | -0.39$^{2}$ | 0.31 | 0.55$^{2}$ | 0.08 | -0.85$^{2}$ | **0.03** | -0.40$^{2}$ | 0.40 | -0.22$^{2}$ | 0.52 | -0.52$^{2}$ | 0.38 | 0.66$^{2}$ | 0.10 |
| | 0.03$^{3}$ | 0.94 | -0.15$^{3}$ | 0.58 | -0.10$^{3}$ | 0.61 | -0.24$^{3}$ | 0.32 | -0.01$^{3}$ | 0.96 | 0.08$^{3}$ | 0.70 | -0.13 $^{3}$ | 0.90 | -0.36$^{3}$ | **0.05** |
| Wellbeing (k=13) | -1.33$^{1}$ | 0.12 | -1.33$^{1}$ | 0.12 | 1.09$^{1}$ | 0.23 | -1.33$^{1}$ | 0.12 | -0.75$^{1}$ | 0.55 | -0.75$^{1}$ | 0.55 | - | - | 0.86$^{1}$ | 0.32 |
| | -1.90$^{2}$ | 0.14 | -1.90$^{2}$ | 0.14 | 1.28$^{2}$ | 0.18 | -1.90$^{2}$ | 0.14 | -0.50$^{2}$ | 0.80 | -0.50$^{2}$ | 0.80 | - | - | 0.97$^{2}$ | 0.30 |
| | -2.52$^{3}$ | **0.009** | -2.52$^{3}$ | **0.009** | - | - | -2.52$^{3}$ | **0.009** | - | - | - | - | - | - | 1.10$^{3}$ | 0.49 |
| Psychological construct excluding wellbeing (k=21) | 0.24$^{1}$ | 0.37 | 0.53$^{1}$ | 0.88 | 0.14$^{1}$ | 0.61 | -0.38$^{1}$ | 0.26 | -0.28$^{1}$ | 0.36 | 0.11$^{1}$ | 0.71 | -0.29$^{1}$ | 0.45 | -0.19$^{1}$ | 0.66 |
| | 0.30$^{2}$ | 0.54 | -0.17$^{2}$ | 0.60 | 0.11$^{2}$ | 0.71 | -0.43$^{2}$ | 0.22 | -0.31$^{2}$ | 0.32 | 0.10$^{2}$ | 0.74 | -0.50$^{2}$ | 0.25 | -0.60$^{2}$ | 0.30 |
| | -0.50$^{3}$ | 0.18 | -0.59$^{3}$ | 0.**002** | 0.04$^{3}$ | 0.83 | -0.60$^{3}$ | **0.000** | -0.10$^{3}$ | 0.63 | -.07$^{3}$ | 0.74 | -0.20$^{3}$ | 0.80 | -0.45$^{3}$ | 0.59 |
| **Aggregated behavioural outcomes (k=28)** | -0.26$^{1}$ | 0.26 | -0.11$^{1}$ | 0.59 | 0.00$^{1}$ | 0.99 | -0.26$^{1}$ | 0.38 | 0.60$^{1}$ | 0.53 | 0.12$^{1}$ | 0.58 | -0.16 $^{1}$ | 0.53 | 0.29$^{1}$ | 0.46 |
| | -0.26$^{2}$ | 0.32 | -0.08 $^{2}$ | 0.73 | 0.02$^{2}$ | 0.93 | -0.25$^{2}$ | 0.41 | 0.62$^{2}$ | 0.52 | 0.13$^{2}$ | 0.53 | -0.13$^{2}$ | 0.72 | 0.25$^{2}$ | 0.53 |
| | 0.01$^{3}$ | 0.98 | 0.06$^{3}$ | 0.76 | -0.15$^{3}$ | 0.37 | 0.19$^{3}$ | 0.31 | - | - | 0.00$^{3}$ | 0.99 | 0.02$^{3}$ | 0.97 | -0.18$^{3}$ | 0.65 |
| **Aggregated physiological outcomes (k=50)** | -0.08$^{1}$ | 0.65 | -0.21$^{1}$ | 0.22 | 0.21$^{1}$ | 0.23 | -0.20$^{1}$ | 0.30 | -0.09$^{1}$ | 0.74 | 0.13$^{1}$ | 0.21 | -0.21$^{1}$ | 0.31 | 0.47$^{1}$ | **0.05** |
| | 0.16$^{2}$ | 0.52 | -0.15$^{2}$ | 0.44 | 0.27$^{2}$ | 0.13 | -0.11$^{2}$ | 0.62 | -0.06$^{2}$ | 0.80 | -0.16$^{2}$ | 0.39 | -0.04$^{2}$ | 0.89 | 0.49$^{2}$ | **0.04** |
| | -0.00 $^{3}$ | 0.98 | 0.15$^{3}$ | 0.25 | -0.09$^{3}$ | 0.45 | -0.00$^{3}$ | 0.99 | -0.04$^{3}$ | 0.85 | 0.02$^{3}$ | 0.89 | 0.14$^{3}$ | 0.60 | -0.25 $^{3}$ | **0.03** |

*Note.* Unstandardised beta coefficients and p values are reported in the table. Steps 1 denotes BCT categories meta-regressed on psychological, behavioural, and physiological outcomes, 2 denotes step 1 whilst controlling for the number of BCT's in interventions and 3 denotes the interaction between BCT categories and number of BCT's. Wellbeing denotes an aggregation of depression, anxiety and QoL. K denotes number of studies. Dash indicates that there was no interaction between variables and /or it was not meaningful to run analysis due to incomplete data. BCT categories were coded dichotomously: present 1 v absent 0. P values are rounded up. Boldface indicates significant results.

### *Moderation by intervention duration*

As reported in Table 2, duration of intervention across studies ranged from 1-54 weeks. Results of the meta-regression with duration as a continuous moderator variable are summarised in Table 7. Significant moderation by duration was observed for the aggregate wellbeing construct ($b$ = 0.21, SE = 0.09, $t(11)$ = 2.36, $p$ = 0.03), such that longer duration interventions were associated with a larger intervention effect. Interventions with a longer duration (above the median) had a larger intervention effect on wellbeing ($g$ = 1.51, $p$ = 0.04) compared to interventions with a duration below the median ($g$ = 0.53, $p$ = 0.10). Intervention duration did not significantly moderate intervention effects for any other outcome.

**Table 7**
*Meta-regression models for moderation by intervention duration on psychological, behavioural, and physiological outcomes*

| Outcome Variable (number of studies) | *b* | SE | *P* |
|---|---|---|---|
| ***Aggregated psychological outcomes (k = 34)*** | 0.01 | 0.01 | 0.25 |
| Knowledge (k = 12) | 0.01 | 0.01 | 0.27 |
| Self-efficacy (k = 6) | 0.06 | 0.17 | 0.73 |
| Outcome expectancies (k = 3) | 0.09 | 0.04 | 0.29 |
| Depression (k = 4) | -0.31 | 0.17 | 0.21 |
| Anxiety (k = 3) | 0.00 | 0.20 | 0.98 |
| Quality of Life (k = 6) | 0.22 | 0.11 | 0.11 |
| Wellbeing (k = 13) | 0.21 | 0.09 | 0.03 |
| Psychological construct excluding wellbeing (k = 21) | 0.01 | 0.01 | 0.06 |
| ***Aggregated*** b***ehavioural outcomes (k = 28)*** | 0.00 | 0.00 | 0.92 |
| Dietary adherence (k = 10) | 0.00 | 0.01 | 0.60 |
| Fluid adherence (k = 7) | 0.05 | 0.04 | 0.29 |
| Medication adherence (k = 11) | 0.01 | 0.05 | 0.78 |
| ***Aggregated*** p***hysiological outcomes (k = 50)*** | 0.00 | 0.01 | 0.47 |
| Potassium (k = 6) | -0.08 | 0.15 | 0.61 |
| Phosphate (k = 22) | -0.00 | 0.00 | 0.31 |
| IDWG (k = 22) | -0.08 | 0.04 | 0.08 |

*Note.* Unstandardised beta coefficients, standard errors (SE) and p-values for the interaction terms are reported in the table. Wellbeing denotes an aggregation of depression, anxiety and QoL.

# Discussion

We present the findings of a meta-analysis and meta-regressions of 46 randomised controlled studies aiming to improve health outcomes amongst dialysis dependant CKD patients. This study provides the first comprehensive meta-analysis synthesising the results of randomised controlled studies that aimed to improve psychological, behavioural, and physiological outcomes. We obtained good evidence that self-regulation interventions can be effective in improving outcomes amongst dialysis patients and that their implementation may contribute to improved patient care. We also extended prior research by examining the contribution of distinct BCTs to intervention effects in order to identify the qualities of stronger interventions.

The meta-analysis obtained moderate and significant effect sizes for improvement in dietary, fluid and medication adherence and correspondingly moderate reductions in serum phosphate and IDWG amongst intervention relative to control groups. A moderate, but non-significant, effect on serum potassium was observed, limited by a small number of available studies testing this outcome. Results extend Murali et al’s (2019) findings with a larger sample of studies and extend their review by providing novel evidence of effects on behavioural adherence. Psychological measures were of two types, mechanisms of action and wellbeing outcomes. Relatively few of the 46 studies assessed proposed mechanisms of action, the most commonly assessed being knowledge, assessed in twelve studies, with six and three studies assessing self-efficacy and outcome-expectancy, respectively. Moderate significant improvements in knowledge were found across studies. The second type of psychological outcome assessed was wellbeing, via assessment of change in depression, anxiety or quality of life. Of these, a large significant positive effect of the interventions on quality of life relative to the control groups was obtained.

Importantly, our investigation of relations between outcomes revealed potential pathways through which these changes in psychological targets may have impacted effectiveness of the interventions. The effect size obtained for knowledge was positively associated with effects on medication adherence and effects on medication adherence were in turn associated with effects in decreasing IDWG. Medication adherence was frequently assessed using objective measures. Whilst phosphate binders commonly prescribed in CKD are not directly known to affect IDWG (Puri et al., 2008), dialysis dependent CKD patients often have comorbidities such as diabetes, hypertension, and cardiovascular conditions, for which medications such as diuretics are prescribed (e.g., Roehm et al., 2020). Thus, enhanced knowledge may have specific effects, possibly through a better understanding of the importance of medication adherence (e.g., Arad et al., 2021; Chang et al., 2021; Griva et al., 2018) that was translated into clinical assessments of IDWG. Additionally, we observed a direct relationship between QoL and IDWG, indicating that as QoL improved, IDWG decreased. This finding is consistent with previous research showing associations between QoL improvement and a reduction in IDWG (Akman et al., 2007; Kahraman et al., 2015; Vasilopoulou et al., 2016).

We observed considerable heterogeneity in effect sizes across outcomes, which could be partly due to the limited number of studies available for some outcomes, and to variations in intervention content and duration. To explore moderators of intervention effectiveness, we conducted meta-regression analyses. We extended previous reviews by examining the intervention contents using the BCT taxonomy (Michie et al., 2013) to understand how and why interventions were effective. The interventions primarily consisted of five BCT categories: *4 shaping knowledge* (e.g., behavioural instructions) was used in 33 studies (71.74%), *2 feedback and monitoring* (e.g., behavioural feedback) was used in 24 studies (52.17%), *5 natural consequences* (health, social and emotional consequences) used in 21 studies (45.65%), *goals and planning* (e.g., goal setting) was used in 19 studies (41.30%), 3 *social support* (e.g., practical and emotional) was used in 16 studies (34.78%). See Table 4 for a detailed breakdown.  In common with meta-reviews of evidence in relation to a range of chronic conditions (e.g., Hennessy et al., 2020; Spring et al., 2020; Suls et al., 2020; Wilson et al., 2020), we observed that most studies employed multiple techniques within a single intervention.

Despite the popularity of BCTs focussing on knowledge, feedback and monitoring, goals and planning, and/or consequences in the interventions, we found little conclusive evidence that their presence versus absence moderated the effects of interventions on either behavioural or physiological outcomes. We examined the effects of these techniques versus their absence and controlled for the presence of multiple additional techniques. It is possible that combinations of techniques other than those tested here might have accounted for the moderate, significant effects on behaviour change observed.

However, we obtained evidence that the inclusion of *therapy* (techniques classified by the BCT as 3.3 emotional social support; such as cognitive behavioural therapy, rational emotive therapy, and motivational interviewing) in interventions resulted in larger significant improvements in aggregated physiological outcomes, compared to when it was absent from interventions, particularly when used as a single technique or with fewer additional techniques. The significant effect of therapeutic techniques on distal physiological outcomes deserves consideration. One possibility is that these interventions had greater delivery fidelity because established procedures exist for the delivery of these techniques, that may have contrasted with less effective delivery of other types of BCT. However, the specific content of these interventions may be driving these findings, notably that they often focus on patients' emotional lives. A high proportion of people with chronic health problems suffer from comorbid depression, and in the context of dialysis dependent kidney disease, there is evidence that depression is associated with medication nonadherence, dialysis withdrawal, suicide and premature mortality (Palmer et al., 2013; Pereira et al., 2017). Recent calls have been made for greater focus on the role of emotion regulation (e.g., successfully reducing negative thoughts and emotions) in the management of goal directed behaviour and self-regulation in chronic illness (e.g., O'Carroll, 2020). It is plausible that a combination of delivery modes, including both individual (e.g., Cukor et al., 2014; Valsaraj et al., 2020) and group formats (e.g., Hare et al., 2014; Sharp et al., 2005), along with an autonomy-promoting, non-directive approach to helping patients discover their own meaning and personal health goals. These therapeutic techniques  were more effective in promoting self-management than many of the BCT techniques that tend to be more directive or controlling in their delivery, or even include punitive rehearsal of threats of non-adherence and rigid monitoring. Findings underline the importance of viewing psychological wellbeing not simply as a by-product or secondary outcome of behaviour change interventions, but as an important primary route to improving outcomes. Future research might examine the moderating effect of psychological wellbeing on outcomes of interventions.

The moderator analyses also revealed that longer intervention duration was associated with increased intervention effects on the aggregated wellbeing construct (depression, anxiety and QoL), consistent with previous findings (e.g., Boiler et al., 2013). It is conceivable that longer intervention durations offered more sustained support, which can provide emotional support, encouragement, and a sense of belonging, factors crucial for psychological wellbeing. Furthermore, longer durations provided more opportunities for patients to develop and practice healthier habits and coping skills, such as stress management techniques or cognitive restructuring. With practice, these skills become more effective in managing the psychological challenges associated with CKD (Kwasnicka et al., 2016).

A small number of studies (*k* = 6) examined intervention effects on self-efficacy, often considered a key construct for behavioural change (Bag & Mollaoglu, 2010; Balaga, 2012; Curtin et al., 2008; Rahimi et al., 2014). The decision to proceed with moderation analysis despite the limited number of studies underscores a critical gap in the current literature on interventions for psychological health outcomes. This scarcity of studies not only highlights the need for more research in this area but also emphasises the importance of extracting as much information as possible from existing data. By conducting this exploratory analysis, we aimed to identify potential moderators that may warrant further investigation in future studies. This approach can help guide subsequent research efforts, potentially leading to more targeted and effective interventions for psychological health outcomes. The limitations of our analysis serve to reinforce the urgent need for additional, well-designed studies in this field to build a more robust evidence base and allow for more definitive conclusions about moderating factors. Although the meta-analysis did not show a significant overall effect of the interventions on improving self-efficacy, the moderator analysis by BCT provided some important insights into why this might have been the case. Examination of techniques that moderated intervention effects on self-efficacy showed that interventions that included *social support* were more successful in changing self-efficacy. This finding provides important insight into how best to improve self-efficacy in dialysis dependent CKD patients. Inspection of the contents of the interventions suggests that social support enhanced self-efficacy via observation of similar others (e.g., administered in peer support contexts: Hare et al., 2014; Griva et al., 2018). The role of peer support has been extensively shown to improve treatment adherence, psychological wellbeing (Husain et al., 2020; Irajpour et al., 2018; Malek-Khahi et al., 2015), and social support including family support has been associated with self-efficacy in the promotion of implementing and maintaining effective self-regulation in CKD patients (Chironda & Bhengu, 2019; Du et al., 2018; Isnaini, Sukma & Aprilina, 2021; Wiwoot et al., 2017). Social support may also contribute to improved self-efficacy via improved emotional state, since unpleasant psychological states tend to undermine feelings of competence (Bandura, 1977; Wood and Bandura, 1989).

The finding that *reward and threat* weakened intervention effects on self-efficacy is also notable and suggests that some techniques may undermine confidence or increase negative emotional states. For example, some patients in the included studies were offered extrinsic rewards (e.g., lottery tickets; Kauric-Klein et al., 2012) only when they reached a specific physiological goal. Overreliance on extrinsic motivation (e.g., lotteries) have previously been linked to poorer self-regulation and self-efficacy in other contexts (e.g., Michaelsen & Esch, 2021; Ryan & Deci, 2020; Schultz & Ryan, 2015; Shin & Bolkan, 2021). By contrast, techniques that enable patients to recognise their strengths and use them to promote understanding of their conditions have been associated with enhanced the self-esteem, self-efficacy, and a reduction in the depressive symptoms of patients with chronic illnesses (Yan et al., 2020).

## Strength, limitations and future research directions

In common with many reviews in this domain (e.g., Suls et al., 2020; Spring et al., 2020) the identification of BCTs from the multicomponent interventions included in the review required us to assess the contributions of individual techniques post hoc by coding the techniques described in the interventions. The coding process relied on the descriptions provided in the studies and supplementary materials. Inadequate descriptions of interventions might have resulted in the omission of some BCTs, and it's uncertain whether the BCTs were implemented accurately or as planned during the interventions. To mitigate the potential bias associated with coding errors, each article was coded independently by two authors, and all coding was cross-checked by a third author. Nonetheless future studies should ensure detailed accounts of the operationalisation of specific BCTs. Additionally, very few studies to date have evaluated changes in proposed mechanisms of action, the few studies that did focused upon change in knowledge, self-efficacy or outcome expectancies. In our meta-analysis, the effects of BCTs could only be inferred from statistical tests adjusting for additional techniques. Primary tests of interventions employing a single technique that include assessment of the technique's efficacy in changing the proposed mechanism of action together with the distal health outcomes would potentially yield better evidence of the causal role of that technique in optimising health outcomes. Such primary tests might ultimately identify a 'bundle' of effective techniques. It is understandable that clinicians may be reluctant to intervene with a single plausible technique, but such an approach ultimately might lead to the goal of creating a replicable intervention approach for use in clinical care.

Studies to date relied on relatively few types of BCT. Dialysis is a long-term treatment for a chronic condition requiring ongoing dietary and fluid restriction. It is therefore perhaps surprising that habit formation techniques (e.g., Gardner et al., 2021) were used in none of the interventions, along with environmental antecedents such as the use of cues or techniques to develop sustained behaviours.

Our study could not account for social contextual factors such as how patients manage their home and social environments, which significantly influence treatment adherence. Factors like food costs, meal preparation responsibility, and available food types impact self-regulation. Reliance on others for meal prep can lead to poor dietary choices due to guilt or a desire not to burden close others. Qualitative studies highlight that CKD affects home relationships, with patients often choosing unhealthy diets to avoid inconveniencing loved ones (Okoyo Opiyo et al., 2020; Walker et al., 2012). The person preparing meals is a key predictor of dietary adherence (Cristovao, 2015). Future research should consider a more comprehensive approach that examines the restructuring of patients' environments and social dynamics as important predictors of treatment adherence and to provide a more nuanced understanding of the circumstances in which certain interventions are more effective than others. Moreover, given the insight that therapeutic techniques providing emotional social support enhanced physiological outcomes, future research might also evaluate the role of psychological states such as depression as moderators of effects of behaviour change interventions.

# Conclusion

This meta-analysis of 46 randomised controlled trials showed that interventions effectively modified psychological, behavioural, and physiological outcomes in patients on dialysis. Notably, interventions incorporating therapeutic techniques for emotional social support were particularly effective in improving physiological outcomes. However, inadequate descriptions of interventions and the simultaneous use of multiple BCTs may have obscured the specific effects of individual BCTs. To advance behaviour change research, future studies should empirically test the effect of individual BCTs on health outcomes. This approach will identify which BCTs are effective, both independently and in combination, for specific health outcomes and enhance our understanding of intervention effectiveness.

## Disclosure statement

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# Chapter 3

# When effort isn’t enough: Self-regulatory strategies among patients on dialysis

## Rationale

While Chapter 2 demonstrated that behavioural change interventions had moderate effects on both behavioural and physiological outcomes, our understanding of how dialysis patients adhere to their treatment regimens and the psychological processes driving their behaviour remains limited. Furthermore, the study did not account for crucial social contextual factors, such as patients' management of their home and social environments, which significantly impact treatment adherence. To address these knowledge gaps, a semi-structured qualitative study was conducted. This research aimed to explore patients on dialysis experiences and attitudes towards self-regulation. The findings from this qualitative exploration are presented in Chapters 3 and 4.

## Abstract

**Background:** Patients receiving  dialysis for kidney disease are recommended to collaborate with health care by self-regulating diet and fluid to minimise poor health outcomes. No previous study has explored whether or how patients on dialysis attempt to implement this advice to self-manage their illness.

**Purpose:** This qualitative study explored the self-regulatory strategies used by patients on dialysis to manage their prescribed dietary and fluid restrictions.

**Methods:** Semi-structured interviews ($N = 46$) were conducted with patients on dialysis ($M_{\text{age}} = 64.78$) at a public hospital in the UK. Patients were classified as either low or high adherence based on objective medical records of physiological outcomes. Interview transcripts were analysed thematically.

**Results:** Three themes with twelve subthemes were identified: planning strategies, behavioural strategies for staying within restrictions, and self-monitoring. Low adherence patients engaged in multiple different strategies more often than high adherence patients. Low adherence patients were more likely to report the use of routines or habits, more drink substitutions and thirst management strategies, more occasional 'cheat days', and more self-monitoring of behavioural outcomes. High adherence patients were more likely to engage in strategic planning to ensure they ‘passed’ monthly medical checks.

**Conclusion**: The findings emphasise the importance of healthcare providers offering personalised and continuous support to patients, ensuring that self-management strategies are implemented correctly and reinforced until they become habitual.

**Keywords:** kidney disease, qualitative, dialysis, adherence, self-regulation, self-management.

# Introduction

Chronic Kidney Disease (CKD) is a progressive condition classified into five stages based on declining kidney function. It is driven by an ageing population and rising incidences of diabetes, hypertension, and obesity (Jager & Fraser, 2017). CKD affects 1 in 8 adults worldwide, with a global prevalence of 8-14%, and is the third fastest growing cause of death globally (Hill et al., 2016; Bikbov et al., 2020). When CKD progresses to a stage where kidney function is insufficient to sustain a healthy life, dialysis or transplantation becomes necessary (known as kidney replacement therapy [KRT]). This study focuses on the experience of patients receiving dialysis, the most prevalent type of KRT worldwide. For patients receiving often thrice-weekly dialysis, dietary and fluid restriction is also recommended to prevent complications such as cardiovascular disease, increased hospitalisation, bone disorders, pulmonary oedema, reduced quality of life, and premature death, that are linked to high plasma potassium concentrations and fluid overload (Evangelidis et al., 2019; Geldine et al., 2017; National Institute for Health and Care Excellence, 2021).

Self-regulation has become a crucial aspect of modern healthcare, with leading guidelines encouraging patients to adopt self-regulatory behaviours to minimise poor health outcomes (Chronic Kidney Disease Prognosis Consortium, 2010; National Institute for Health and Care Excellence, 2021). These behavioural changes involve strictly following dietary guidelines, by avoiding foods high in salt, potassium, and phosphate, managing fluid intake, and consistently taking prescribed medications. These parameters are closely monitored by the patients' healthcare team through monthly blood tests and weighing before and after each dialysis session. Despite advancements in the management of CKD and increased efforts to educate patients about fluid restrictions and dietary changes, poor adherence remains a well-recognised issue among patients on dialysis (Beto et al., 2016; Ghimire et al., 2015). Research indicates that approximately 41% to 86% of these patients struggle with adhering to their dietary restrictions, with 22% to 77% specifically struggling with fluid restrictions (Geldine et al., 2017; Nerbass et al., 2011). Many patients on dialysis continue to face persistent challenges in achieving optimal self-regulation (Geldine et al., 2017; Ghimire et al., 2015). This ongoing struggle highlights a critical gap in our understanding of behaviour change and treatment adherence. Although a variety of psychosocial and contextual factors, such as psychological distress and social support, have been identified as reasons for non-adherence (e.g., Cardol et al., 2022; Noviana & Zahra, 2022), there remains a significant gap in our knowledge about the specific strategies patients try to employ to self-regulate and implement necessary behavioural changes and how their efforts relate to outcomes.

## Mechanisms and strategies for self-regulation

Self-regulation involves patients consciously modifying their behaviour through deliberate effort and planning to achieve specific health-related goals (Hagger, 2010). It serves as a fundamental mechanism driving various health behaviours (Carver & Scheier, 1996; Eisenberg et al., 2018; Hagger et al., 2006), including dietary changes (Tao et al., 2024) and adhering to fluid restrictions (Howren et al., 2016). Patients on dialysis face a considerable and complex challenge. They need to work out what aspects of their diet should be restricted to avoid potassium and phosphate and to develop, implement and maintain new patterns of consumption, perhaps of unfamiliar foods, including permanent fluid restriction. Hospitals monitor the outcomes of their presumed efforts, via blood tests, but it is for the patient to implement behaviour change that will lead to satisfactory blood test results. Despite the importance of self-regulation for improving health outcomes, the approaches taken by patients and their effects on outcomes are not understood. Consequently interventions aimed at enhancing outcomes are often not grounded in empirical evidence (Bonner et al., 2014) and the underlying reasons for what makes an intervention effective remains unclear (Murali et al., 2019). Patients on dialysis need to self-regulate and can employ a range of strategies to manage their restrictions effectively. For instance, they might set specific health goals, such as avoiding foods high in potassium and phosphate. To achieve these goals, they can implement practical strategies like refraining from purchasing unsuitable food items. Continuous self-monitoring, such as logging meals, allows them to track their progress. Importantly, they can adjust their strategies as needed, based on their observations and feedback from their healthcare team (Carver & Scheier, 1996).

## Present study

Despite established CKD guidelines promoting self-regulatory behaviours to reduce mortality and morbidity (e.g., National Institute for Health and Care Excellence, 2021), the implementation of dietary recommendations is the patient's responsibility. It is not known exactly *how* or indeed *whether* patients on dialysis self-regulate to adhere to their dietary and fluid regimens, or if their efforts contribute to successful outcomes. Understanding the specific "how" of patients' self-regulation efforts might provide actionable insights to improve patient care and support in managing this challenging chronic condition. Consequently, the aim of this qualitative study was to identify the specific self-regulatory strategies used or overlooked by patients to adhere to their dietary and fluid restrictions through thematic analysis (Braun & Clark, 2006). Additionally, patients were classified into adherence categories based on three physiological indicators: blood serum levels of potassium and phosphate, and interdialytic weight gain (IDWG), as provided by their direct care team. This categorisation was used to determine whether certain strategies were more prevalent among patients with high or low adherence.

# Study 2

## Methods

### Participants

All registered patients in the partner hospital's dialysis unit were screened for inclusion by a medical consultant. Patients under 18, with impaired consent capacity, or recent acute admissions were excluded. Medical records were examined by the consultant to identify patients as high or low adherence on IDWG (low adherent > 5.7%), potassium (low adherent > 6 mmol/l) and phosphate serum (low adherent > 1.7 mmol/l) levels averaged over 3 months. Patients were categorised for the study as low adherent if their records indicated low adherence on at least 2 of the 3 measures. 116 patients were classified as high, and 23 as low adherence. The adherence grouping was concealed from both patients and the lead researcher until after the final stages of thematic analysis were completed. The categorisation of patients according to their adherence was undertaken to deepen our understanding of the factors that enable certain individuals to self-regulate more effectively than others. This approach allows us to pinpoint the specific techniques that contribute to successful self-management, thereby informing the development of tailored interventions.

We initially aimed to interview 60 patients (30 high adherence, 30 low adherence). Of the 23 low adherence patients, 2 died during the study, and 15/21 (70%) consented and were interviewed. We drew an age and gender matched random sample of 45 high adherent patients of whom 5 died, moved away, ceased dialysis, or had a transplant, and 31/40 (78%) consented and were interviewed. Since 31 patients had been consented by the healthcare team, it was decided to interview all 31. The sample size for the study was determined through the consideration of the power to detect instances of themes and the estimated prevalence of those themes in the population (Fugard & Potts, 2015). We established that a total sample size of 46 (31 high adherence and 15 low adherence) provides 90% power to detect one instance of a theme with 5% expected prevalence in the population whilst accounting for attrition (Fugard & Potts, 2015).

Participants were aged 34 to 94 years ($M_{\text{age}}$ = 64.78 years, $SD_{age}$ = 14.81), 59% were men. The ethnicity of the patients was: 84.78% White, 10.87% Black, 2.17% Mixed/Multiple ethnic groups, and 2.17% Other ethnic group. Adherence groups did not differ as a function of age ($M_{age\ high}$ = 67.16, $SD_{age}$ = 13.40; $M_{age\ low}$ = 59.87, $SD_{age}$ =16.78; $t(44) = 1.59$, $p = .12$), by gender ($n_{men\ high\ adherence}$ = 17; $n_{men\ low\ adherence}$ = 10 ; $X^2$ (1, $N$ = 46) = .58, $p$ = .44) or by ethnicity ($n_{White\ high\ adherence}$ = 26; $n_{White\ low\ adherence}$ = 13 ; *Fisher's Exact Test* (1, $N$ = 46, $p$ = 1.00).

## Procedures

Patients at a UK hospital dialysis unit with Stage 5 CKD were invited to participate in one-to-one semi-structured interviews between August 2022 and January 2023. The interview schedule (see Appendix C) included 18 open-ended questions derived from CKD literature, in addition to feedback from patients and staff in the renal ward. Probes were used to encourage elaboration and discussion of relevant areas with interviews lasting between 30 to 100 minutes (*Mdn* = 46.33 min). Recordings were made via Microsoft Teams and transcribed verbatim, with field notes taken afterward. Data were securely stored, and the first author cross-referenced transcripts with audio recordings for accuracy, removing identifiable information. Patients were assigned pseudoanonymised numeric codes for anonymity and data protection. Written informed consent was obtained from all patients. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline (Tong et al., 2007). Ethical approval was obtained from HRA REC and the university. This study is pre-registered on the Open Science Framework (https://osf.io/7mbj6/?view_only ).

## Data analysis

Reflexive inductive thematic analysis (Braun & Clarke, 2006) was used to analyse patient transcripts. Transcripts were analysed manually and using N-Vivo software (Version 1.6.4, 2023). A systematic coding approach involved transcript familiarisation, initial code generation, theme collection, review, refinement, and labelling. This process grouped common ideas across transcripts, facilitating the generation of higher and lower codes. The lead coder, who was blind to adherence grouping, repeatedly reviewed transcripts to identify patterns and initial coding ideas, enhancing data immersion. The themes were revised through discussions between the lead coder and two other members of the research team until 100% consensus was reached. Following finalisation of codes, the lead coder became unblinded regarding patients' adherence grouping so proportional differences in representation of adherence groups per theme could be evaluated.

# Results

Results have been structured based on the three themes identified during coding: (1) using planning strategies, (2) behavioural strategies to keep within restrictions, and (3) self-monitoring. Table 8 offers a summary of these emergent themes, along with their definitions and typical examples comprising of pseudonyms. These themes reflect both adherence groups, and we address instances where differences arose between low and high adherence groups based on proportions, as outlined in Table 9.

**Table 8**
*Emergent themes, subthemes, their definitions, and prototypical examples*

| Theme | Definition | Subtheme and example quotes |
|---|---|---|
| 1. Using planning strategies | The intentional, specific planning that patients engage in to facilitate the adoption of new behaviours or the modification of existing ones whilst trying to follow their dietary and fluid restrictions. | **Planning to follow restrictions subtheme**<br>"Well, I realise now what I can eat, so I only buy… you know… foods I can eat. I don't buy the bad stuff… well it's not bad but it's just unsuitable" (Rob low adherence)<br>**Planning to 'pass' the medical tests subtheme**<br>"Don't get me wrong I also know how to play the system. You gotta make sure you know when your bloods are, where you are in the month. For example, my bloods are always done on the 1st Wednesday of the month. Yeah, so you gotta make sure that you don't have a pot noodle, or anything crap or anything like that the week beforehand." (Mark low adherence)<br>**No active planning subtheme**<br>"Obviously in the beginning its all new but as times go on it becomes a way of life, a habit. Now it's just a force of habit knowing roughly what's what" (Luke low adherence) |
| 2. Behavioural strategies to keep within restrictions | The strategies used by patients to adhere to dietary and fluid restrictions. | **Food substitutions subtheme**<br>"If I want something at home with a sandwich, I'll have maize based wotsis or quavers things that aren't high in potassium" (Anne high adherence)<br>**Dietary portion control subtheme**<br>"If I'm having like, in summertime I tend to have salad, but I limit the amount of tomatoes I have" (Charles low adherence)<br>**Cooking from scratch subtheme**<br>"If it comes say passat or pasta sauce with extra salt in it is easier to make it from scratch." (Samuel low adherence) |

| | | |
|---|---|---|
| | | **Drink substitutions and thirst management strategies subtheme**<br>"When I'm dry, I'll take sips rather than gulp a lot down. So, I'm just sipping a little" (Oliver high adherence)<br>**Using occasional treats and cheat days subtheme**<br>"I mean sometimes I cheat a little bit; I might have things that are not really allowed or have a little bit extra or whatever. I don't really cheat with the fluids just the food. Plus, I am diabetic, I might have an extra cake or whatever" (Luke low adherence)<br>**No dietary restrictions subtheme**<br>"I must admit I don't really watch what I eat like most people do on dialysis and don't think that as soon as the blood test changed then they will change" (Linda high adherence) |
| 3. Self-monitoring | Participants continuous process of tracking and evaluating their progress towards their dietary and fluid intake. | **Monitoring what I eat subtheme**<br>"I think because I'm trying to lose weight that helps me by watching what I am eating. And I log everything [chuckled] calorie counter app" (Rosie high adherence)<br>**Monitoring what I drink subtheme**<br>"I have a drinking bottle with measurements along the side and so I can track how much I have had" (Samuel low adherence)<br>**Self-monitoring of behavioural outcomes subtheme**<br>"I do weigh myself on quite a regular basis. With that if I have a bowel movement, I will weigh myself before and after" (Adele low adherence) |

*Notes.* The names used are pseudonyms.

**Table 9**

*Occurrence and proportions of themes in low and high adherence groups*

| Themes | Subthemes | Number (%) of occurrences in total sample $n_{total}$ = 46 | Number (%) of occurrences in high adherence group reporting theme $n_{high}$ = 31 | Number (%) of occurrences in low adherence group reporting theme $n_{low}$= 15 |
|---|---|---|---|---|
| **Using planning strategies** | Planning to follow restrictions | 19 (41.30) | 12 (38.71) | 7 (46.67) |
| | Planning to pass the medical tests | 6 (13.04) | 5 (16.13) | 1 (6.67) |
| | No active planning | 22 (47.83) | 13 (41.94) | 9 (60.00) |
| **Behavioural strategies to keep within restrictions** | Food substitutions | 8 (17.39) | 5 (16.13) | 3 (20.00) |
| | Dietary portion control | 8 (17.39) | 5 (16.13) | 3 (20.00) |
| | Cooking from scratch | 13 (28.26) | 9 (29.03) | 4 (26.67) |
| | Drink substitutions and thirst management strategies | 19 (41.30) | 10 (32.26) | 9 (60.00) |
| | Using occasional treats and cheat days | 23 (50.00) | 14 (45.16) | 9 (60.00) |
| | No dietary restrictions | 8 (17.39) | 6 (19.35) | 2 (13.33) |
| **Self-monitoring** | Monitoring what I eat | 12 (26.09) | 8 (25.81) | 4 (26.67) |
| | Monitoring what I drink | 23 (50.00) | 15 (48.39) | 8 (53.33) |
| | Self-monitoring of behavioural outcomes | 11 (23.91) | 6 (19.35) | 5 (33.33) |

## Theme 1: Using planning strategies

A common self-regulatory strategy used by patients in both groups was planning. The use of planning varied, with some patients actively devising predetermined strategies to adhere to their dietary and fluid restrictions, others strategically planning to 'succeed' in the monthly blood tests conducted by their health care team, and some reporting no longer needing to actively plan.

### *Sub-theme 1: Planning to follow restrictions*

Patients in both groups reported ongoing planning, which encompassed pre-planning meals, using grocery delivery services to select and ensure the availability of suitable food items at home, and scheduling regular times for meal and fluid intake. Esther (high adherence) elaborated on how proactive planning enabled her to manage her dietary restrictions effectively. By ordering in advance, she mitigated impulsive or inappropriate food selections, thereby staying committed to her dietary goals.

> I place my order with Tesco’s, and they deliver it, so they deliver <u>what I want</u>. Well, obviously when I place my order because I'm doing it in advance so that if I change my mind, I haven't got the food there to eat that I shouldn't have.

Other patients discovered that planning and adhering to a predetermined schedule for their dietary and fluid intake, and consistently maintaining this schedule, facilitated successful self-regulation of their restrictions. For instance, Noah (high adherence) explained how maintaining a structured and repetitive schedule of fluid intake fostered a feeling of stability and consistency in his daily routine.

> I have 3 teas and one coffee when I’m at home. And then I’ll have little drops of water when I have my medication. I’ll have 2 of them when I’m here [pointed at paper cup approx. 250ml). it’s always the same.

### *Sub-theme 2: Planning to ‘pass’ the medical tests*

Some patients discussed strategically organising their dietary and fluid intake in alignment with their monthly blood tests taken at the renal unit. They adhered particularly closely to their diet and fluid regimen in the week leading up to their blood tests to ensure that any nonadherence would not be reflected in their test results. The use of strategic planning was more prevalent in the high adherence group (16.13%) than in the low adherence group (6.67%). For example, Emily (high adherence) detailed her stringent approach in the week preceding these tests.

> Well, I always make sure a week before bloods that I try and be <u>exceptionally good</u>. Umm, and if I was to have a can of coke,

> it's the first in the first fortnight after bloods then I know that's fine, you know.

Equally, Rita (high adherence) emphasised a mindful and deliberate attitude towards dietary decisions, especially in the week preceding the blood tests, where moderation and restraint are prioritised over impulsive indulgence.

> I'm aware that they're coming up. So, I don’t go eating a load of cheese when I have a blood test the next day. The bloods don’t do anything to me, I just know what to to eat and what not to eat as to influence the results. You know, I wouldn't go and do something stupid.

### ***Sub-theme 3: No active planning***

Many patients in both groups stated that they did not need to engage in deliberate ongoing planning of their diet or fluid intake. Patients in the low adherence group were more likely to assert that they did not need to plan (60%) compared to 41.92% in the high adherence group. For some patients active planning was unnecessary because they had established habitized routines by eating exactly the same thing every day. Ben (high adherence) described how he consumed the same meals and drinks each day, suggesting a structured and repetitive approach to his diet.

> Well, you know, I nearly have the same every day. So, I know that you know If I have an extra cup of tea or something else and… I suppose over the course of the day, I know how much I’ve had or eaten. Really, I nearly have the same every day you know. I don’t change from one thing to another you know.

John (low adherence) reported that his many years of experience meant that he didn’t need to actively plan what he ate, because he just ‘knew’ by now what foods were high or low in potassium.

> I've been doing this for 15 years, so I pretty much know what is high in potassium, where it comes from. I know roughly why my potassium is high before they even tell me [laughs]. Oh, I think mainly the amount of time I’ve been doing it. You know, it's it's it's in me, it's part of me It's part of, it’s in my head.

Both Anne and John's narratives exemplify how self-regulatory behaviours evolve into routine, following repeated practice over time.

## Theme 2: Behavioural strategies to keep within restrictions

Another theme that emerged from patients' narratives involved employing problem-solving techniques to overcome obstacles in adhering to their dietary and fluid restrictions. These strategies encompassed tactics like consuming polos to alleviate thirst sensations and substituting items on the "avoid" list (provided by dieticians in their care team) with alternatives (e.g., opting for sweet potatoes over regular potatoes, or increasing cheese consumption instead of milk).

### *Sub-theme 1: Food substitutions*

Some patients in both groups described substituting certain foods with healthier options, in order to adhere with dietary restrictions but also to make these restrictions more acceptable. For instance, Arthur (low adherence) described a commitment to making informed food choices that aligned with his dietary restrictions by replacing regular potatoes with sweet potatoes, emphasising its lower potassium and salt content.

> You know, I do, potatoes, I don’t eat potatoes now, no now I eat sweet potatoes which is low potassium and salt which I only have now.

For Ken (high adherence), the aim of incorporating alternative food options into his meals was to try to enhance the palatability and variety of his diet while adhering to dietary restrictions.

> I try to have additional things in my diet that make it a bit more … bearable really. There are the foods that I can eat instead of potatoes which are high in potassium, um rice and pasta.

### *Sub-theme 2: Dietary portion control*

Patients described regulating the quantity of potassium rich foods consumed during meals and snacks as part of an effort to adhere to their dietary restrictions. For Lola (low adherence), instead of completely cutting tomatoes from her diet, she opted for a more controlled strategy by decreasing her tomato intake. This moderation reflected a newfound mindfulness toward her eating patterns, as she had previously consumed copious quantities of tomatoes.

> Tomato stew I’ll probably just take about a tablespoon and put on white rice as opposed to before I’ll heap it all on, but I don't do that again.

Equally, Rosie (high adherence) embraced the principle of moderation by acknowledging her ongoing enjoyment of dishes such as Bolognese, yet deliberately opting for smaller portions. This approach enabled her to consume the meals she once preferred without indulging excessively.

> I still make Bolognese and things and just having … so, I am having those things just in a probably a diluted small quantity as opposed to eating a plate of tomato.

### *Sub-theme 3: Cooking from scratch*

Some patients revealed that they had started to cook their meals from scratch using recipes or leaflets provided by the dietician instead of relying on pre-packaged or convenient options. By doing so, they were better at regulating the levels of minerals such as sodium, potassium, and phosphate in their diet, leading to a clearer understanding of how their food choices affected their bodies and whether adjustments were necessary.

Adele (low adherence) mentioned that having additional time afforded by her illness status has allowed her to start cooking a diverse array of meals from scratch rather than resorting to processed foods. Her decision to make homemade dishes signified a deliberate choice to opt for healthier options that she believed were suitable for her kidney health.

> All the information I’ve got and the menu from dietician, there’s got to be about 100 recipes on this ranging from homemade fish and chips right through to umm… there’s umm… [thinking] an African one pot dish and all that kind of stuff. So, it's got a whole range of things and there's some nice things on there as well. I cook a lot more because you know I'm I'm I'm I'm home so I might as well make decent meals from scratch rather than eating processed stuff.

Conversely, a handful of patients acknowledged their inability to prepare homemade meals, resulting in their reliance on processed foods. This dependence made it challenging for them to foster healthy dietary changes. For instance, Nathan (low adherence) recognised that his reliance on processed foods was detrimental to his kidney health.

> I can’t prepare food stuff you know what I mean, so I eat microwave meals but that is not good for kidneys.

Nathan illustrates the challenge faced by some patients who lack the experience, ability or resources to prepare healthier homemade meals, ultimately impacting their dietary choices and potentially exacerbating kidney issues.

***Sub-theme 4: Drink substitutions and thirst management***

Patients in both adherence groups reported a range of deliberate strategies to manage feelings of thirst without surpassing their daily fluid intake target. Patients used methods such as sucking on frozen items (e.g., ice cubes, ice pops, or frozen fruits), consuming mints, and sitting in front of a cool fan. These strategies were reported frequently by the low adherence patients (60.00%) compared to 32.26% of high adherence patients. For example, Charles (low adherence) expressed dedication to adhering to his limited fluid intake, despite its difficulty, by resorting to mints as a makeshift solution to relieve thirst. This approach provided a temporary sense of hydration, effectively acting as a substitute for consuming additional liquids beyond his one litre fluid restriction.

> I stick to just 1 litre. Which is quite difficult, more so in the summer. This is why I use this thing [trebor mints] as my thirst quencher [laughs]. I just literally suck on them, leave them at the back of my throat just to give me some… saliva basically and quenches my thirst as well, that’s what I used them for.

Rita (high adherence) described a shift from her previous habit of "guzzling" to more controlled intake and the use of several techniques to quench her thirst without consuming excessive fluids. Her approach reflects a conscious effort to self-regulate and find creative ways to adhere to her fluid restrictions.

> I suck on ice cubes or sometimes with grapes in the fridge or frozen grapes and they quench thirst quite well. I would always guzzle it but now it's not… it's sipping and… and have ice in it because you can't drink it.

### *Sub-theme 5: Using occasional treats and cheat days*

Both high and low adherence patients articulated intentional strategies involving planned indulgences or treats while maintaining their overall dietary and fluid goals. This entailed departures from their usual eating habits to indulge in foods they typically had to refrain from due to their high calorie, salt, preservative, or fat content. These strategies were more frequently reported among low adherence patients (60.00%) than high adherence patients (45.16%).

Mark (low adherence) acknowledged his pragmatic approach to health with admissions to occasional deviations from his dietary restrictions. He reported occasionally enjoying treats like a quarter pounder with cheese without dwelling excessively on the potential consequences of occasional indulgences, recognising larger life priorities beyond strict dietary adherence.

> I'm pretty good, I have the odd blowout stuff like that. But I'll work on the basis of… something's gonna kill me, and if I die, eating them, eat a quarter pounder with cheese, shit happens, don't it? It's the least my fucking worries.

Likewise, Jennifer (low adherence) shared similar attitudes on dietary discipline and indulgence. She described occasional lapses in sticking to her dietary restrictions whilst emphasising the importance of enjoying food and treats in moderation.

> I don't always do it, don't always stick to it. you can train yourself to enjoy what you can and have a treat occasionally like a chicken and mushroom pie, or a sausage roll. You can still have them, just be careful. you know that sometimes you're gonna get off the waggon and you're gonna have ummm I dunno cream cake, it doesn't matter cos you're enjoying it and its enjoyment.

### *Sub-theme 6: No dietary restrictions*

Some patients in both adherence groups reported consuming foods and drinks without regard for dietary advice. For example, Cheryl (high adherence) acknowledged her lack of deliberate attention or concern regarding her food choices in the context of her health needs.

She described eating "what I want" suggesting an approach driven by personal preference rather than health considerations, noting that since she is not a ‘big eater’ anyway.

> I can’t really say I have, never really taken that much notice. It’s like I said, I just eat what I want. I mean I have fish and chips sometimes. You know, I just think that I’m not a big eater and I eat what I want to eat. I don’t eat because you know I think I shouldn’t have that; I just eat what I want to eat.

Similarly, Susan (high adherence) considered the dietary restrictions overly restrictive and difficult to follow and doubted that other patients really stuck to the prescribed diet. This resulted in a more relaxed approach to adherence, whereby she was prioritising her personal needs over adherence.

> I mean I don't restrict myself, but… I mean to, you know, not to make my life a misery. It's a funny diet really… I mean, if you stuck to it, it would be very dismal [unimpressed]. I shouldn't think many people who do stick to it. If you did, you would have absolutely nothing to eat.

## Theme 3: Self-monitoring

The final theme represented patients’ active checking, documenting, and assessment of their behaviours (behavioural monitoring) and the resulting outcomes (outcome monitoring) as they strive to adhere to their dietary and fluid restrictions through self-regulation. To monitor their behaviours, patients employed various strategies such as recording their dietary and fluid intake, tracking nutritional values, and pre-measuring their daily fluid intake limit. Evaluating the outcomes of these behaviours usually entailed patients measuring their urine output, or regularly weighing themselves.

### *Sub-theme 1: Self-monitoring what I eat*

Patients reported the use of food diaries, mobile apps, and kidney websites to measure and record their consumption. Daniel (high adherence) described a methodical strategy for regulating his dietary consumption, especially concerning the management of phosphate levels. He maintained an intricate diary documenting every meal and its cooking method, displaying a keen commitment on nutrition. He acknowledged the significance of relying on his diary as a tool to inform his dietary efforts.

> I keep the diary of everything I eat including how its cooked… say if next week on the monthly bloods, someone says your phosphates have gone up to 2.5. I'll keep a note of not just what the food contained, but how it's been cooked. I tend to bulk out my food with other ingredients to reduce phosphate contents. Before I try something new, I always look it up on either online and see what it is or look it up in the dietician guidelines.

For Samuel (low adherence), he expressed adopting a proactive attitude towards diet by incorporating a routine of self-monitoring while shopping for groceries or dining out. He used his phone to access information on calorie and phosphate content, showing a commitment to making informed choices about his diet.

> I check myself when shopping for meals or when I eat out for how much calories, I use my phone to check how much it has phosphates in it.

***Sub-theme 2: Self-monitoring what I drink***

Many patients in both adherence groups diligently monitored their fluid intake to ensure they didn't exceed their fluid restrictions. Tracking their fluid intake offered tangible insights into their drinking patterns, aiding in the development of strategies to enhance or sustain appropriate fluid intake levels. This monitoring process included strategies such as manual recording in diaries and pre-measuring daily allowances using containers. For example, Alex (high adherence) exemplified his commitment to adhering to fluid restrictions by meticulously measuring and regulating his intake using a marked jug.

> We've got a jug with a sort of a measure on the side of it. So, say for example if I have a small glass of water, I make sure I measure it and put it in the jug.

Likewise, Daniel (high adherence) implemented a systematic method for monitoring his fluid intake and output. He employed a small glass to measure his fluid intake and documented each instance of drinking on a whiteboard. This practice of recording every drink consumed provided a concrete and visual means to track his daily intake, promoting accountability and heightened awareness.

> Everything is measured, I have a standard size 200ml glass and every time I drink, I just put a tick on the white board on the wall for that day. I measure how much urine I pass.

***Sub-theme 3: Self-monitoring of behavioural outcomes***

Some patients assessed the impact of their self-regulation endeavours in adhering to dietary and fluid constraints by scrutinising the consequences of their actions. This process most commonly comprised monitoring their body weight. By observing the outcomes of their behaviour, they could gauge their progress regarding treatment adherence and discern if adjustments were necessary. Interestingly, the monitoring of behavioural outcomes was more prevalent among low adherence patients (33.33%) compared to high adherence patients (19.35%). For instance, Ken (high adherence) detailed his practice of consistently self-monitoring to track fluctuations in body weight, which served as an indicator of shifts in fluid volume.

> By weighing myself, yeah, just well, before I go to bed and when I wake up in the morning, because it gives me an idea of um…how much fluid I put on.

John (low adherence) described his use of scales to monitor his weight at home and even on holiday to account for variations in temperature that might affect fluid retention. By weighing himself regularly, John could track any changes in his body weight that might signal fluid gain or loss, allowing him to adjust his intake accordingly.

> you have to sort of keep an eye yourself, which I do with scales just then. I weigh myself at home and I go all over the world with it… my scale, on holiday, because you can never tell with with different temperatures in the places you go. And you know how much you're losing or gaining depending on the temperature.

## Number of different self-regulatory strategies across adherence groups

Patients reported a wide range of strategies. We further examined whether the adherence groups tended to make use of more or fewer strategies. Almost all (93%) of low adherence patients were recorded in two or three of the themes; planning, behavioural strategies and self-monitoring. However, only 71% high adherence patients were recorded in two or three themes, with 19% reporting the use of only one thematic strategy and 3 patients (9.68%) reporting that they did not implement any strategies at all.

## Discussion

Patients undergoing dialysis are recommended to adopt self-regulatory behaviours to mitigate mortality and morbidity risks (National Institute for Health and Care Excellence, 2021). They are advised to collaborate with their health care team by restricting their consumption of foods high in potassium and phosphate, and by limiting their fluid intake. However the implementation of this advice is the responsibility of the patient in their home context. Despite the importance of self-regulation for patients on dialysis, previous literature has not addressed the question of 'how' or indeed 'whether' patients attempt to self-manage their kidney disease at home, or if their at home self-regulatory practices are associated with objective outcomes assessed by the hospital.

Following thematic analysis of semi structured interviews with patients on dialysis we identified three broad themes with twelve subthemes that illustrate the wide range of approaches taken to self-management by both high and low adherent patients; using planning strategies, behavioural strategies to keep within restrictions, and self-monitoring. These themes are consistent with established theoretical models of self-regulation and goal attainment (e.g., Carver & Scheier, 1982; Harkin et al., 2016; Nielsen et al., 2018). Patients used various self-regulatory strategies within these themes such as prospectively planning what to buy, or eat at each meal on an ongoing basis, or keeping a close eye on the dates of their monthly blood tests and planning what they ate during the week leading up to these tests. Although many patients reported forms of proactive planning, others amongst both the high and low adherence patients frequently perceived no need to actively plan, instead employing habitized routines such as eating the same thing every day. Behavioural strategies to keep within restrictions and cope with the challenges encountered in following a restricted diet included cooking from scratch, implementing food substitutions, and practicing portion control for restricted food types. Patients in both groups also monitored their food intake, tracked their fluid consumption or monitored their weight regularly. These findings depict a patient population that were aware of the prescribed dietary and fluid goals and attempted to implement a range of strategies to manage their dietary and fluid restrictions. Whilst the identification of these themes occurred prior to categorising patients by adherence group based on objective data from medical records, it was evident post-blinding that high and low adherence patients were differentially represented in some of the themes.

Both groups described prospective planning (e.g. Schwarzer, 2014; Hagger & Luszczynska, 2014 ) to pre-order food online, and plan meals. However, patients categorised as high adherence were more likely to disclose strategic planning to ensure high adherence to restrictions when their monthly medical tests were approaching. Concerns about achieving good blood test results clearly featured in their motivations, whilst the ability to selectively and, apparently successfully, increase regulatory adherence for a week, relax it in the weeks following and step up again prior to the next set of blood tests suggests a remarkably high level of self-regulatory control amongst the high adherence patients. This approach to periodic relaxation of certain restrictions may offer patients a sense of normalcy and enable social engagement that contributes to wellbeing.

Patients in both groups also commonly stated that they no longer needed to actively engage in planning, and low adherence patients were more likely to be amongst those who reported that over time living with CKD, they had acquired routines or habits. Habitizing diet by, for example, eating exactly the same thing at each meal may be viewed as an effective low resource alternative to proactively regulating, planning and adjusting dietary intake. The establishment of familiar habits and routines enables people to bypass the cognitive effort needed to evaluate or modify their actions. Habits endure over time, and are resistant to wavering motivation, supporting long term behavioural maintenance (Lally & Gardner 2013; Verplanken & Orbell 2022; Wood & Neal, 2007 ). Conversely if inappropriate dietary choices become habitized, they will be very difficult to change without significant effort and sustained motivation (Gardner & Lally, 2022; Kwasnicka et al., 2016; Wood & Rünger, 2016*)* so that responding flexibly to feedback that a change in diet or drinking habit is needed will be difficult and likely to fail.

Patients in both adherence groups described similar behavioural strategies, including food substitutions, controlling portion sizes, and preparing meals from scratch. However, patients from the low adherence group were more likely to be among those who described using drink substitutions and thirst management strategies, indicative perhaps of their greater struggle with thirst sensations. Low adherence patients were also more likely to describe indulging in occasional treats and cheat days.

Self-monitoring of behaviour (what I eat and drink) or of behavioural outcomes (such as weight) is known to be an effective form of self-regulation for goal pursuit (Harkin et al., 2016) and dietary management (Michie et al., 2009). Both adherence groups used various self-monitoring strategies to manage and record their dietary and fluid intake behaviour. These included using apps and online tools to identify hidden sources of sodium, potassium, and phosphorus in food, maintaining daily food and fluid intake records, pre-measuring daily fluid limits, and opting for smaller cups. Many patients kept records, such as a written food diary or using a white board to record how many cups of fluid they had consumed each day. Harkin et al.'s meta-analysis of self-monitoring found monitoring that was recorded was more effective in goal achievement than monitoring that was not recorded, suggesting that these patients were spontaneously using optimal strategies.

While both groups of patients engaged in behaviour monitoring a notable distinction emerged between the high and low adherence groups in relation to outcome monitoring. Low adherence patients demonstrated a higher tendency to monitor the outcomes of their dietary and fluid restriction behaviours by measuring urine output, or weighing themselves regularly, in one instance taking a weighing scale everywhere they went. Outcome monitoring is employed by the hospital to assess goal progress and patients are weighed before every dialysis session, commonly three times a week, and blood tests are taken monthly. Self-weighing may be considered unnecessary. Our observation that patients who self-monitored their own outcomes were over-represented amongst those classified on the basis of their medical outcome records as having poorer outcomes is intriguing. They may assume that because the hospital weighs them, this is an important outcome for them to check. Their monitoring may represent a  conscious effort to compensate for adherence difficulties, by reactively 'checking' if, for example, if they drank too much yesterday. Outcome monitoring is rarely an effective means to promote behaviour change. Harkin's (2016) meta-analysis tested and obtained evidence for a 'matching' hypothesis so that increasing monitoring of outcomes was not reliably associated with changes in behaviour, whereas monitoring behaviour was reliably associated with changes in behaviour. Outcome monitoring that provides evidence of lack of progress towards goals may also undermine future efforts or deplete self-esteem (Myrseth & Fishbach, 2009; Webb et al., 2013).

## Multiple strategy use

Patients categorised as low adherence were more likely to be represented in multiple themes, suggesting more diverse strategy use compared to high adherence patients who used fewer strategies. There are a number of possible interpretations for this observation. First, it is plausible that objectively low adherence patients are unlucky. It is feasible that those patients classified as high adherence on the basis of blood serum and IDWG averaged over a three month period are simply biologically ‘lucky’, so that patients’ self-regulatory efforts do not directly account for the variability in blood serum outcomes between groups (Kalantar-Zadeh et al., 2015). Similarly they may be ‘lucky’ because they experience fewer obstacles to sticking to the diet by virtue of their own pre-existing dietary and drinking habits, thereby requiring less effort or adjustment (if a person never previously loved tomatoes, giving them up is not a challenge).

Second, high adherence patients, (defined here as those whose medical records of blood serum and IDWG are satisfactory) are also less likely to receive negative feedback at their monthly blood tests, results that for low adherence patients may prompt renewed effort to try harder, implement an additional or different strategy that may or may not be effective. Low adherence patients appeared to be preoccupied with thirst and fluid management, being more likely to report using thirst management strategies, monitoring their fluid intake, and weighing themselves frequently at home. Low adherence patients were also more likely to report using habits or routines to manage their intake. If these routines are associated with poor outcomes, and they try to implement strategies to change their habits they are likely to find this very challenging, and may fail, default to habit, or try something else. The use of multiple different approaches is likely depleting their self-regulatory capacity over time (Hagger et al., 2009; 2013).

Thirdly, patients with low adherence may lack a supportive network to assist with their treatment adherence. Research indicates that when individuals anticipate insufficient self-control, they often rely on external sources, such as close others, to help them stay on track (Ackerman et al., 2009). This support can help patients adhere to their restrictions despite reduced self-control. Previous research has suggested positive associations between social support and self-management among patients on dialysis (e.g., Noviana & Zahra, 2022).

Lastly, high adherence patients may have found a straightforward approach that 'works for them' and stick to it. Low adherence patients may not be using strategies correctly or consistently or have established dietary habits that are inappropriate or hard to change due to a lack of proper guidance, personalised instructions, and a clear understanding of what is required.

## Strengths, limitations and future directions

The study benefitted from a systematic approach to sampling and a high response rate (75% overall) and included, importantly, patients whose medical records indicated objectively low as well as high adherence. A few limitations should be acknowledged. The unequal sample sizes between high (*n* = 31) and low (*n* = 15) adherence groups, potentially affecting the comparative analysis and generalisability of the findings. While caution is warranted in theme comparisons, the low adherence group's sample size still exceeds typical qualitative study standards, and no significant demographic differences were observed between groups. The present sample comprised 15% non-White ethnicity which is representative of the dialysis population at the hospital in which the study was conducted. People from Black, Asian, and Mixed ethnic backgrounds have a higher risk of kidney failure, develop the disease at a younger age than those of White ethnicity, and account for approximately 32.50% of all patients receiving hospital dialysis in the UK (UK Kidney Association, 2023). Future research might examine the role of ethnicity in self-regulation.

Despite the comprehensive exploration in this study, we did not identify emotional management strategies such as stress management, cognitive reframing, or relaxation techniques. Recognising that these strategies are crucial for effective self-regulation, future research should focus on investigating the role of emotional management among patients on dialysis adhering to dietary and fluid restrictions. Given the differences in strategies used by low and high adherence groups to manage dietary and fluid restrictions, future research should investigate the effectiveness of multiple strategies versus focused strategies in improving health outcomes for patients on dialysis. Identifying the optimal balance of strategies and examining how patient characteristics, social support, and psychological wellbeing influence strategy use and adherence is crucial. These research directions could lead to tailored interventions for patients struggling with adherence and establish a robust evidence base for strategy effectiveness in enhancing health outcomes for patients on dialysis.

# Conclusion

Patients on dialysis lead very restricted lives. In addition to attending dialysis and monthly blood tests they are asked to stick to a low potassium, low phosphate diet and limit their fluid intake. Their adherence to diet is monitored by outcomes from blood tests. Their challenge is to work out for themselves what to eat and to implement restrictions in their home environment in order to achieve good blood test results. Despite employing multiple different strategies, patients with low adherence struggled to meet optimal blood serum and fluid targets compared to high adherence patients, who used fewer but possibly more effective strategies. The challenge for healthcare providers is how to provide personalised guidance and ongoing support for patients. Strategies should be broken down into simpler steps tailored to each patient's understanding and introduced sequentially. This approach will help ensure accurate implementation and consistency, allowing these strategies to become habitual.

This chapter was submitted for peer review publication and currently under review at Psychology and Health.

# Chapter 4

# “When you’re thirsty, you’re thirsty”: A qualitative biopsychosocial approach to understanding influences on self-regulation among patients on dialysis

## Rationale

The findings from Chapter 3 provided a robust basis for a follow-up study aimed at exploring the contextual factors that influenced how patients on dialysis with varying adherence levels self-regulated their kidney disease management. Firstly, the observation that low adherence patients employed a greater number of strategies, such as more drink substitutions, thirst management techniques, and self-monitoring of behavioural outcomes, compared to high adherence patients, suggested that merely using multiple strategies did not necessarily lead to better outcomes. This raised important questions about the effectiveness of different self-regulatory techniques. Secondly, the use of "cheat days" and habitual behaviours by low adherence patients indicated the potential influence of psychological and behavioural factors, such as motivation, stress, or willpower, on their ability to adhere to treatment regimens. Finally, the finding that patients with high adherence could strategically plan to meet their target monthly blood tests by relaxing and intensifying their regulatory efforts between tests suggested that they possessed an exceptionally high level of self-regulatory control compared to those with low adherence. Given these observations, it became logical to investigate the reasons behind or “*why* “these differences. Specifically, the questions arose as to why some patients struggled while others managed effectively. Understanding the barriers and facilitators to self-management could provide valuable insights into how patients navigate their kidney disease and guide the development of tailored interventions to improve adherence and overall patient outcomes.

# Abstract

Grounded in a biopsychosocial model of health we examined factors influencing self-regulation following interviews with patients on dialysis with chronic kidney disease. Using a thematic analysis approach, we identified six themes: competing priorities, the need for personalised support from healthcare team, social support, intrinsic and extrinsic motivation, physiological feedback, and outcome expectancies. While most themes were represented similarly among both high and low adherence patients, some notable differences emerged. Although all patients described how important instrumental and emotional social support was in helping them to effectively self-regulate their disease management, people low in adherence were more likely to discuss the challenges associated with not having a support network. Low adherence patients were also more likely to experience issues associated with competing priorities and were motivated by poor health outcomes. Further, they were more demotivated by the lack of improvement in their health. However, a potential vulnerability among high adherence patients was also identified, as these patients were more likely to eschew self-regulatory efforts if they had not experienced worsening health. All patients' self-regulatory efforts were also influenced by positive and negative emotions regarding test results and changes in health. Overall, the findings provide valuable insights into understanding why some patients on dialysis are more successful at self-regulating their chronic kidney disease and highlight sources of resilience and vulnerability.

**Keywords:** kidney disease, dialysis, interviews, self-regulation, adherence, social support, qualitative.

# Introduction

Self-regulation is a key contributor to effective illness self-management, and consequently improved health outcomes across physical, emotional, and social domains (e.g., Bandura, 2004; Carver & Scheier, 1982; Heisler et al., 2003; Leventhal et al., 2012; Lorig et al., 2001; Zimmerman & Schunk, 2011). Chronic kidney disease (CKD) management is greatly hindered by poor self-regulation (Lin et al., 2017), which involves patients' ability to plan, initiate, monitor, and evaluate their behaviour towards achieving self-management goals (Hagger, 2010; Vohs & Baumeister, 2016). This is particularly true for patients on dialysis, who need to follow strict dietary and fluid restrictions, and medication regimes, to avoid complications, hospitalisation, reduced quality of life, and mortality (Saran et al., 2003; Santana et al., 2020), and to be eligible for a kidney transplant which is their only hope of improving their condition.

However, many patients on dialysis with CKD struggle to manage their illness, resulting in poor treatment plan adherence (Beto et al., 2016; Ghimire et al., 2015). Approximately 41% to 86% of patients on dialysis struggle to adhere to their dietary restrictions (Gebrie & Ford, 2019; Geldine et al., 2017; Lambert, Mullan & Mansfield, 2017; Santana et al., 2020), 22% to 77% struggle with fluid restrictions (Geldine et al., 2017), and 17% to 74% struggle with their medication plans (Burnier et al., 2015). Biopsychosocial models of health (e.g., Engel, 1977; Nair et al., 2021) posit that individual health outcomes are influenced by an interaction between the biological, psychological and social forces in a person’s life. This approach is notably different from biomedical models of health which focus restrictively on biological factors and medical interventions to treating health (Sadler et al., 2014). Despite the more holistic approach to medicine, adoption of the biopsychosocial approach has been slow and often not implemented in primary care contexts (Kusnanto et al., 2018). However, the demands associated with self-managing CKD for patients on dialysis are disruptive, impacting many different aspects of a patients' life (e.g., emotional, psychological, social, financial), and require complex combinations of behaviours. For example, to restrict fluids on permanent basis, patients must set specific consumption targets, monitor their behaviours and outcomes, and problem solve when they encounter obstacles. Each step of this self-regulatory process could be influenced by a number of contextual factors influencing their success (e.g., willpower, resources, understanding of their illness, social support, availability of reliable feedback).

Despite the importance of self-regulation for improving health outcomes, the factors influencing effective self-regulation among patients with CKD on dialysis are still not fully understood (Havas et al., 2016; Molzahn et al., 2008). Consequently, interventions aimed at enhancing patients' treatment adherence are often not grounded in empirical evidence, nor do they allow for a patient-centred approach to treatment (Bonner et al., 2014). Many interventions focus on education and prescriptive behaviour change, without acknowledging the patient's broader social and financial context (Sadler et al., 2014). Unsurprisingly, there is limited evidence for the efficacy of self-regulatory interventions targeting adherence among patients with CKD, and the underlying reasons for what makes an intervention effective remains unclear (Murali et al., 2019). Thus, there is an urgent need to identify the broader contextual factors that both facilitate and hinder the self-regulatory efforts of patients on dialysis so that more effective, patient-centred, and empirically grounded interventions can be developed.

## Current research

Patients on dialysis are expected by their healthcare teams to use a lot of self-regulatory effort in order to effectively manage their illness and prevent further deterioration in their overall health (Tsai et al., 2021). However, there is a lack of patient-centred empirical evidence that identifies what contributes to self-regulatory success among this patient group.

Grounded in a biopsychosocial model of health (Engel, 1977), the aim of the current study was to examine the contextual factors that influence self-regulation among patients with CKD on dialysis using thematic analysis (Braun & Clark, 2006) following semi-structured interviews with patients on a dialysis unit at a hospital based in the United Kingdom. Patients were also categorised according to their adherence levels as identified by objective health indices provided by their primary care team, in order to see whether certain facilitators and/or barriers were more common for patients at high and low adherence.

# Study 3

# Methods

## Participants

All registered patients in the partner hospital's dialysis unit were screened for inclusion by a medical consultant. Patients under 18, with impaired consent capacity, or recent acute admissions were excluded. Medical records were examined by the consultant to identify patients as high or low adherence on IDWG (low adherent > 5.7%), potassium (low adherent > 6 mmol/l) and serum phosphate (low adherent > 1.7 mmol/l) levels averaged over 3 months. Patients were categorised for the study as low adherent if their records indicated low adherence on at least 2 of the 3 measures. 116 patients were classified as high, and 23 as low adherence The adherence grouping was concealed from both patients and the lead researcher until after the final stages of thematic analysis were completed.

We initially aimed to interview 60 patients (30 high adherence, 30 low adherence). Of the 23 low adherence patients, 2 died during the study, and 15/21 (70%) consented and were interviewed. We drew an age and gender matched random sample of 45 high adherent patients of whom 5 died, moved away, ceased dialysis or had a transplant, and 31/40 (78%) consented and were interviewed. Since 31 patients had been consented by the healthcare team, it was decided to interview all 31. The sample size for the study was determined through the consideration of the power to detect instances of themes and the estimated prevalence of those themes in the population (Fugard & Potts, 2015). The final sample comprised $n = 46$ patients; 31 high adherent and 15 low adherent, ensuring 90% power to detect one instance of a theme with 5% expected prevalence in the population whilst accounting for attrition (Fugard & Potts, 2015). Participants were aged 34 to 94 years ($M_{\text{age}} = 64.78$ years, $SD_{age} = 14.81$), 59% were men. The ethnicity of the patients was: 84.78% White, 10.87% Black, 2.17% Mixed/Multiple ethnic groups, and 2.17% Other ethnic group. Adherence groups did not differ as a function of age ($M_{age\ high} = 67.16$, $SD_{age} = 13.40$; $M_{age\ low} = 59.87$, $SD_{age} =16.78$; $t(44) = 1.59$, $p = .12$), by gender ($n_{men\ high\ adherence} = 17$; $n_{men\ low\ adherence} = 10$ ; $X^2$ (1, $N = 46$) = .58, $p = .44$) or by ethnicity ($n_{White\ high\ adherence} = 26$; $n_{White\ low\ adherence} = 13$ ; *Fisher's Exact Test* (1, $N = 46$, $p = 1.00$).

## Procedures

Patients at a UK hospital dialysis unit with Stage 5 CKD were invited to participate in one-to-one semi-structured interviews between August 2022 and January 2023. The interview schedule (see Appendix C) included 18 open-ended questions derived from CKD literature, in addition to feedback from patients and staff in the renal ward. Probes were used to encourage elaboration and discussion of relevant areas with interviews lasting between 30 to 100 minutes ($Mdn = 46.33$ min). Recordings were made via Microsoft Teams and transcribed verbatim, with field notes taken afterward. Data were securely stored, and the first author cross-referenced transcripts with audio recordings for accuracy, removing identifiable information. Patients were assigned pseudoanonymised numeric codes for anonymity and data protection. Written informed consent was obtained from all patients. The study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline (Tong et al., 2007). Ethical approval was obtained from HRA REC and the university. This study is pre-registered on the Open Science Framework (https://osf.io/7mbj6/?view_only ).

### Data analysis

Reflexive inductive thematic analysis (Braun & Clarke, 2006; 2021) was used to analyse patient transcripts. Transcripts were analysed manually and using N-Vivo software (Version 1.6.4, 2023). A systematic coding approach involved transcript familiarisation, initial code generation, theme collection, review, refinement, and labelling. This process grouped common ideas across transcripts, facilitating the generation of higher and lower codes. The lead coder, who was blind to adherence grouping, repeatedly reviewed transcripts to identify patterns and initial coding ideas, enhancing data immersion. The themes were revised through discussions between the lead coder and two other members of the research team until 100% consensus was reached. Following finalisation of codes, the lead coder became unblinded regarding patients' adherence grouping so proportional differences in representation of adherence groups per theme could be evaluated.

## Results

Results are organised according to the six themes identified during coding: (1) competing priorities (2) personalised support from the healthcare team, (3) social support, (4) intrinsic and extrinsic motivation, (5) physiological feedback, and (6) outcome expectancies. Table 10 provides an overview of the themes and subthemes (where applicable), their definitions, and prototypical examples. Examples of quotes comprise of pseudonyms. These themes are representative of both adherence groups. We discuss, where appropriate, the proportionate differences in thematic representation among adherence groups (see Table 11).

**Table 10**
*Emergent themes, subthemes, their definitions, and prototypical examples*

| Theme | Definition | Subtheme (if applicable) and example quotes |
|---|---|---|
| 1. Competing priorities | Other competing demands in life, such as financial concerns, parenting responsibilities, and illness co-morbidities that influenced patients ability to manage their disease. | "Problem is that what they want me to do doesn't always agree with diabetes" (Kate – high adherence) |
| 2. Personalised support from the kidney healthcare team | Patients desire for tailored support and guidance from their healthcare team. | **Person-centered support**<br>"What you actually want, is to sit down with someone and then for them to say to you, right? I like this meal, that meal, and for you to then hand them back. Ok, here's three weeks of recipes, go and eat this for the next three weeks and that's all it is, have this breakfast, then the following meals helps you get into the mindset. You don't get that out of the UK." (Mark – low adherence )<br>**Misinformed and contradicted**<br>"When I was first diagnosed, they kept telling me I was you know I was very dehydrated so drink more also to the point where I got on this machine, I was pretty much still drinking quite a lot, and it was Doctor S that said actually you don't need to drink so much fluid" (Rosie – high adherence) |
| 3. Social support | The support, both instrumental and emotional, that patients either received or lacked from various individuals in their lives (e.g., spouses, children, friends, other patients), also encompassing the sense of connection patients felt with other patients on dialysis. | **Receiving instrumental support**<br>"Family and friends are very good as well, they don't sort of like when I ask for a drink, they won't give me a great big mug because they know me enough [laughs]. Everyone I know has got a little cup in their house that's mine [chuckles]. It's my little cup and that's so because I don't like it if they just give me half a cup because I feel, that's when you feel excluded you know what I mean" (Anne – high adherence)<br>**Receiving emotional support**<br>"My two sons, give me courage, speak to me not to worry, to be more calm about everything. They will help me with anything Yeah, because of my, my my sickness I'm very down sometimes. … But they encourage me, friends you know and family, encourage me to carry on because the only way to stay alive" (Rafael)<br>**Connecting with other patients**<br>"You get to obviously know other people in here as well. So, you talk about you know, families and friends and stuff. It's that bit like a social gathering" (Anne – high adherence)<br>**Absence of support**<br>"When you see what families are eating, yeah, it is very tempting" (Paul – high adherence) |
| 4. Intrinsic and Extrinsic Motivation | Patients perceived various motivational factors, both intrinsic and extrinsic, as influencing their ability to self-regulate. | **Having willpower**<br>"I follow it to the letter but ummm I say it's not always easy, will power helps I suppose" (Samuel – low adherence)<br>**Having a sense of responsibility**<br>"I want to live as long as possible. I'm 80 and trying to live as long as possible because it's for my own benefits, if I don't follow advice and do as am told… I'm making it worse for myself… if that makes sense" (Tiffany – high adherence) |
| 5. Physiological feedback | How patients responded to physical cues from | "I do sometimes get a little bit breathless and that means I'm overloaded" (Cheryl – high adherence) |

| | | |
|---|---|---|
| | their body (e.g., thirst, bloating, change in weight, feeling hot/cold) to determine whether to self-regulate. | |
| 6. Outcome expectancies | How patients' expectations regarding the consequences, or lack thereof, of their illness influenced their self-regulatory behaviours. | **Nothing bad has happened before**<br>“Honestly, I don't know [laughs]. I don't know. I don't know what what too much looks like from their point of view. Yeah, I'm sure someone mentioned that that that I'm. I'm retaining too much and need to reduce them. So, yeah, until someone tells me otherwise…” (Jason – high adherence)<br>**Waiting for a sign**<br>“I had fluids in my lungs at one point and that scared me, obviously that's just something I’m concerned about like so; I stick to just 1 litre” (Charles – low adherence)<br>**Efficacy of effort**<br>“But as improvements on my overall health, I wouldn’t think it massively helps so no, I haven’t noticed much improvements” (Adele – low adherence)<br>**Emotionally driven**<br>“Oh, it would worry me, you know… make me make sure that I was eating the right things” (Julia – high adherence) |

*Notes.* The names used are pseudonyms.

**Table 11**

*Occurrence and proportions of themes in low and high adherence groups*

| Themes | Subthemes | Number (%) of occurrences in total sample $n_{total}$ = 46 | Number (%) of occurrences in high adherence group reporting theme $n_{high}$ = 31 | Number (%) of occurrences in low adherence group reporting theme $n_{low}$= 15 |
|---|---|---|---|---|
| **Competing priorities** | | 12 (26.09) | 7 (22.58) | 5 (33.33) |
| **Personalised support from the kidney healthcare team** | Person-centred support | 17 (36.96) | 12 (38.71) | 5 (33.33) |
| | Misinformed and contradicted | 19 (41.30) | 13 (41.93) | 6 (40.00) |
| **Social support** | Receiving instrumental support | 21 (45.65) | 13 (41.93) | 8 (53.33) |
| | Receiving emotional support | 18 (39.13) | 12 (38.71) | 6 (40.00) |
| | Connecting with other patients | 8 (17.39) | 6 (19.35) | 2 (13.33) |
| | Absence of support | 11 (23.91) | 3 (9.68) | 8 (53.33) |
| **Intrinsic and Extrinsic Motivation** | Having willpower | 15 (32.61) | 10 (32.26) | 5 (33.33) |
| | Having a sense of responsibility | 17 (36.96) | 11 (35.48) | 6 (40.00) |
| **Physiological feedback** | | 34 (73.91) | 23 (74.19) | 11 (73.33) |
| **Outcome expectancies** | Nothing bad has happened before | 23 (50.00) | 18 (58.06) | 5 (33.33) |

| | | | | |
|---|---|---|---|---|
| | Waiting for a sign | 20 (43.48) | 11 (35.48) | 9 (60.00) |
| | Efficacy of effort | 34 (73.91) | 21 (67.74) | 13 (86.67) |
| | Emotionally driven | 46 (100.00) | 31 (100.00) | 15 (100.00) |

## Competing priorities

For patients in both adherence groups, competing priorities like finances, parenting, and the management of other health conditions hindered effective self-regulation. It was not due to a lack of understanding, but rather a lack of time or resources as a consequence of other demands.

The pragmatic challenges and demands of daily life created significant barriers for many patients.  For example, Charles (low adherence) expressed the challenges associated with following his own dietary restrictions on top of caring for his children.

> Trouble is that I'm a stay-at-home dad so, it's quite hard to do what I want to eat when I've got two kids wanting to have chicken nuggets and chips [giggles]. Sometimes just you can't be bothered, when you've got two young kids constantly waiting to be fed. You know what, I'm just not gonna eat, I'm just gonna cook their food and I'll be fine.

Patients with comorbidities, like diabetes, struggled to manage their CKD alongside other treatments, often prioritising one illness over another. Mark (low adherence) described managing all his conditions as consuming and unattainable.

> The problem is, I'm trying to please diabetes and endocrine people, my kidney consultant and everybody else. I'm not going to please them all, so one […] is gonna be upset. You just… as long as you don't upset the same one repeatedly, then you just work in rotation.

Low adherence patients were slightly more likely to report challenges associated with competing priorities compared to the high adherence group (33.33% vs. 22.58%), highlighting how structural inequities (e.g., money; childcare support; time) can contribute to health inequities.

## Personalised support from the kidney healthcare team

Patients expressed a desire for personalised care from their healthcare team to support effective self-regulation. They also felt sceptical about the information provided by their primary care teams, finding it inconsistent and conflicting. This scepticism influenced their disease management, as some patients relied on feedback from their healthcare team to initiate or sustain self-regulatory efforts.

### *Patient-centred support*

Several patients wanted more patient-centre guidance on how to manage their unique dietary and fluid needs. For instance, Peter (high adherence) found it challenging to retain and use received kidney information for self-regulation because the staff were unable to adjust it to his level of understanding, causing confusion.

> When the consultants talk to you, they talk to you like you're a doctor and that's like… a lot of the time they've explained about the bloods before, but high globulins and things, that means nothing to me, you know, I know the word, but I don't really understand it… like you know what they're on about umm, like well, you know it just goes over your head.

By contrast, patients who felt they received patient-centred care emphasised how it encouraged and facilitated their self-regulation. For example, Adele (low adherence) benefitted from personalised guidance provided by her dietitian. She particularly highlighted how the personalised care improved her understanding of dietary restrictions, such as foods to avoid and alternatives, and recipes that matched her cooking abilities.

> She's given me loads of information sheets about what foods I can eat and what I can't, what things have potassium and stuff. Umm she's also given me, menu ideas, recipes which even I could cook, and they are low in potassium and low in phosphate, which is really handy. So, having an alternative like like she's done, it's brilliant, especially when they're relatively easy to cook as well because I'm not the best chef you know, I'm the kind of person that lived on the little, you know, shoving the oven meal, and those are really, really, really bad [laughs].

Thus, many patients highlighted how tailored support was often used to better understand exactly what they needed to do to effectively self-regulate and manage their illness.

### *Misinformed and contradicted*

Several patients believed that their ability to self-regulate was hindered by inconsistent, conflicting, or a complete lack of information that prevented them from getting personalised support from their healthcare team. For instance, Tom (high adherence) was left confused about his dietary restrictions after his team seemingly changed what was and was not restricted out of nowhere.

> When I started, I couldn’t have any tomatoes but now I can have 2 small tomatoes. Before, you couldn’t have any of them. So, it’s not clear whether dialysis has gotten better, or they have become more lax.

For others, like Peter (high adherence), it was not contradictions by the medical team which they felt hindered their ability to self-regulate, but rather a complete absence of information. This meant that they had to keep engaging in whatever behaviours they felt were appropriate, regardless of whether this reflected their actual health status or not.

> Well occasionally I’m on a restricted fluid intake but they never tell me when, if it stopped or size, I keep, I stick to it anyway. Well, you don't get enough information, and maybe if I ask, they will tell me. it means when [laughing] when, it could be once a year (bloods). But my nurse is a bit lacking in getting information.

While it was recognised that inconsistent information was sometimes the result of advances in medical research, it nonetheless created additional self-regulatory challenges. Samuel (low adherence) highlighted how changing food guidelines required him to change his eating behaviours to stay “up-to-date" with the medical field.

> Medical research changes, you find out new things and things that were… it’s okay to do, few months later become no you shouldn’t do that. I find something, you can still find new things up that you didn’t realise.

Whether it was due to contradictions, changing policies, or an absence of information altogether, many patients clearly relied on consistent information from their healthcare team to feel as though their treatment was being personalised to their own needs, and not applied in a random "broad-strokes" approach.

## Social support

Every patient emphasised the importance of instrumental and emotional support from their personal social network (e.g., spouses/partners, children, friends) in managing their kidney disease. By contrast, the absence of support created acute and chronic challenges for self-regulation and management.

### *Receiving instrumental support*

Instrumental support (e.g., practical assistance) was highly valued by patients as it lessened the perceived burdens associated with self-regulation and disease management. For instance, Arthur's (low adherence) daughter measured his fluid allowance precisely, preventing him from exceeding his daily intake easing his self-regulation efforts.

> My daughter measures everything out. She puts everything in the the this, so I have 5 of those a day [points at small plastic bottle] which I never drink any more than that.

Many patients shared how their loved ones independently educated themselves to effectively assist them in self-regulation. For instance, Samuel's (low adherence) partner independently learned the appropriate kidney diet and then taught it to him. Furthermore, it was his partner, rather than the healthcare team, who prompted the changes in his diet.

> It was my partner who looked into sort of the renal diet as I didn't know anything about it when I first started. It was my partner, who discovered it and had changed my diet to a renal diet. my wife is quite important, she researched into things like the renal diet.

Instrumental support extended beyond family and partners to friends. David (high adherence) emphasised the importance of friendships in helping with practical tasks both at home and outside, which he couldn't manage due to the demands of his disease management.

> I wouldn't be able to survive without my friends. They'll help me cut the grass, help me go shopping, also help me walk my dog and stuff like that. I have people who will do that with no problem.

### *Receiving emotional support*

Close others also provided valuable emotional support. Patients described that this encouragement and praise from loved ones, including pets, made disease management easier. For example, Linda (high adherence) highlighted the understanding and support of her husband and son, who gave her space to navigate her mood and physical limitations.

> My home life, my husband and my son, they are so good in what they do. They allow for me if I need to go for a nap or if my moods change, which also could be my umm menopause, so, I'm not quite sure. Umm they are backing me 100% and that makes things a lot easier. If I didn't have that backing at home, I think I would struggle.

Similarly, Emily (high adherence), credited her pets with providing a reassuring safe space for her, especially on days when she was struggling.

> My dogs are my life and soul. They are the 2 little things that gets me up in the morning and look after me and everything else. No, I I tend to if I get really bad, I will go into my safe space, which is my bed. I find my bed is my safe space and I'll get to bed early with the boys and try and stay in there and that's my safe space and that's how I I would do it. But yeah, it it's difficult, it's difficult [despondent with face down].

### *Connecting with other patients on dialysis*

All patients mentioned how dialysis sessions connected them with other patients on dialysis. This fostered a sense of belonging and shared understanding, creating a "kidney family" which alleviated felt isolation. For example, Linda's (high adherence) connection to other patients helped her to overcome her initial fears and reduced her likelihood of skipping sessions.

> Some people, I remember when I first came here, I was in shock seeing the machines. We are shown on the first time here and you know, it's just like a little family, you come here and see the same people.

Similarly, Nathan (low adherence) looked forward to seeing his "friends" at dialysis sessions, who gave him an important sense of shared understanding.

> Friends, the people you meet here. I do look forward to coming here as a social thing. yeah, we all kind of understand each other and I look forward to coming here. This is for me… as mad as it sounds… I dunno, seeing everybody again I suppose.

The community of patients is therefore a valuable tool for encouraging self-regulatory behaviours that facilitate attendance at dialysis sessions, in addition to the emotional support mutually reciprocated during these experiences.

### *Absence of support*

The absence of social support notably hindered self-regulatory efforts among patients. For instance, Nathan’s (low adherence) experience with unexpected caregiving demands meant he no longer had the support he needed to effectively manage his own illness.

> I moved back in with my parents, and it's turned out to be the biggest mistake. Well, the idea was, cos I lived on my own, then when my eyes … failed, I go back to my mum and dads, and my mum was meant to be my carer but now she’s got Alzheimer’s. It’s just all sorts of mess…

For others, the absence of support came in the form of others' unwillingness to change their own behaviours or creating temptations which undermined self-regulation. For example, Jason (high adherence) felt his self-regulatory efforts weakened when he was around friends who pressured him to keep drinking.

> It's it's, it's difficult, it's more difficult when I'm out. So, when I'm at home and I'm doing my day to day, it's more difficult when I'm out with friends because it's everyone else is drinking. But I'll get with my friends, and they are like have another drink, another drink.

For some, temptations introduced by others made them welcome the loss of their wider social network. For example, patients living alone found it effective to avoid temptations created by others, as illustrated by Esther (high adherence).

> I haven’t got someone popping in every 5 minutes asking for cream cakes [laughs].

A lack of social support significantly contributed to self-regulation struggles, especially among the low adherence group (53.33% vs. 9.68% high adherence), suggesting that social support plays a very significant role in self-regulatory success.

## Intrinsic and extrinsic motivation

Intrinsic and extrinsic motivation played a significant role in patients’ self-regulatory experiences. Intrinsically, patients' self-regulation was fuelled by their willpower to change and a desire for behaviours that improved disease outcomes. Externally, some patients were driven to self-regulate by a desire to prolong life, a sense of responsibility, and concerns about how significant others (e.g., close others and healthcare team) would perceive their actions (avoidance of negative consequences, accountability, and rewards).

### *Having willpower (or not)*

Some patients described having the willpower needed to resist temptations and make intentional decisions aligned with their desired health behaviours and outcomes. For example, Patricia (high adherence) expressed that it was primarily her commitment to self-regulation which enabled her adherence to her treatment plan.

> I try with with every fibre of my body to make sure that it's not gonna be out of sync and I try to keep to the rules sort of like the phosphate and also the basic thing is to remember, take this phosphate binders after every meal there.

By contrast, some patients felt they lacked the willpower to self-regulate despite the consequences and encouragement from others. For example, Jennifer (low adherence) recognised her inconsistency in following her dietary restrictions, attributing it to a lack of effort.

> I don't always do it, don't always stick to my diet plan…cos I don't try.

### *Having a sense of responsibility*

Some patients expressed that they self-regulated out of a sense of responsibility to themselves, close others, and their healthcare team. For example, Rita (high adherence) was driven by her responsibility to her family to effectively self-regulate.

> If I don't do it nobody else is going to do it. These people are going to be saying here she comes; we are fighting a losing battle. I have 2 grandsons, and I intend to see them grow up. So, if I don't fight and do what I'm doing, nobody else is going to do it for me.

Charles (low adherence) similarly felt that if he was single, he would not have the motivation to self-regulate, and attributed his adherence to his responsibility to his family.

> To please my children and my wife, it wouldn't be fair on them. If I was single, chances are it would be a case of you know [shrugs shoulder] I mean … I try as hard possibly can to to, to to keep it under control because I don't… I don't wanna leave them. So, that's why I try as hard as I possibly can. And to be fair you feel terrible as well and I wouldn't wanna feel that.

For Daniel (high adherence), his sense of responsibility to his healthcare team motivated him to self-regulate as an act of gratitude and respect.

> It's been a, I'd like to think that I try to be a good patient. Because I think, you know, if someone's treating you, it pays to, sort of show your gratitude for the effort that they are putting in. So basically, I look forward to this is my job…

## Physiological feedback

Many patients relied on physiological cues from their body in order to determine when self-regulatory efforts were (or were not) needed to manage their illness. Some patients believed physiological cues provided them with insights into the efficacy of their self-regulatory efforts and relied on these embodied cues to adjust their behaviours. For example, Tiffany (high adherence) used changes in how her clothes fit as an indicator of potentially concerning weight fluctuations, prompting her to eat more to prevent malnutrition.

> I only worry when my clothes are getting too loose… my clothes getting loose then I worry. I know I lost weight… but [shrugged].

Patients also felt that physiological feedback prompted them to engage in self-regulatory behaviours. For instance, Linda (high adherence) noticed that she felt less thirsty, which ultimately made regulating her fluid intake much easier.

> My taste in being thirsty has changed a lot over the years and I’d say the past year and a half, I’ve not been as thirsty. So, can control it a lot.

For other patients, self-regulating their fluid intake was particularly challenging due to the fundamental biological imperative to drink when thirsty, as expressed by Alison (low adherence).

> When you’re thirsty, you’re thirsty aren’t you?

Similarly, many patients found that thermo-self-regulatory needs undermined their efforts to self-regulate. For example, Rita (high adherence) noted that hot weather caused her to perspire more and become thirstier, leading to self-regulatory failure.

> I try to limit it but during the hot weather because you’re sweating more, I probably had a bit more.

## Outcome expectancies

Patients' expectations about the consequences of changes in their health, based on their personal anecdotal experiences, influenced their self-regulation and sometimes led them to ignore their healthcare team's advice.

### *Nothing bad has happened before*

A number of patients felt that they could disregard medical advice because they had never experienced any consequences associated with failing to self-regulate in the past. For example, Peter’s (high adherence) belief that there would not be any physical symptoms associated with poor blood-test results meant he also felt he did not need to self-regulate and follow dietary restrictions.

> I can't tell when they [phosphate/potassium] are high, but I don’t think I get any physical symptoms from them. They appear

> to be fine [my bloods and weight] so umm I don't analyse things too deeply. If it feels okay, then that's enough for me. It's good enough.

Similarly, Luke (low adherence) acknowledged that occasional deviations from strict adherence to his treatment plan hadn't affected his existence.

> I mean I'm still here after several years so… I mean sometimes I cheat a bit.

People in the high adherence group (58.06%) were more likely to believe that there had been no adverse effects attributable to their lack of self-regulation compared to those in the low adherence group (33.33%). This suggests a potential vulnerability among those in the high adherence groups who may be willing to take risks provided they do not see immediate consequences.

### *Waiting for a sign*

Some patients were waiting for a sign, such as a change in health status, to begin self-regulatory efforts. For instance, Adele's (low adherence) hospitalisation following a failure to regulate her fluid intake facilitated her future self-regulatory efforts.

> I was a little bit blasé about my fluid restrictions, I wound up in the hospital for four days and couldn't breathe because the fluid obviously builds up around your heart and your lungs. And umm yeah, I was in a hell of state.
> And I got here, oxygen, the works and they had to drain over a couple of days next to four litres off me cause I've been very, very silly and I'm not gonna do that again because I don't want to wind up back in hospital.

Changes in eligibility for kidney transplantation also influenced self-regulatory efforts. For example, Rosie (high adherence) was motivated to engage in weight-loss effort to improve her likelihood of being eligible for transplant.

> My ultimate aim is to get a transplant, but I have to lose the weight first. I've got to lose another 4 and a half stone and so I know my BM is my BMI is holding me back at the minute and then I'll just go on the list and wait I presume.
> well, I'm trying to lose weight, becoming more active, trying to keep as healthy as possible.

By contrast, Tom's (high adherence) self-regulatory efforts were completely hindered once he realised he was ineligible for transplant.

> I was doing cycling to get myself fit, going out 3 times a week… in the gym doing like 30/ 40 miles ride at the weekends. Soon as they said no to the transplant, there was no point to keep myself fit for nothing. I wasn't getting nothing for it.

Low adherence patients were more likely to have shared that they had been motivated to change their self-regulatory efforts following an adverse change in their health, compared to those in the high adherence group (60.00% vs. 35.48%).

### *Efficacy of effort*

Many people relied on the perceived efficacy of their regulatory efforts to determine whether they were worthwhile to continue or not. For example, Rafael (low adherence) maintained his current self-regulatory efforts because he had more energy as a consequence.

> I have more energy, I can do stuff, I take out carpet out on floor and put laminate, walking more- walk to town and back like 2 to 3 miles and gardening.

Similarly, Arthur (low adherence) acknowledged that if he reverted to his old dietary habits, his health would worsen.

> I think if I went back to my diet what I used to be on, I would, I would I'd have phosphate and er what you call it problems, phosphate, and calcium. Otherwise, I'd be ill, seriously ill I'll be. I know I'm ill now, but I mean, you know I'd be ill.

By contrast, patients who experienced worsened health despite their self-regulation were less inclined to persist with these efforts. Emily (high adherence) struggled to sustain her self-regulatory efforts because she saw no improvements, leading to distress.

> [thinking] no, not really and to be honest with you, it gets me down, and it doesn't improve with my health it it it it really pulls me down and like it very depressed about it and very despondent so, yeah. I do find that very hard even when I try [unhappy]

People in the low adherence group (86.67%) were more likely to report that their regulatory efforts had been stalled by negative changes in their overall health than those in the high adherence group (67.74%), highlighting that adverse health outcomes despite best efforts were a demotivating force among some patients, but had motivated positive action among others (i.e., those waiting for a sign).

***Emotionally driven***

Every patient described how their experiences with strong emotional responses to feedback about their health influenced their self-regulatory efforts. For instance, Emily's (high adherence) rumination and subsequent self-chastisement and self-anger, following a bad test result made it difficult for her to continue her self-regulatory efforts,

> Awful, I feel that I'm a failure, I get very downhearted and occasionally, I will actually get quite cross with myself, and that is the likelihood that I would take it out on myself. Because ummm that's how much that makes me feel you know… I'll say I failed again you know, yeah, it's hard [despondent]. Oh, I'm always disgusted.

By contrast, Charles' (low adherence) sense of relief following good test results made his self-regulatory efforts easier to maintain.

> I feel um… relieved that the effort you're putting in is working. Also, that so if I know that's worked, then I know I can copy it. You get a clear picture of what you can and can't do.

In a small number of cases, patients felt regret because they believed their positive tests results were an indication that they had overregulated their behaviours. For instance, Tom (high adherence) felt a sense of regret that he had not consumed *more* fluids between sessions, despite his overall satisfaction with his health outcome.

> I feel fine about it [indifferent], was a bit lower to be honest and I thought could have a few more drinks. I feel I missed out now. I didn't feel I missed there until I saw my weight [chuckles], the only problem is you can't do anything about it now.

These experiences with strong positive and negative emotions highlight the importance of understanding how emotionality shapes patients' self-regulatory efforts, for both better or worse outcomes.

# General discussion

Patients with CKD on dialysis are recommended to strictly adhere to treatment plans to avoid serious health complications and death (Santana et al., 2020). This adherence demands extensive self-regulation (Hagger, 2010). Despite the importance of self-regulation for patients on dialysis (Howren et al., 2016), little is actually known about the specific facilitators and barriers patients on dialysis experience with regards to their self-regulatory efforts. Additionally, few studies have examined whether factors influencing self-regulation are associated with objective adherence outcomes. To our knowledge, this is the first qualitative study to examine the contextual factors that influence self-regulation among patients with CKD on dialysis and that compares them across adherence outcomes.

Following semi-structured interviews with patients on dialysis, we identified six key themes that illustrate the factors influencing self-regulatory efforts in illness management for both high and low adherent patients (competing priorities; personalised support from healthcare team; social support; intrinsic and extrinsic motivation; physiological feedback; and outcome expectancies). These themes align with established theoretical models of self-regulation and behaviour change (Bandura, 2004; Carver & Scheier, 1982; Leventhal et al., 2012) and biopsychosocial models of health (e.g., Engel, 1977). Patients who had competing priorities, such as financial concerns, childcare, or treatment plans associated with other illnesses, described struggling with self-regulation, as did patients who felt they did not receive adequately personalised treatment from their healthcare team, those who felt they lacked the willpower and motivation to adhere to their treatment plans, those who did not see a direct association between their self-regulatory efforts and positive/negative changes in their health, those who felt their bodies were giving mixed signals (e.g., thirst), and those without social support. By contrast, self-regulation was made easier by highly engaged social support networks, as well as a sense of responsibility to the self, healthcare teams and loved ones, an appreciation for how much their overall health had improved as a consequence of their self-regulatory efforts, and their emotional reactions to feedback regarding their health.

While these themes were identified prior to categorising patients by adherence group, it was evident post-blinding that high and low adherent patients were overrepresented within some themes. Broadly, patients who had been classified as low adherence based on their health indices encountered more barriers to self-regulation when it came to managing their kidney disease. Patients who felt that their self-regulatory efforts had been negatively impacted by competing demands from family and finances were slightly more likely to be from the low adherence group. These findings highlight sociodemographic barriers that may contribute to poor health outcomes among CKD patients on dialysis (Alvarez-Villarreal et al., 2021; Banerjee et al., 2017). However, patients who were categorised as high adherence were not always proactive self-regulators. Notably, high adherence patients were much more likely to be among those who believed that the absence of negative consequences from their lapses in self-regulation justified further regulatory lapses. By contrast, low adherence patients were more likely to have been motivated to improve their self-regulatory efforts by a negative change in their health. Consistent with past work on denial and the minimisation of symptoms among patients with CKD (Gagani et al., 2016), some of the patients in the high adherence group who had not experienced the negative consequences of their self-regulatory failures may simply be playing the long game to becoming low adherence patients through inaction. Worsening health outcomes was not always an impetus for improvement either. Patients from the low adherence group were more likely to be among those who said they felt discouraged from self-regulating because they had not seen evidence that their efforts were paying off.

Social support from family, friends, partners, pets, and other patients was overwhelmingly identified as an essential component to effective self-regulation among all patients from both the high and low adherence groups. Furthermore, patients who felt that they lacked a social support system to help them with their self-regulation and illness management were overwhelmingly overrepresented among those in the low adherence group. The clear benefits of strong social networks, and consequences of inadequate ones, complement the extensive research demonstrating the role of social support on health, wellbeing and mortality (Holt-Lunstad et al., 2010, 2021; Kiecolt-Glaser et al., 2002, Uchino et al., 2018), including studies demonstrating the positive associations between social support and self-management among patients with CKD (e.g., Noviana & Zahra, 2022). Our findings emphasise the benefit of social prescribing models of health which advocate for holistic approaches to healthcare that leverage patients' social support network for improved patient outcomes and to reduce the burden on the healthcare system (Bickerdike et al., 2017; Chatterjee et al., 2018), as well as the need for empirically based interventions aimed at strengthening patients' social networks, particularly among those who may be more vulnerable.

Similarly, all patients shared how their emotional reactions test results and feedback from the healthcare team influenced self-regulatory efforts. Many patients experienced negative emotions, such as rumination and guilt. However, some experienced positive emotions, such as relief. The influence of emotions on self-regulation are well documented (e.g., Baumeister, Zell, & Tice, 2007). While positive emotions are typically associated with greater self-regulatory success, our findings suggest that negative emotions may immediately support self-regulatory efforts among some patients. However, our data cannot speak to the long-term consequences of these negative emotions on self-regulation. Potential (self-identified) facilitators, such as negative emotions, which may feel effective in the moment, could nonetheless undermine efforts in the long term, if they are not complemented by more positive coping strategies.

### Limitations and future directions

Despite the strengths of the current research, this work is not without its limitations. First, while there were no differences in age, gender or ethnicity across the high and low adherence groups, the sample size meant that it was not possible to make more probative comparisons across specific sociodemographic groups to identify more specific patient-level differences in barriers to self-regulation. Second, the study benefitted from a research team from different cultural backgrounds (e.g., British, North American, Nigerian). Our intersecting identities contributed nuanced insights and necessitated continual reflexivity whilst acknowledging the subjective lenses through which this research was conducted and analysed. However, the sample is ethnically restricted in a few meaningful ways: First, all of the patients in this sample were from a public hospital in the United Kingdom. The barriers, and implications for adherence, may manifest differently in healthcare systems where patients have to pay for treatments and medication, or where treatment plans are dictated by insurance providers. Second, the majority of the sample were white. Studies indicate that patients from low socioeconomic backgrounds and ethnic minority communities face more systemic obstacles to effective self-management, such as barriers to affordable food, and challenges related to the access to information about their illnesses and accessible guidance (Block et al., 2004). Thus, the current research would benefit from being replicated in different countries and marginalised populations to help identify how the self-regulatory barriers and facilitators identified in this work are represented among these communities.

## Conclusion

Consistent with biopsychosocial models of health (Engel, 1977), the factors which facilitate and create barriers for patients’ self-regulatory efforts are multifaceted, stemming from differences in support, motivation, responses to biological feedback, and competing demands. The work also highlights the importance of avoiding “one-size-fits-all" interventions, instead focusing on patient-centred approaches to kidney disease management which acknowledge a patient’s unique self-regulatory resources and vulnerabilities.

# Chapter 5

# Help that matters: The role of regulatory support on fluid management

This final empirical chapter quantitatively assessed the findings observed in Studies 1 and 3. The findings from Study 1 highlighted the positive impact of social support-based interventions on enhancing self-efficacy among patients on dialysis. The results presented in Study 3 build on this, revealing that both the presence of quality support and the absence of support significantly influenced the self-regulatory abilities of patients undergoing dialysis. These observations align with the broader body of research on social support, which has consistently demonstrated strong connections with various physical health outcomes (e.g., Holt-Lunstad, Smith, & Layton, 2010; Uchino et al., 2018). The convergence of these findings highlights the critical need to thoroughly investigate the role of social support in influencing disease outcomes for patients on dialysis. This research direction not only complements existing literature but also offers potential avenues for improving patient care and outcomes in the context of dialysis treatment. The question that is addressed in this study is whether there is a relationship between social support aimed at fulfilling self-regulatory needs and self-reported fluid management (measured via interdialytic weight gain – IDWG) among patients on dialysis, using a novel social support scale—the Regulatory Effectiveness of Support (Zee et al., 2020).

## Self-regulation and fluid management

It is now widely recognised that patients on dialysis should actively manage their condition to avoid complications and premature death (Lin et al., 2017; Saran et al., 2003). Such disease management involves medical treatments and significant self-regulation, including strict adherence to dietary and fluid restrictions. One of the most challenging tasks for patients on dialysis is regulating their daily fluid intake, typically limited to a litre, while managing thirst-inducing medication side effects (Denhaerynck et al., 2007; Kartini et al., 2020). This difficulty is reflected in high rates of fluid non-adherence, ranging from 30% to 76% among dialysis patients (Denhaerynck et al., 2007; Nerbass et al., 2011). The effectiveness of a patient's fluid management between dialysis sessions is assessed by measuring the difference in their weight between the end of one treatment and the start of the next treatment (known as IDWG) a time when fluid accumulation will be determined predominantly by the patients ability to regulate fluid intake. Thus, IDWG indicates how well patients adhere to fluid restrictions, which are crucial to preventing fluid overload, hypertension, and pulmonary oedema (Christensen & Ehlers, 2002; Evangelidis et al., 2019). These complications increase mortality risk and impact health outcomes (Geldine et al., 2017; Nerbass et al., 2011). To prevent or minimise these complications, patients need the support of others (e.g., partners, family, friends, healthcare providers) to enact the necessary behavioural changes and improve their quality of life.

## What is social support?

Social relationships are vital to human health, wellbeing, and survival (Holt-Lunstad, 2018). These relationships take on even greater significance when individuals are confronted with challenging situations, such as having an illness and in the context of this thesis, living with kidney disease and undergoing dialysis treatment. In such circumstances, the presence of close social ties can prove invaluable. Supportive actions from family, friends, and other close others can serve to alleviate the challenges associated with living with kidney disease. Moreover, these supportive relationships can play a crucial role in enhancing the patient's ability to cope with their condition and its treatment demands.

Social support can be defined in two primary ways. First, it refers to the extent to which close others help during times of need, encompassing emotional, informational, and instrumental help (Tay et al., 2013; Uchino et al., 1996). Alternatively, it can be understood as the degree of an individual's social integration within their community (Berkman et al., 2000). The impact of social support on both physical and mental health outcomes is extensively documented in the literature, making it one of the most thoroughly researched psychosocial factors (Berkman et al., 2000; Cohen, 1988; Harandi et al., 2017; Reblin & Uchino, 2008; Smith et al., 1994).

### ***Social support and physical health outcomes***

Research consistently demonstrates a strong link between social support and physical health outcomes. A meta-analysis by Holt-Lunstad, Smith, and Layton (2010) examined 148 studies with over 300,000 participants across multiple continents, revealing that social support and integration were associated with a 50% reduction in mortality rates. This association remained robust across various demographic and health factors (e.g., age, sex, initial health status, cause of death). Further meta-analyses have explored the biological mechanisms underlying this relationship, focusing on inflammatory cytokines (Kiecolt-Glaser, Gouin, & Hantsoo, 2010; Uchino et al., 2018). These studies consistently show that positive social relationships are associated with lower inflammation levels, decreased chronic illness risk, and reduced mortality risk. The protective effect of supportive interactions is believed to operate through stress buffering mechanisms, leading to lower stress hormone levels and reduced inflammatory markers (Kiecolt-Glaser, Gouin, & Hantsoo, 2010; Uchino et al., 2018). Social support's influence extends to a wide range of health conditions, including cardiovascular health (Yang, Boen & Harris, 2015), management of chronic pain conditions (Hughes et al., 2014; Jaremka et al., 2014), and cancer outcomes and progression (Hughes et al., 2014; Pinquart & Duberstein, 2010). Beyond direct health outcomes, social support significantly impacts health-promoting behaviours. Individuals with higher levels of perceived support are more likely to engage in regular physical activity (Rackow, Scholz & Hornung, 2015; Rieger et al., 2018), adhere to medication regimens (Magrin et al., 2015; Wu et al., 2013), maintain healthy eating patterns (Karfopoulou et al., 2016; Rieger et al., 2018), and reduced smoking and alcohol consumption (Stewart, Gabriele & Fisher, 2012). These findings collectively highlight the extensive role of social support on physical health, encompassing both acute and chronic conditions, as well as its role in fostering and maintaining health-promoting behaviours.

### ***Social support and mental health outcomes***

There is compelling evidence that social support has beneficial influences on psychological and mental health outcomes. For example, research has consistently shown that social support is associated with improved quality of life in individuals with chronic illnesses such as cancer (Waters et al., 2013), HIV (Bekele, Rourke, et al., 2013; McDowell and Serovich, 2007), and multiple sclerosis (De Maria et al., 2020; Gil-González et al., 2020; Vogel et al., 2012). Additionally, social support has been found to play a crucial role in mitigating the effects of post-traumatic stress disorder (PTSD). Two recent meta-analyses, incorporating both cross-sectional and longitudinal studies, conducted by Zalta et al. (2021) and Wang et al. (2021), demonstrated a significant inverse relationship between social support and PTSD symptoms. Their findings consistently revealed that individuals with higher levels of social support experienced lower levels of PTSD symptoms. Similarly, inadequate social support has been linked to worse outcomes in depression, including symptom severity and recovery rates (Backs-Dermott et al., 2010; Gariepy et al., 2016; Hybels et al., 2016). Additionally, cross-sectional studies have consistently shown a positive association between social support quality and self-esteem (Luciano & Orth, 2017; Neff & Geers, 2013).

### *Social support and treatment adherence in patients on dialysis*

Social support from close others such as family, friends, and neighbours plays a crucial role in helping patients on dialysis to achieve seemingly unattainable goals like fluid adherence (Feeney & Collins, 2014; Fitzsimons & Fishbach, 2010), and stress management (Baay et al., 2019; Thong et al., 2007). Research has linked social support to reduced mortality rates, fewer hospitalisations (Kallenberg et al., 2016; Porter et al., 2016; Untas et al., 2011), and improved quality of life (Alexopoulou et al., 2016). Instrumental support, such as meal preparation, transportation, and treatment reminders are vital components of this support (Whitehead et al., 2018). Studies consistently show positive links between social support and enhanced self-management behaviours among patients on dialysis, including improved self-care behaviours, treatment adherence, and psychological wellbeing (Chen et al., 2018; Dinh & Bonner, 2023; Song et al., 2022; Noviana & Zahra, 2022; Silva et al., 2016; Sousa et al., 2019; Harandi et al., 2017; Patel et al., 2005). Given the significant demands of dialysis, fostering supportive environments is essential for effective treatment management and overall health maintenance.

## Regulatory support and giving the help that is needed

A crucial function of close relationships is the provision of social support during challenging times. However, the efficacy of this support is largely dependent on how well it aligns with the patient's specific needs. It is important to recognise that despite the well-meaning intentions of those offering support, the assistance provided may not always be appropriate or beneficial. The effectiveness of social support is not solely determined by its presence, but rather by its relevance and suitability to the patient's unique circumstances.

Paradoxically, support that is misaligned with the patient's needs can have detrimental effects on their wellbeing (e.g., Gable et al., 2012; Marigold et al., 2014; Uchino, 2009). This mismatch between provided support and actual needs can inadvertently compromise the patient's capacity to effectively manage their condition (e.g., Bolger & Amarel, 2007; Bolger et al., 2000). Such ineffective support, despite being well-intentioned, may create additional stress or feelings of inadequacy, potentially exacerbating the challenges already faced by the patient.

Guided by a new concept of social support – Regulatory Effectiveness of Support (RES. Zee et al., 2020) – this study explored how support that addresses self-regulatory needs influences self-reported fluid management among patients on dialysis. RES posits that social support is most effective when it addresses patients' dual needs of understanding and managing their situation. This concept is rooted in the premise that individuals experiencing an illness have two fundamental self-regulatory needs: the need for truth (understanding their circumstances) and the need for control (managing these circumstances). According to RES, support that addresses both truth and control needs is not only more effective but also promotes enhanced patient wellbeing, reduced negative affect, improved coping strategies, and increased resilience. The efficacy of support is further influenced by several factors, including the nature of the relationship between the support provider and recipient, the timing of support, the recipient's responsiveness, and their regulatory focus. Importantly, the theory suggests that individuals with a promotion focus (oriented towards gains and advancement) benefit more from support that emphasises understanding, while those with a prevention focus (oriented towards safety and security) derive greater benefit from support that emphasises management strategies. This framework provides a new lens through which to examine and understand the complex dynamics of social support in the context of fluid management among patients on dialysis, potentially offering insights into more effective support strategies.

In this context, for patients undergoing dialysis, receiving support that addresses their self-regulatory needs by promoting both understanding (truth) and confidence in disease management (control) will experience improved self-regulation outcomes. These improvements include better emotional regulation, increased motivation, and a higher likelihood of achieving goals such as adhering to fluid restrictions. Evidence supports the importance of these truth and control facets. Studies show that a patient's understanding of their illness (truth) can be significantly shaped by information and perspectives provided by their support network. Similarly, effective support can bolster patients' confidence or self-efficacy, thereby enhancing their perceived control over disease management (Bolger & Amarel, 2007; Zee et al., 2020). These findings suggest that to foster effective support and promote self-regulation, patients need assistance in better understanding their illness and feeling capable of managing it, while also considering individual differences in regulatory focus.

## Current study

Given that socially integrated individuals with supportive relationships tend to experience better wellbeing, higher quality of life, lower rates of mortality and hospitalisation (e.g., Cohen, 2004; Mapes et al., 2003; Holt-Lunstad & Smith, 2012), it is crucial to explore how social support impacts health outcomes in patients on dialysis, whose treatment necessitates frequent interactions with various individuals. Additionally, since self-regulation is vital in effectively managing kidney disease, social support addressing self-regulatory needs in illness management may be particularly crucial for disease management outcomes. Understanding the provision of support matching the self-regulatory needs of patients on dialysis is essential in helping them to not only understand their disease but also actively engage in and achieve their goals. Consequently, this study had four hypotheses.

First, it was hypothesised that regulatory support (RS: truth and control) will be positively associated with self-reported fluid management.

Second, we were interested in whether or not different social support targets including family, friends and neighbours, other patients on dialysis, and the kidney healthcare team were more beneficial in enhancing fluid management. Previous research suggests that social support is more beneficial the more instrumental people are in patients’ lives (e.g., Uchino et al., 1996). Therefore, it was anticipated that regulatory support from family, followed by friends and neighbours, would be more strongly associated with fluid management than other support targets. However, shared knowledge among patients on dialysis and the healthcare team could make their regulatory support beneficial in other ways.

Third, we were interested in identifying the mechanisms through which effective regulatory support influences fluid management because these exact mechanisms in relation to kidney disease remains unclear (e.g., Cohen et al., 2007). Consequently, it was proposed that self-efficacy, self-monitoring, and commitment to disease management were vital mechanisms through which regulatory support influences self-reported fluid management and would be positively associated with regulatory support.

Self-efficacy, defined as the belief in one's ability to perform a specific behaviour or task successfully, is essential for adherence in patients with kidney disease (Bandura, 1986; Finnegan-John & Thomas, 2013). Thus, it was hypothesised that the association between regulatory support and IDWG may be through the indirect effect of self-efficacy. Further we explored whether this indirect effect was due to a specific type of regulatory support (truth vs. control), hypothesising that the indirect effect of self-efficacy is likely to be stronger for regulatory support that helps people feel like they can manage their illness (control).

Fourth, because self-monitoring is known to facilitate behaviour change and its maintenance (Harkin et al., 2016; Wilkowski & Ferguson, 2016), it was predicted that the association between regulatory support and IDWG would be mediated by the indirect effects of self-monitoring.

Finally, because intention (or commitment) plays a significant role in driving health behaviour change and maintenance (e.g., Ajzen, 1991; Eccles et al., 2006), it was hypothesised that the association between regulatory support and fluid management would be mediated by patients' commitment to disease management.

# Study 4

# Method

## Design and sample

Using a cross-sectional survey; convenience and snowball sampling techniques were employed to recruit a total of 225 patients on dialysis aged 18 and over (98 males, 127 females, $M_{age}$ = 54.69 years, $SD_{age}$ = 10.93). They were recruited from various Facebook kidney support groups (e.g., Chronic Kidney Disease UK, Kidney Research UK), Dialysis centres in Nigeria (e.g., Kidney Global) and emails, between March and May 2024. Ethical approval was obtained from the University of Essex Ethics Sub-Committee 1 (ETH2324-0524), and the study was pre-registered on OSF (https://osf.io/5u4kg/?view_only).

The study was administered anonymously online using Qualtrics software (Provo, UT). Patients were told that we were interested in their views on how they managed their kidney disease and the role of others in their management. They were not allowed to skip questions, and participation was voluntary, with informed consent obtained before beginning the measures. The sample size was calculated using G*power 3.1 which indicated that a sample size of 107 would provide 95% power (1-beta = 0.95) to detect a medium effect size of .15 with a type 1 error rate (α) of 0.05.

## Measures

### *Demographic and clinical information*

Patients provided information on age, gender, nationality, ethnicity, employment status, educational level, relationship status, occupational status, income, country of residence (including postcode if residing in the United Kingdom), social network density, chronic kidney disease (CKD) stage, estimated glomerular filtration rate (eGFR) transplant eligibility, and comorbidities. Following the demographics questionnaire, patients completed the following measures:

### ***Independent variable***

Regulatory support was measured using the Regulatory Effectiveness of Support scale (Zee et al., 2020). This scale was evaluated across four relationship targets: family (including romantic partners), friends and neighbours, other patients on dialysis, and the kidney healthcare team. The scale assessed two facets: truth and control, each measured by three items per support facet. Truth items evaluated understanding of kidney disease management across the four relationship targets (e.g., "The help my [family, friends, etc.] gives me leaves me with a better understanding of how to manage my kidney disease"). Control items assessed assistance in disease management across the four relationship targets (e.g., "The help my [healthcare team, other patients on dialysis, etc.] gives me helps me to stay on track with managing my kidney disease"). Responses were recorded on a 6-point Likert-type scale (1 = strongly disagree, 6 = strongly agree), with higher scores indicating greater regulatory support. Subscale scores were calculated by averaging the three items for truth and control separately. An overall regulatory support score for each support target was computed by averaging all six items. Additionally, scores were aggregated across all four relationship targets to create an index of overall regulatory support, as well as separate scores for total truth and total control. The alpha reliability for the truth facet was α = .92 and control facet was α = .80. The Cronbach’s alphas for the four support targets were as follows: Family truth (.93), Family control (.97), Friends and neighbours’ truth (.97), Friends and neighbours’ control (.98), Other dialysis patients’ truth (.96), Other dialysis patients’ control (.97), Healthcare team truth(.92), and Healthcare team control (.96).

To mitigate potential order effects, the presentation of regulatory support target question blocks was randomised across patients. This meant that the sequence in which patients were asked about receiving regulatory support from different relationship targets (such as friends, family, healthcare team, or other patients on dialysis) varied from one respondent to another. For instance, one patient might first encounter questions about regulatory support from friends, while another might begin with questions about support from their healthcare team.

### *Dependent variables*

Self-reported fluid management (IDWG) was measured using 10-items (e.g., "In general, I keep my dry weight within the target range set for me) and were answered on 6-point Likert-type scale (1 = strongly disagree, 6 = strongly agree). Items were averaged, and higher scores reflected greater self-reported fluid management. The alpha reliability was α = .91.

Self-efficacy was measured using a 12-item measure (e.g., "I feel confident I can manage my kidney disease") and were answered on 6-point Likert-type scale (1 = strongly disagree, 6 = strongly agree). Items were averaged, and higher scores indicated greater self-efficacy. The Cronbach alpha was α = .95.

Self-monitoring was assessed using an 8-item measure (e.g., "I weigh myself at home using a scale") and rated on 5-point Likert-type scale (1 = never, 5 = frequently). Items were averaged with higher scores reflecting greater self-monitoring. The Cronbach alpha was α = .71.

Commitment to disease management was measured with a 4-item measure (e.g., "I am committed to sticking to my fluid allowance") and were answered on 6-point Likert-type scale (1 = strongly disagree, 6 = strongly agree). Items were averaged with higher scores indicating greater commitment to disease management. The scales for the dependent variables were created from qualitative studies involving patients on dialysis, focusing on their experiences with kidney disease and their attitudes toward self-regulation (as detailed in Chapters 3 and 4). The Cronbach alpha was $\alpha = .94$.

### ***Measures of control variables***

To ensure a more accurate estimation of regulatory supports unique contribution on fluid management, several control variables were incorporated into the regression models. These included demographic characteristics such as age, gender, and nationality, as well as measures of relationship satisfaction, and supportive and strained exchanges (Walen & Lachman, 2000). The inclusion of these variables was based on their well-established associations with both physical health and psychological wellbeing. Nationalities were categorised into geographical regions: the Global North (Germany, Slovakia, Spain, the UK, and the USA) and the Global South (Ghana, India, Nigeria, and the Philippines).

Social Support and Strain (SSS) contained eight items scored on 6-point Likert-type scale ranging from 1 (strongly disagree) to 6 (strongly agree). Items were adapted to suit patients on dialysis. Supportive network exchanges were measured through four items (e.g., “My family understand the way I feel about things”) and strained network exchanges are measured through four parallel items (e.g., “My family often criticise me”).

Relationship satisfaction was measured with a single question created for the study. This question was: “I am satisfied with the relationship I have with my kidney healthcare team.” It was scored on a 6-point Likert-type scale ranging from 1 (extremely unsatisfied) to 6 (extremely satisfied). Both relationship satisfaction and support and strain were measured for four relationship groups: family (including partners), friends and neighbours, other dialysis patients and kidney healthcare team.

### *Measures of mental health*

To gain insight into the overall mental health status and emotional functioning of the patients, data on mental health were collected. Anxiety and depression were assessed using the Hospital Anxiety and Depression Scale ([HADS] Zigmond & Snaith, 1983), a 14-item scale that evaluates emotional and cognitive aspects of both conditions. The scale includes seven items for anxiety (e.g., “I feel tense or wound up”) and seven for depression (e.g., “I still enjoy the things I used to enjoy”), with each item rated from 0 to 3 based on symptom intensity or frequency. The total score for the scale, reflecting overall emotional distress, ranges from 0 to 42, with higher scores indicating greater distress. The alpha reliability for the anxiety subscale is $\alpha = .82$, $\alpha = .77$ for depression, and $\alpha = .86$ for combined scores.

Loneliness was measured using the three-item UCLA Loneliness scale (Hughes et al., 2004). The scale comprises of three dimensions of loneliness: relational connectedness, social connectedness, and self-perceived isolation. The three items are: (i) I often feel that I lack companionship, (ii) I often feel left out, and (iii) I often feel isolated from others. All items are scored on a 6-point Likert-type scale ranging from 1 (strongly disagree) to 6 (strongly agree). The alpha reliability ranges from $\alpha = .89$ to $\alpha = .94$.

A copy of the full study questionnaire is provided in Appendix D.

## Data analysis

Statistical analyses were conducted in R version 4.2.3 (R Core Team, 2023) implementing mixed models with the *Psych* (Revelle & Revelle, 2015), *Mediation* (Tingley et al., 2013), *Stat* and *Lavaan* (Rosseel, 2012) packages. Descriptive statistics, Pearson correlations and Cronbach’s alpha were conducted to assess the internal consistency of the scales. Scores were calculated by averaging item responses following any reverse scoring for each dimension with a Holm-Bonferroni (Holm, 1979) correction used to control family-wise error rate. A *p*-value of less than 0.05 was deemed significant and Cronbach alpha with coefficients above .70 required for acceptability (Polit & Beck, 2008). The strength of correlations was interpreted as follows: very strong (0.90 to 1.00 or -0.90 to -1.00), strong (0.70 to 0.90 or -0.70 to -0.90), moderate (0.50 to 0.70 or -0.50 to -0.70), weak (0.30 to 0.50 or -0.30 to -0.50), and negligible (0.00 to 0.30 or 0.00 to -0.30) (Hinkle et al., 2003; Mukaka, 2012).

### ***Regression analyses***

To test against the main research question regarding the association between self-reported fluid management and regulatory support, separate linear, multiple, and hierarchical regression analyses were conducted. In subsequent models, we examined whether the association was better explained by one of the regulatory support facets (truth or control), and whether these effects varied depending on the support target (e.g., family, friends). In the individual regression analyses, the demographic variables of sex, age and global region were entered as covariates to control for their predictive value on predictor variables. Further, interaction terms related to demographics variables (e.g., geographical regions) and other social support measures (e.g., relationship satisfaction) were entered in follow-up models.

### ***Mediation analyses***

Mediation analyses were conducted using 10,000 sample bootstrapping to estimate the indirect effects of self-efficacy, self-monitoring, and commitment to disease management on the association between regulatory support and fluid management.

### ***Exploratory analyses***

Additional analyses were conducted to examine the relationship between nationality and self-reported fluid management, the mental health scales (HADS and loneliness) and self-reported fluid management. The study also examined how age and global region related to emotional distress. Furthermore, it investigated the effects of age, sex, and global region on social network density.

# Results

Patients on average, reported a high level of effective regulatory support from their social network, (*M* = 4.94, *SD* = 1.26). Similarly, patients indicated a strong perception of their own fluid management, ( *M* = 5.02, *SD* = 1.20). These findings suggest that, overall, patients felt well supported by their social network in ways that addressed their regulatory needs, and they also maintained a positive view of their capacity to manage their fluid intake effectively.

## Sociodemographic characteristics

The final analysis included 225 participants aged between 25 to 76 ($M_{age}$ = 59.46, $SD_{age}$ = 10.93), comprising 98 men (43.56%) and 127 women (56.44%). Of these, 145 (64.44%) were from Global South, 80 (35.56%) from Global North, 207 (92.00%) were on haemodialysis, and 18 (8%) were on peritoneal dialysis. Additionally, 41 (18.22%) had diabetes mellitus, 80 (35.56%) were employed full-time, 114 (50.67%) were engaged, 143 (63.56%) lived with romantic partners and/or family members, 118 (52.44%) had education up to college or university level, and 192 (85.33 %) earned below £36,000. Participant characteristics are summarised below in Table 12.

**Table 12**
*Participants demographic information (n=225)*

| **Variables** | | ***N* (%)** | **Mean (*SD*)** |
|---|---|---|---|
| **Age** | | | 54.69 (10.93) |
| **Sex** | Male | 98 (43.56 %) | |
| | Female | 127 (56.44 %) | |
| **Relationship Status** | Single | 27 (11.49 %) | |
| | Casually dating | 1 (0.43 %) | |
| | Exclusively dating | 18 (7.66 %) | |
| | Engaged | 114 (50.67 %) | |
| | Married | 48 (21.33 %) | |
| | Widowed | 17 (7.56 %) | |
| **Nationality** | Germany | 1 (0.43 %) | |
| | Ghana | 1 (0.43 %) | |
| | India | 1 (0.43 %) | |
| | Nigeria | 141 (63.11 %) | |
| | Philippines | 1 (0.43 %) | |
| | Slovakia | 1 (0.43 %) | |
| | Spain | 1 (0.43 %) | |

| | | |
|---|---|---|
| | UK | 54 (24.00 %) |
| | USA | 23 (10.22 %) |
| **Ethnicity** | Asian | 5 (2.22 %) |
| | Black | 146 (64.80 %) |
| | Mixed/Multiple Ethnic groups | 1 (0.43 %) |
| | Other | 1 (0.43 %) |
| | White | 72 (32.00 %) |
| **Educational Attainment** | Secondary school up to 16 years | 1 (0.43 %) |
| | Higher or further education (A-levels, BTEC, etc.) | 57 (25.33 %) |
| | Apprenticeships | 5 (2.22 %) |
| | College or university | 118 (52.44 %) |
| | Postgraduate | 15 (6.67 %) |
| | Specialist training | 11 (4.89 %) |
| | Other | 5 (2.22 %) |
| **Employment Status** | Disabled, unable to work | 2 (0.89 %) |
| | Full-time but sick leave | 2 (0.89 %) |
| | Full-time employment | 80 (35.56 %) |
| | Looking after home and family | 17 (7.56 %) |
| | Not working due to health issues | 5 (2.22 %) |
| | Part-time employment | 51 (22.67 %) |
| | Retired | 50 (22.22 %) |
| | Unemployed | 17 (7.56 %) |
| | Self-employed | 1 (0.43 %) |
| **Living Situation** | Alone | 14 (6.22 %) |
| | Romantic partner and/or family members | 143 (63.56 %) |
| | Unrelated people/ shared accommodation | 68 (30.22 %) |
| **Gross Monthly Income** | Under £35,999/ $36,809USD | 192 (85.33 %) |
| | £36,000-£89,999/ $50,968USD to $127,420USD | 24 (10.67 %) |
| | Over £90,000/ $127,421USD | 9 (4.00 %) |

## Correlational analysis

To examine the relations between all independent and dependent variables, a correlation matrix with Pearson correlations was produced (see Table 13). The analysis revealed strong positive correlations ($r > .90$, $p < .001$) between self-efficacy and intentions, regulatory support with control and truth regulatory support, and between control and truth regulatory support. Moderate to strong positive correlations ($r = .60$ to $.80$, $p < .001$) were observed between self-efficacy and various support measures, and between supportive exchanges and most other variables. Self-monitoring showed weak negative correlations with most variables, some not reaching statistical significance. Most correlations were statistically significant ($p < .001$), except for some involving self-monitoring.

**Table 13**

*Bivariate correlations between measures, their mean, standard deviations, and observed range in the sample*

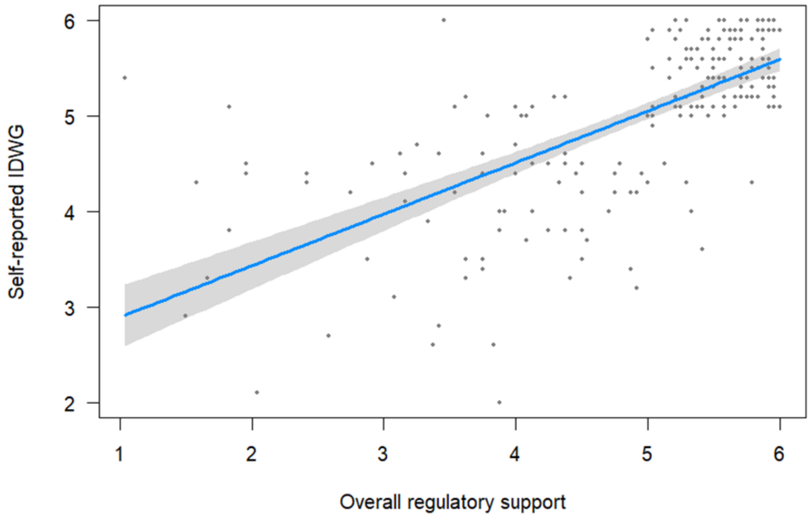
| **Variables** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **11** | **12** | **13** | **14** | **15** | **16** | **17** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Self-efficacy | 1.00 | | | | | | | | | | | | | | | | |
| 2. Commitment | 0.81$^{**}$ | 1.00 | | | | | | | | | | | | | | | |
| 3. Self-monitoring | -0.12 | -0.09 | 1.00 | | | | | | | | | | | | | | |
| 4. Total supportive exchanges | 0.76$^{**}$ | 0.67$^{**}$ | -0.23$^{**}$ | 1.00 | | | | | | | | | | | | | |
| 5. Total strained exchanges | 0.57$^{**}$ | 0.48$^{**}$ | -0.45$^{**}$ | 0.73$^{**}$ | 1.00 | | | | | | | | | | | | |
| 6. Fluid management (IDWG) | 0.77$^{**}$ | 0.73$^{**}$ | -0.22$^{**}$ | 0.70$^{**}$ | 0.73$^{**}$ | 1.00 | | | | | | | | | | | |
| 7. Overall RS | 0.68$^{**}$ | 0.61$^{**}$ | -0.18$^{**}$ | 0.92$^{**}$ | 0.72$^{**}$ | 0.67$^{**}$ | 1.00 | | | | | | | | | | |
| 8. RS control facet | 0.67$^{**}$ | 0.60$^{**}$ | -0.17$^{**}$ | 0.92$^{**}$ | 0.70$^{**}$ | 0.65$^{**}$ | 0.99$^{**}$ | 1.00 | | | | | | | | | |
| 9. RS truth facet | 0.67$^{**}$ | 0.60$^{**}$ | -0.19$^{**}$ | 0.92$^{**}$ | 0.72$^{**}$ | 0.67$^{**}$ | 0.99$^{**}$ | 0.97$^{**}$ | 1.00 | | | | | | | | |
| 10. Family truth | 0.64$^{**}$ | 0.60$^{**}$ | -0.06$^{**}$ | 0.80$^{**}$ | 0.57$^{**}$ | 0.66$^{**}$ | 0.86$^{**}$ | 0.83$^{**}$ | 0.87$^{**}$ | 1.00 | | | | | | | |
| 11. Family control | 0.65$^{**}$ | 0.60$^{**}$ | -0.06 | 0.81$^{**}$ | 0.53$^{**}$ | 0.59$^{**}$ | 0.87$^{**}$ | 0.88$^{**}$ | 0.85$^{**}$ | 0.90$^{**}$ | 1.00 | | | | | | |
| 12. FN truth | 0.65$^{**}$ | 0.54$^{**}$ | -0.22$^{**}$ | 0.88$^{**}$ | 0.75$^{**}$ | 0.66$^{**}$ | 0.93$^{**}$ | 0.91$^{**}$ | 0.93$^{**}$ | 0.77$^{**}$ | 0.76$^{**}$ | 1.00 | | | | | |
| 13. FN control | 0.62$^{**}$ | 0.53$^{**}$ | -0.17$^{**}$ | 0.85$^{**}$ | 0.70$^{**}$ | 0.63$^{**}$ | 0.92$^{**}$ | 0.93$^{**}$ | 0.90$^{**}$ | 0.76$^{**}$ | 0.77$^{**}$ | 0.94$^{**}$ | 1.00 | | | | |
| 14. OPD truth | 0.45$^{**}$ | 0.44$^{**}$ | -0.23$^{**}$ | 0.71$^{**}$ | 0.63$^{**}$ | 0.50$^{**}$ | 0.83$^{**}$ | 0.81$^{**}$ | 0.85$^{**}$ | 0.62$^{**}$ | 0.63$^{**}$ | 0.74$^{**}$ | 0.69$^{**}$ | 1.00 | | | |
| 15. OPD control | 0.50$^{**}$ | 0.46$^{**}$ | -0.23$^{**}$ | 0.79$^{**}$ | 0.68$^{**}$ | 0.56$^{**}$ | 0.88$^{**}$ | 0.87$^{**}$ | 0.88$^{**}$ | 0.67$^{**}$ | 0.68$^{**}$ | 0.80$^{**}$ | 0.74$^{**}$ | 0.94$^{**}$ | 1.00 | | |
| 16. HT truth | 0.58$^{**}$ | 0.51$^{**}$ | -0.12 | 0.79$^{**}$ | 0.53$^{**}$ | 0.49$^{**}$ | 0.81$^{**}$ | 0.80$^{**}$ | 0.81$^{**}$ | 0.60$^{**}$ | 0.63$^{**}$ | 0.68$^{**}$ | 0.69$^{**}$ | 0.61$^{**}$ | 0.65$^{**}$ | 1.00 | |
| 17. HT control | 0.57$^{**}$ | 0.51$^{**}$ | -0.15$^{**}$ | 0.77$^{**}$ | 0.53$^{**}$ | 0.49$^{**}$ | 0.80$^{**}$ | 0.81$^{**}$ | 0.75$^{**}$ | 0.54$^{**}$ | 0.60$^{**}$ | 0.67$^{**}$ | 0.70$^{**}$ | 0.57$^{**}$ | 0.63$^{**}$ | 0.89$^{**}$ | 1.00 |
| *18. M* | 5.11 | 5.24 | 2.25 | 5.20 | 4.50 | 5.02 | 4.94 | 4.87 | 4.94 | 4.85 | 5.08 | 4.60 | 4.77 | 4.92 | 4.97 | 5.11 | 5.23 |
| *19. SD* | 1.08 | 0.87 | 1.19 | 1.12 | 1.82 | 1.20 | 1.26 | 1.26 | 1.26 | 1.30 | 1.27 | 1.54 | 1.48 | 1.13 | 1.21 | 0.96 | 1.00 |
| *20. Range* | 1-6 | 1-6 | 1-5 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1-6 | 1.3-6 | 1-6 |

*Notes.* N= 225 for all correlations. * *p* < .05, ***p* < .01. RS = Regulatory support, IDWG = Interdialytic weight gain which is a measure of patients' fluid management. FN = friends and neighbours, OPD = other patients on dialysis, HT = healthcare team, *M* = Mean, *SD* = standard deviation.

## Primary analyses

We hypothesised that regulatory support would be positively associated with self-reported fluid management. Further, we anticipated that regulatory support from family, followed by friends and neighbours, would be more strongly associated with fluid management than other support targets. Regression analyses without the addition of covariates were used to predict these associations. As hypothesised, there was a significant positive relationship between regulatory support and fluid management ($b = 0.54$, $SE = 0.04$, $t(223) = 13.42$, $p < .001$). Higher levels of regulatory support were associated with better fluid management (Figure 6). As hypothesised, hierarchical regression analysis indicated that family regulatory support had the strongest influence on fluid management ($b = 0.44$, $SE = 0.04$, $t(223) = 12.50$, $p < .001$) and this model significantly predicted fluid management ($R^2 = .41$, $F(1, 223) = 156.2$, $p < .001$). When friends and neighbours were added in the second model, the model continued to significantly predict fluid management ($R^2 = .47$, $F(2, 222) = 97.92$, $p < .001$). Both family ($b = 0.23$, $SE = 0.06$, $t(222) = 4.14$, $p < .001$), and friends and neighbours ($b = 0.23$, $SE = 0.05$, $t(222) = 4.87$, $p < .001$) were significant predictors of fluid management. However, including other patients on dialysis ($b = 0.03$, $SE = 0.06$, $t(221) = 0.50$, $p = 0.62$) and healthcare team ($b = 0.03$, $SE = 0.07$, $t(220) = 0.50$, $p = 0.62$) in subsequent models did not significantly enhance the prediction of fluid management (Table 14).

**Figure 6**
*Association between regulatory support and self-reported fluid management*



*Notes.* Shading shows 95% confidence interval. IDWG = Interdialytic weight gain which is a measure of patients' fluid management.

**Table 14**
*Regression coefficients and model summaries for regulatory support target predicting fluid adherence*

| **Model** | **Regulatory support target** | ***b (SE)*** | $R^2$ | **Adj.** $R^2$ | $\Delta R^2$ | $F$ | $\Delta F$ | $p$ |
|---|---|---|---|---|---|---|---|---|
| 1 | Family | .44 (.04)$^{***}$ | 0.41 | 0.41 | - | 156.20 | - | <.001 |
| 2 | Family,<br>Friends/Neighbours | .23 (.06),<br>.23 (.05) | 0.47 | 0.46 | 0.06$^{***}$ | 97.92 | 23.72$^{***}$ | <.001 |
| 3 | Family,<br>Friends/Neighbours,<br>Other patients on dialysis | .22 (.06),<br>.21 (.05),<br>.03 (.06) | 0.47 | 0.46 | 0.00 | 65.15 | .25 | .62 |
| 4 | Family,<br>Friends/Neighbours,<br>Other patients on dialysis, Healthcare Team | .22 (.06),<br>.20 (.06),<br>.02 (.06),<br>.03 (.07) | 0.47 | 0.46 | 0.00 | 48.76 | .25 | .62 |

*Notes.* $R^2$ and Adjusted $R^2$ have been rounded up to two decimal places. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. Changes in R-squared ($\Delta R^2$) and F-statistic ($\Delta F$) for each model.

## Mediation analyses

In order to understand the possible mechanisms through which regulatory support contributes to fluid management, mediation analyses were conducted using 10,000 bootstrap samples. As hypothesised, regulatory support was positively associated with self-efficacy ($r$ = 0.77), and the association between regulatory support and fluid management was mediated by self-efficacy. The indirect effect of regulatory support on fluid management through self-efficacy was examined (Figure 7). The direct effect model (c') was significant, $F(2, 222) = 194.2$, $p < .001$, explaining 64% of the variance ($R^2 = 0.64$). Regulatory support had a significant direct influence on fluid management ($b = 0.54$, $SE = 0.04$, $t(223) = 13.42$, $p < .001$), which remained significant but reduced when controlling for self-efficacy ($b = 0.22$, $SE = 0.04$, $t(222) = 4.91$, $p < .001$). Bootstrap analyses indicated significant indirect effects of regulatory support on fluid management through self-efficacy ($b = 0.32$, $SE = 0.06$, 95% CI [0.22, 0.44]). Further analysis investigated whether this indirect effect was specific to a particular type of regulatory support (truth vs. control), with the hypothesis that the indirect effect of self-efficacy would be stronger for regulatory support that helps patients feel they can manage their illness (control). Self-efficacy partially mediated the relationship between both types of regulatory support (control and truth) and fluid management. The indirect effect of self-efficacy was slightly stronger for control regulatory support ($b = 0.33$, $SE = 0.06$, 95% CI [0.22, 0.44]) compared to truth regulatory support ($b = 0.32$, $SE = 0.06$, 95% CI [0.21, 0.43]). Despite the slight difference, both indirect effects were substantial, highlighting the important role of self-efficacy in mediating these relationships.

We predicted that regulatory support would be positively associated with self-monitoring, and that the association between regulatory support and fluid management would be mediated by self-monitoring. Contrary to our prediction, self-monitoring was negatively correlated with fluid management ($r = -0.22$). Furthermore, bootstrap analyses revealed no significant indirect effects of regulatory support on fluid management through self-monitoring ($b = 0.01$, $SE = 0.02$, 95% CI [0.00, 0.04]; see Figure 8). Comparison of the bootstrapped indirect effects of truth and control on fluid management through self-monitoring showed minimal and insignificant results for both types of regulatory support:

truth (*b* = 0.02, *SE* = 0.01, 95% CI [0.00, 0.04]) and control (*b* = 0.02, *SE* = 0.01, 95% CI [0.00, 0.04]).

Finally, as hypothesised, regulatory support showed a strong positive correlation with commitment to disease management (*r* = 0.73). The relationship between regulatory support and fluid management was mediated by commitment to disease management (Figure 9). The direct effect (c') model was statistically significant, *F*(2, 222) = 174.6, *p* < .001, explaining 61% of the variance ($R^2$ = 0.61). Regulatory support had a significant direct effect on fluid management (*b* = 0.54, *SE* = 0.04, *t*(223) =13.42, *p* < .001) which remained significant but was reduced when controlling for commitment (*b* = 0.29, *SE* = 0.04, *t*(222) = 6.85, *p* < .001). Bootstrap analyses confirmed a significant indirect effect of regulatory support on fluid management through commitment to disease management (*b* = 0.25, *SE* = 0.04, 95% CI [0.16, 0.33]). Further analysis investigated whether this indirect effect was specific to a particular type of regulatory support (truth vs. control), without an a priori hypothesis. Analysis revealed comparable indirect effects for both types of regulatory support. Truth regulated support had an indirect effect of *b* = 0.24 (*SE* = 0.04, 95% CI [0.16, 0.33]), while control regulatory support had an indirect effect of *b* = 0.25 (*SE* = 0.04, 95% CI [0.17, 0.34]).

These results suggest that both truth and control regulatory support influenced fluid management through similar pathways involving commitment to disease management.

**Figure 7A**
*Indirect effect of self-efficacy on regulatory support fluid management*

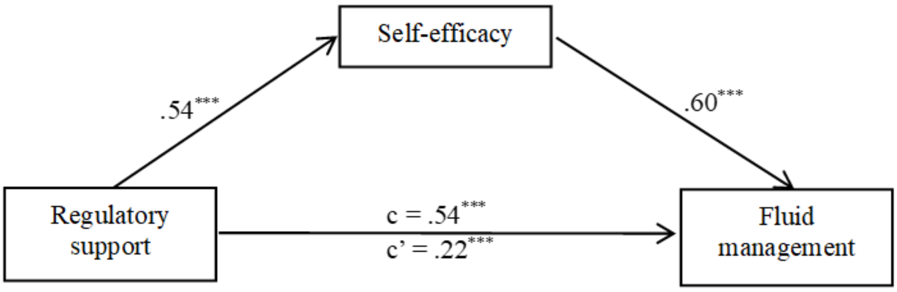


**Figure 7B**
*Indirect effect of self-efficacy on truth regulatory support and fluid management*

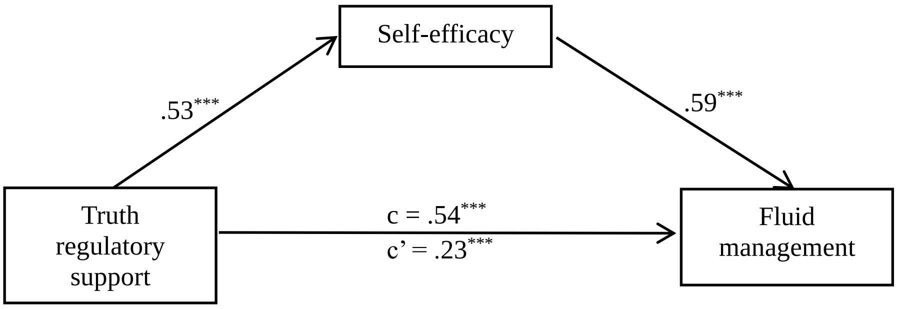
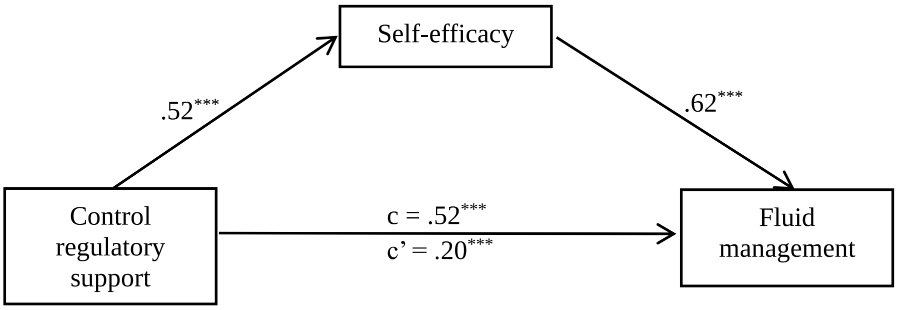


**Figure 7C**
*Indirect effect of self-efficacy on control regulatory support and fluid management*



*Notes.* *** $p < 0.001$.

**Figure 8A**

*Indirect effect of self-monitoring on regulatory support fluid management*

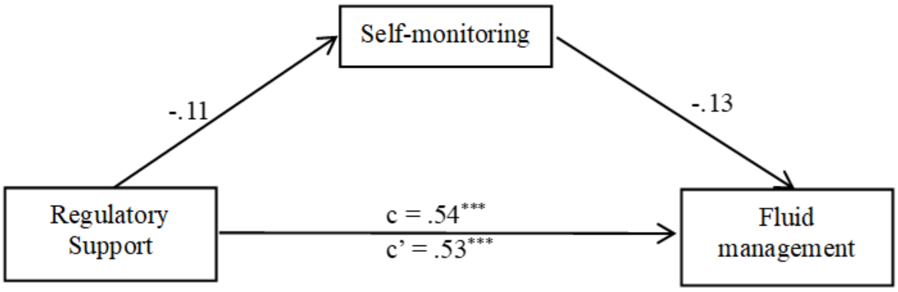


**Figure 8B**

*Indirect effect of self-monitoring on truth regulatory support and fluid management*

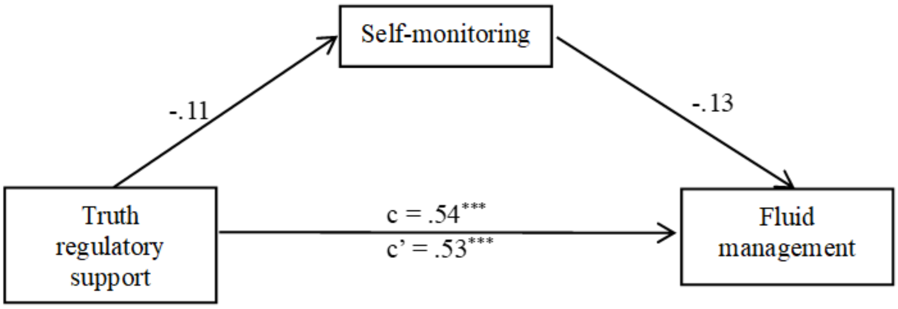
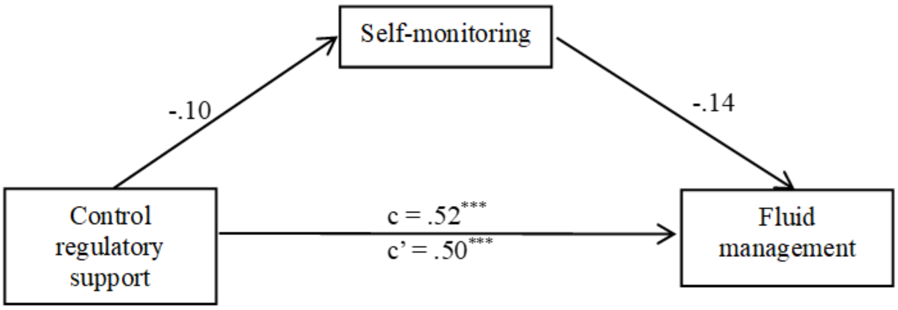


**Figure 8C**

*Indirect effect of self-monitoring on control regulatory support and fluid management*



*Notes.* *** $p < 0.001$.

**Figure 9A**
*Indirect effect of commitment to disease management on regulatory support fluid management*

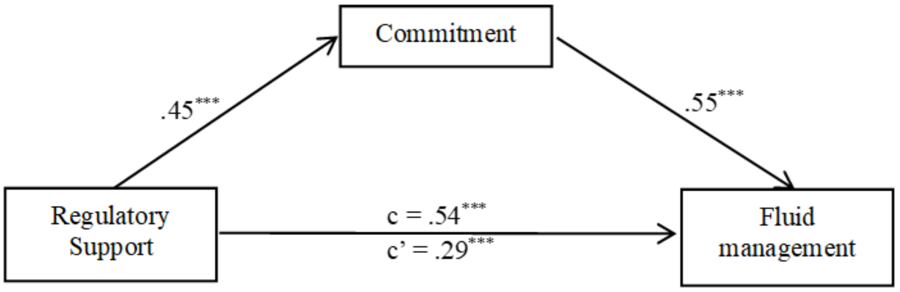


**Figure 9B**
*Indirect effect of commitment to disease management on truth regulatory support and fluid management*

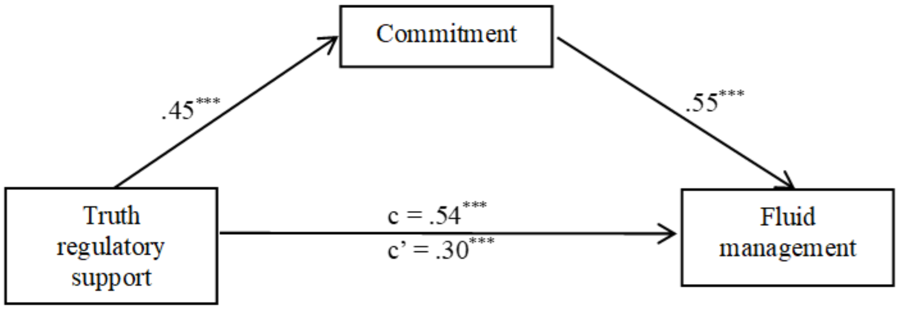
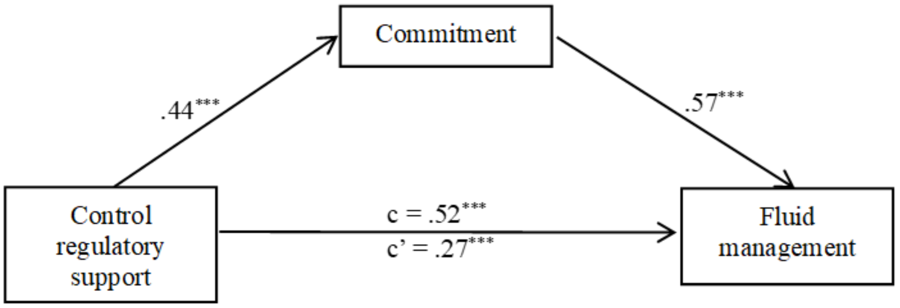


**Figure 9C**
*Indirect effect of commitment to disease management on control regulatory support and fluid management*



*Notes.* *** $p < 0.001$.

## Covariate analyses

### *Regulatory support*

Following the initial regression analyses (see page 145) finding that patients on dialysis who received support matching their regulatory needs reported improved fluid management, additional regression analyses were conducted. These models incorporated age, gender, nationality, relationship satisfaction, and both supportive and strained exchanges as covariates to control for their potential effects on the relationship between regulatory support and fluid management (Table 15). When controlling for nationality, regulatory support remained a significant predictor of fluid management (*b* = 0.15, *SE* = 0.06, *t*(222) = 2.66, *p* = .01). Global South region significantly predicted fluid management (*b* = -3.16, *SE* = 0.58, *t*(222) = -5.49, *p* < .001) and interacted with regulatory support (*b* = 0.75, *SE* = 0.11, *t*(222) = 6.71, *p* < .001). Simple slopes analyses revealed a stronger effect of regulatory support on fluid management for patients in the Global South (*b* = 0.89, *SE* = 0.10, *t*(222) = 9.35, *p* < .001) compared to the Global North (*b* = 0.15, *SE* = 0.06, *t*(222) = 2.66, *p* = .01; Figure 10A). Controlling for relationship satisfaction, regulatory support remained a significant predictor of fluid management (*b* = 0.51, *SE* = 0.05, *t*(222) = 9.40, *p* < .001). The main effect of relationship satisfaction on fluid management was not significant (*b* = 0.07, *SE* = 0.07, *t*(222) = 0.94, *p* = 0.35). When controlling for supportive and strained exchanges, regulatory support showed a marginally significant main effect (*b* = -0.33, *SE* = 0.19, *t*(219) = -1.78, *p* = .076), with its relationship to fluid management varying by level of strained exchanges. Strained exchanges demonstrated a significant main effect (*b* = -0.41, *SE* = 0.185, *t*(219) = -2.19, *p* = .030) and interacted with regulatory support (*b* = 0.12, *SE* = 0.04, *t*(219) = 3.31, *p* = 0.001). Simple slopes analysis indicated that the positive effect of regulatory support on fluid management was not significant with fewer strained exchanges (*b* = 0.13, *SE* = 0.19, *t*(219) = 12.46, *p* < .001) but significantly stronger with higher levels of strained exchanges (*b* = 0.49, *SE* = 0.17, *t*(219) = 2.75, *p* < .001; Figure 10B). Neither the interaction between regulatory support and supportive exchanges (*b* = 0.01, *SE* = 0.042, *t*(219) = 0.333, *p* = .739) nor the main effect of supportive exchanges (*b* = 0.13, *SE* = 0.188, *t*(219) = 0.678, *p* = .498) were significant.

**Table 15**

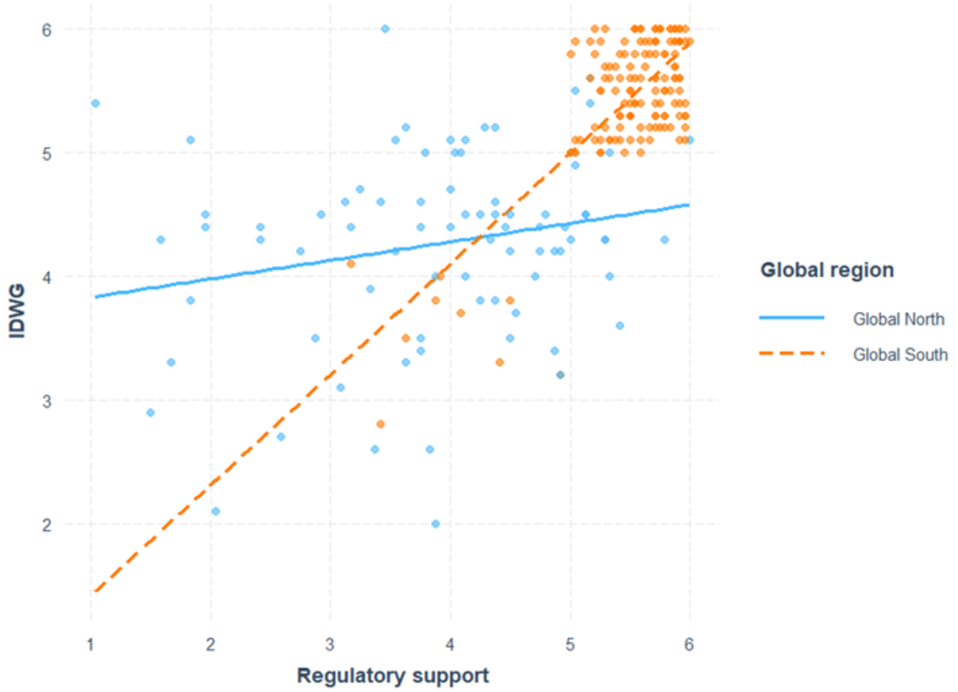
*Table of full model from the regression analysis investigating the effect of regulatory support on self-reported fluid management. Subsequent models included support and strain, relationship satisfaction, age, gender, and nationality (global region) as covariates*

| **Model** | **Variable** | ***b*** | ***SE*** | ***t*** | ***p*** | ***R²*** | ***Adj. R²*** |
|---|---|---|---|---|---|---|---|
| 1 | Regulatory Support on fluid management | 0.54 | 0.04 | 13.42 | <.001 | 0.45 | 0.44 |
| 1.1 | Regulatory Support | 0.51 | 0.05 | 9.40 | <.001 | 0.45 | 0.44 |
| | Relationship Satisfaction | 0.07 | 0.07 | 0.94 | 0.35 | | |
| 1.2 | Regulatory Support | -0.33 | 0.19 | -1.78 | 0.08 | 0.62 | 0.61 |
| | Supportive exchanges | 0.13 | 0.19 | 0.68 | 0.50 | | |
| | Strained exchanges | -0.41 | 0.19 | -2.19 | <.0.05 | | |
| | RS*Strained exchanges | 0.12 | 0.04 | 3.13 | <0.01 | | |
| 1.3 | Regulatory Support | 0.15 | 0.06 | 2.66 | 0.01 | 0.59 | 0.59 |
| | Global region (South) | -3.16 | 0.58 | -5.49 | <.001 | | |
| | Interaction | 0.75 | 0.11 | 6.71 | <.001 | | |
| 1.4 | Regulatory Support | -0.05 | 0.21 | -0.24 | 0.81 | 0.52 | 0.51 |
| | Age | -0.02 | 0.02 | -1.27 | 0.20 | | |
| | Interaction | 0.01 | 0.00 | 2.52 | 0.01 | | |
| 1.5 | Regulatory Support | 0.54 | 0.05 | 10.79 | <.001 | 0.45 | 0.44 |
| | Gender (Male) | -0.22 | 0.43 | -0.52 | 0.61 | | |
| | Interaction | 0.02 | 0.09 | 0.24 | 0.81 | | |

*Note*. N = 225.Unstanderdised beta coefficients (b). *R²* values are rounded to two decimal places. RS = Regulatory support.

**Figure 10A**

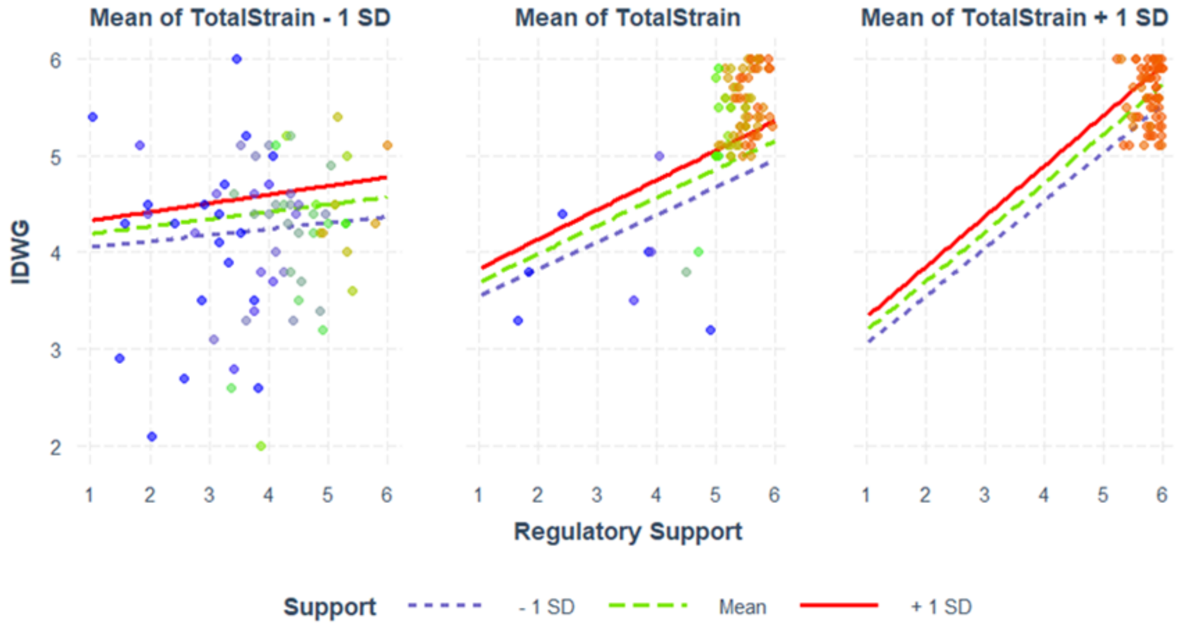
*Interaction between the effects of regulatory support and global region on self-reported fluid management*



*Notes.* IDWG = Interdialytic weight gain which is a measure of patients' fluid management.

**Figure 10B**

*Interaction between the effects of regulatory support and strained exchanges on self-reported fluid management*



*Notes.* IDWG = Interdialytic weight gain which is a measure of patients' fluid management.

### ***Regulatory support targets***

We re-ran the hierarchical multiple regression to examine the effects of the four regulatory support targets on fluid adherence controlling for age, gender, and nationality. These analyses assessed the relative contributions of different targets of regulatory support to fluid management outcomes in patients on dialysis, considering key demographic variables.

When controlling for age, family regulatory support (*b* = 0.38, *SE* = 0.04, *t*(222) = 7.33, *p* < .001), and friends and neighbours' regulatory support (*b* = 0.21, *SE* = 0.04, *t*(221) = 4.69, *p* < .001) were significant predictors of fluid management. Age itself was also a significant predictor (*b* = 0.02, *SE* = 0.00, *t*(222) = 5.31, *p* < .001). The inclusion of regulatory support from other dialysis patients and healthcare team members did not significantly improve subsequent models. When controlling for gender, family regulatory support (*b* = 0.45, *SE* = 0.04, *t*(222) = 12.68, *p* < .001), and friends and neighbours' regulatory support (*b* = 0.23, *SE* = 0.05, *t*(221) = 4.91, *p* < .001) remained significant predictors of fluid management. Regulatory support from other patients on dialysis and healthcare team members did not contribute significantly. Gender showed a trend towards significance (*b* = -0.16, *SE* = 0.09, *t*(221) = -1.90, *p* = 0.05), suggesting potential gender differences in fluid management. After controlling for nationality, both family regulatory support (*b* = 0.29, *SE* = 0.04, *t*(222) = 7.60, *p* < .001) and Global South (*b* = 0.77, *SE* = 0.10, *t*(222) = 7.80, *p* < .001) were significant predictors. The addition of regulatory support from friends and neighbours, other patients on dialysis and healthcare team members did not significantly improve the model's explanatory power, nor were they significant predictors of fluid management. These findings suggest that family regulatory support and nationality were the primary predictors of fluid management (see Table 16).

**Table 16**

*Hierarchical regression predicting the effects of regulatory support targets on fluid management controlling for age, gender, and nationality (global region)*

| Model and Variables | Age Covariate | Gender Covariate | Nationality Covariate |
|---|---|---|---|
| Model 1 | $R^2$ = .48$^{***}$ | $R^2$ = .42$^{***}$ | $R^2$ = .54$^{***}$ |
| *F*-value | *F*(2,222) = 101.70$^{***}$ | *F*(2,222) = 80.45$^{***}$ | *F*(2,222) = 129.50$^{***}$ |
| Family RS | 0.38 (.04)$^{***}$ | 0.45 (.04)$^{***}$ | 0.29 (.04)$^{***}$ |
| Covariate | 0.02 (.00)$^{***}$ | -0.16 (.09) $^{\dagger}$ | 0.77 (.10)$^{***}$ |
| | | | |
| Model 2 | $\Delta R^2$ = .47$^{***}$ | $\Delta R^2$ = .57$^{***}$ | $\Delta R^2$ = .00 |
| *F*-value | *F*(3,221) = 81.53$^{***}$ | *F*(3,221) = 67.25$^{***}$ | *F*(3,221) = 87.01$^{***}$ |
| Family RS | 0.19 (.05)$^{***}$ | 0.24 (.06)$^{***}$ | 0.24 (.05)$^{***}$ |
| Friends/Neighbours RS | 0.21 (.05)$^{***}$ | 0.23 (.05)$^{***}$ | 0.06 (.05) |
| Covariate | 0.02 (.00)$^{***}$ | -0.16 (.09) $^{\dagger}$ | 0.70 (.12)$^{***}$ |
| | | | |
| Model 3 | $\Delta R^2$ = .00 | $\Delta R^2$ = .00 | $\Delta R^2$ = .00 |
| *F*-value | *F*(4,220) = 60.88$^{***}$ | *F*(4,220) = 50.24$^{***}$ | *F*(4,220) = 65.24$^{***}$ |
| Family RS | 0.19 (.05)$^{***}$ | 0.24 (.06)$^{***}$ | 0.25 (.05)$^{***}$ |
| Friends/Neighbours RS | 0.21 (.05)$^{***}$ | 0.22 (.05)$^{***}$ | 0.08 (.06) |
| OPOD RS | 0.00 (.05) | 0.02 (.06) | -0.04 (.06) |
| Covariate | 0.02 (.00)$^{***}$ | -0.16 (.09) $^{\dagger}$ | 0.71 (.12)$^{***}$ |
| | | | |
| Model 4 | $\Delta R^2$ = .00 | $\Delta R^2$ = .00 | $\Delta R^2$ = .00 |
| *F*-value | *F*(5,219) = 48.56$^{***}$ | *F*(5,219) = 40.12$^{***}$ | *F*(5,219) = 51.97$^{***}$ |
| Family RS | 0.19 (.05)$^{***}$ | 0.23 (.06)$^{***}$ | 0.25 (.05)$^{***}$ |
| Friends/Neighbours RS | 0.20 (.06)$^{***}$ | 0.21 (.06)$^{***}$ | 0.08 (.06) |
| OPOD RS | 0.00 (.06) | 0.00 (.06) | -0.04 (.06) |
| Healthcare team RS | 0.03 (.06) | 0.04 (.07) | -0.01 (.06) |
| Covariate | 0.02 (.00)$^{***}$ | -0.16 (.09) $^{\dagger}$ | 0.71 (.12)$^{***}$ |
| Final Model $R^2$ | .53$^{***}$ | .48$^{***}$ | .54$^{***}$ |

*Note*. N = 225.Unstanderdised beta coefficients (*b*) with standard errors (SE) in parentheses. $R^2$ values are rounded to two decimal places. $\Delta R^2 = R^2$ change. RS = Regulatory support, OPOD other patients on dialysis. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

## Exploratory analyses

Additional exploratory analyses were carried out without directional predictions. Firstly, an independent-samples *t*-test was conducted to compare fluid management between global regions North and South. The analysis revealed a statistically significant difference in fluid management scores between the Global North (*M* = 4.27, *SD* = 0.78) and Global South (*M* = 5.44, *SD* = 0.58); *t*(223) = -12.68, *p* < .001, *d* = -1.69 (Figure 11). These results suggested that global region had a significant effect on fluid management. Specifically, patients on dialysis from Global South reported greater adherence to their fluid intake compared to those from Global North.

**Figure 11**

*Box plot of global region on self-reported fluid management*

*Notes.* IDWG = Interdialytic weight gain is a measure of patients' fluid management. Nationality N = global north (Germany, Slovakia, Spain, the UK, and the USA), S = global south (Ghana, India, Nigeria, South Korea, and the Philippines).

Secondly, a correlation matrix between HADS and loneliness revealed that loneliness was positively correlated with anxiety, *r* = .26, *p* <.001, indicating that higher levels of loneliness are associated with higher levels of anxiety. Conversely, loneliness was negatively correlated with depression, *r* = −.54, *p* <.001, suggesting that higher levels of loneliness are associated with lower levels of depression. Anxiety did not show a significant correlation with depression, $r = .08$, $p = .24$. In the analysis of correlations between HADS and fluid management, fluid management was not significantly correlated with anxiety, $r = -.06$, $p = .39$, implying no significant relationship between fluid management and anxiety. However, fluid management was negatively correlated with depression, $r = -.44$, $p < .001$, suggesting that greater fluid management is associated with lower levels of depression.

Thirdly, a one-way ANOVA examined the effect of nationality on emotional distress scores (total anxiety and depression scores). Nationality significantly impacted emotional distress, $F(1, 223) = 78.80$, $p < .001$, $\eta^2 = 0.26$, accounting for 26% of the variance. Tukey HSD post hoc analysis showed that the Global South had significantly lower distress scores than the Global North ($M_{difference} = -0.34$, 95% CI [-0.41, -0.26], $p < .001$). Thus, nationality significantly influenced distress levels, with the Global South experiencing less distress.

Fourthly, a simple linear regression was conducted to examine whether age significantly predicted emotional distress. The results indicated that age was a significant predictor of emotional distress, $b = -0.01$, $t(223) = -5.45$, $p < .001$. Specifically, older patients on dialysis reported lower levels of emotional distress. The regression model was significant, $F(1, 223) = 29.74$, $p < .001$, and accounted for approximately 12% of the variance in emotional distress scores ($R^2 = 0.12$).

Fifthly, a one-way ANOVA was conducted to examine the effect of nationality on social network density scores and demonstrated a significant main effect of nationality on social network density, $F(1, 223) = 42.55$, $p < .001$, $\eta^2 = 0.16$. Tukey's HSD post hoc analysis indicated that there was a significant difference in social network density scores between the two global groups (mean difference = -5.46, $p < .001$). This result suggested that patients in Global South had significantly lower social network density scores compared to those in Global North.

Sixthly, the same analysis looked at the effects of gender on social network density scores and found that there was no significant difference in social density scores between genders ($F(1, 223) = 0.46$, $p = .498$, $\eta^2 = .002$).

Finally, a linear regression analysis examined the effect of age on social network density. Age was a significant predictor of social network density, with a negative effect ($b = -0.18$, $SE = 0.04$, $t(223) = -4.83$, $p < .001$), suggesting that as age increases, social network density decreases. The model was statistically significant, $F(1, 223) = 23.34$, $p < .001$, and explained approximately 9% of the variance in social density scores ($R^2 = 0.094$, adj. $R^2 = 0.091$).

# Discussion

Social support plays a significant role in how successfully patients manage their disease. Patients on dialysis must self-regulate by adhering to strict fluid restrictions amongst other treatment regimes, often relying on support from partners, family, and friends. Receiving support from others is not always beneficial, as some support may not align with patients' needs, impacting their ability to effectively self-regulate (e.g., Gable et al., 2012). Additionally, the mechanisms through which social support influences health outcomes remains unclear (Cohen et al., 2007). Therefore, it was crucial to use a self-regulatory social support measure to identify the needs of patients on dialysis, ensuring the support received is beneficial. This study employed a new social support construct, the Regulatory Effectiveness of Support (Zee et al., 2020), to investigate whether social support that addresses the self-regulatory needs of patients on dialysis influences their self-reported fluid management.

The findings from our regression analyses (one for regulatory support across the four support targets and one for the four support targets) supported our hypotheses that regulatory support that matches patients need for understanding (truth) and managing (control) their disease would lead to better fluid management. Further, that regulatory support from family, followed by friends and neighbours, would be more strongly associated with fluid management.

Overall, our findings are consistent with existing research on the role of social support in improving health outcomes (Holt-Lunstad et al., 2021; Thong et al., 2007) and enhancing self-management capabilities among patients on dialysis (Noviana & Zahra, 2022). However, we extend such findings in the context of patients on dialysis by adding to understanding of how effective support, which matched the need of patients on dialysis to better understand and manage their kidney disease, improved their self-regulatory behaviours to achieve their fluid adherence goals. Furthermore, our findings build on a body of research emphasising the importance of effective support that matches recipients' needs (e.g., Cavallo et al., 2016; Zee et al., 2020).

Additionally, patients reported that regulatory support significantly enhanced their fluid management, with family members, including romantic partners, providing the most effective assistance, followed by friends and neighbours (Jager et al., 2004; Rambod & Rafii, 2010; Silva et al., 2016). This indicates that patients found the support from family, friends, and neighbours as well-suited to their needs. Such support not only helped them understand the requirements for adhering to fluid restrictions but also empowered them to implement the necessary behaviours for maintaining fluid adherence. Additional covariate analyses demonstrated that effects of regulatory support on fluid management varied based on global region and support quality. Notably, regulatory support had a stronger effect on fluid management for patients in the Global South (e.g., India, Nigeria) compared to those in the Global North (e.g., UK, USA). This finding was supported by *t*-test results, which revealed that patients on dialysis from the Global South ($M = 5.44$) reported higher adherence to fluid intake restrictions than those from the Global North ($M = 4.27$). This finding was unexpected given that extensive research suggests patients in the Global North should have better disease outcomes due to superior healthcare infrastructure, socioeconomic conditions, and access to medical resources. For example, 98% of these countries provide haemodialysis, 90% offer peritoneal dialysis, and 85% have kidney transplant services (Bello et al., 2024). In contrast, the Global South has significantly lower availability, with only 35% offering peritoneal dialysis and 12% providing kidney transplant services, often relying on live donors (Bello et al., 2024; Crew et al., 2019). Additionally, patients from low socioeconomic backgrounds face obstacles to effective self-management, such as unreliable transportation, accessing continuous healthcare, seeking relevant information, and understanding healthcare guidance (Block et al., 2004; Rivera et al., 2022).

The unexpected finding that patients in the Global North do not necessarily have better disease outcomes, despite superior healthcare infrastructure, highlights the complex interplay between socioeconomic factors and health management. Advanced medical resources alone may not overcome barriers to effective self-regulation and healthcare engagement. Robust support in the Global South may function as a protective factor, encouraging strict adherence to fluid restriction (Rivera et al., 2022). This could be attributed to support matching patients' needs, collectivist cultures emphasising shared responsibilities and moral obligations (Pelham et al., 2022; Triandis, 1993), and the high stakes associated with limited medical infrastructure.

We found evidence for the buffering effect of regulatory support on strained exchanges, which emerged as a significant predictor of fluid management in patients on dialysis. Specifically, patients experiencing strained exchanges were less likely to adhere to their fluid restrictions. However, receiving regulatory support positively influenced their ability to effectively manage their fluid intake. This result contributes to the existing literature suggesting that quality support can mitigate the negative effects of strained interactions with others (Cohen & Wills, 1985; Jackson, 1992; Uchino et al., 2012; Walen & Lachman, 2000).

The buffering effect of regulatory support highlights its importance in helping patients maintain adherence to fluid restrictions, even in the face of challenging social interactions.

Mediator analyses revealed that both self-efficacy and commitment to disease management were positively associated with fluid management, indicating that patients who believed they could adhere to fluid restrictions and were committed to doing so experienced better fluid management. Supporting our hypotheses, both self-efficacy and commitment to disease management emerged as crucial mechanisms through which regulatory support influenced fluid management. Our finding regarding self-efficacy aligns with existing literature showing that higher self-efficacy is linked to better fluid adherence in dialysis patients (Gartika et al., 2021; Kartini et al., 2020). It also highlights the role of social support in boosting patients' confidence in managing their disease, which subsequently improved fluid management (Chironda & Bhengu, 2019; Isnaini, Sukma & Aprilina, 2021).

Additionally, the finding that commitment to disease management played a crucial role in the relationship between regulatory support and fluid management demonstrates that patients more dedicated to managing their disease were better able to use the support they received to adhere to fluid restrictions. This finding is consistent with a recent randomised control trial by Tao et al. (2024), which evaluated an intervention based on temporal self-regulation theory to enhance patients' self-management behaviours. The study showed that patients on dialysis who received the intention based intervention exhibited improved fluid management, suggesting that strengthening patients' intentions can lead to better adherence to fluid restrictions. These findings offer valuable insights into strategies for enhancing patient care and outcomes. They suggest that improving patient support should go beyond merely helping and should focus on fostering a sense of achievement through treatment adherence. By bolstering patients' confidence in their ability to manage their condition and strengthening their commitment to treatment, healthcare providers and support systems can help patients thrive. This approach not only improves the quality of support patients receive but also empowers them to take a more active and effective role in their own care, potentially leading to better health outcomes and an increased sense of personal accomplishment. Unexpectedly, self-monitoring showed an inverse correlation with fluid management and did not mediate the relationship between regulatory support and fluid management. This suggests that patients who engaged in more frequent self-monitoring of their fluid intake tended to have poorer adherence to fluid restrictions. Several factors may contribute to this counterintuitive finding. Constant monitoring of fluid intake may increase patients' stress and anxiety levels, potentially leading to poorer adherence. The strict limits on fluid intake may become overwhelming, causing some patients to disregard restrictions. Additionally, self-monitoring might be perceived as an additional, burdensome task, diminishing motivation for adherence. This idea aligns with research in behavioural medicine and psychopathology suggesting that patients with low distress tolerance may struggle with the continuous self-monitoring required, impacting their self-regulation abilities (Leyro et al., 2010; Lillis et al., 2009). The current study did not assess patients' perceptions regarding fluid management. However, previous research has demonstrated that constructs such as illness representations can significantly influence fluid management behaviours in patients on dialysis (Chilcot et al., 2010; Vélez-Vélez & Bosch, 2016). This presents an important avenue for future research that could potentially help identify patients who may be at higher risk for nonadherent behaviours.

The lack of mediation by self-monitoring in the relationship between regulatory support and fluid management indicates that it may not be the primary mechanism through which support influences fluid management. This aligns with mixed findings on self-monitoring's impact on fluid adherence in patients on dialysis (Harkin et al., 2016; Howren et al., 2016). While self-monitoring alone may be insufficient, studies combining it with other strategies like reinforcement and goal setting have shown significant reductions in IDWG (Welch & Thomas-Hawkins, 2005).

Exploratory analysis revealed that older patients and those in the Global South reported significantly lower levels of emotional distress. This finding may be attributed to numerous factors. For patients in the Global South, collectivist cultures may provide quality support and group-based coping strategies such as communal problem-solving and shared religious or cultural practices that provides effective means to deal with stress. However, there is also the possibility of underreporting depressive symptoms due to mental health stigma in these cultures (Limenih et al., 2024). Additionally, depression may manifest differently in collectivist cultures, with a greater focus on physical rather than psychological symptoms (Gbadamosi et al., 2022). For older patients, lower distress levels may be due to more experience with stressful situations and developed coping strategies, as noted by Carstensen et al. (2020). Established social support networks which offer emotional and practical support and comforting routines may also contribute to reduced stress in older adults. The strong correlations among self-efficacy, intention and social support in fluid management for patients on dialysis stem from their interrelated nature in chronic disease management. Self-efficacy, one's belief in their ability to perform a behaviour, is closely linked to intention, the plan to engage in that behaviour. Higher self-efficacy often leads to stronger behavioural intentions (Mirmazhari et al., 2022). Moreover, social support enhances self-efficacy by providing encouragement, modelling successful behaviours and offering resources, thus boosting both self-efficacy and intention in a positive feedback loop (Safi et al., 2024). The study's specific focus on fluid management may have contributed to the strong correlations, as context-specific measures across scales may have become more similar than general health behaviour measures. This specificity could have led to items tapping into multiple constructs, potentially inflating the observed correlations. Whilst these strong correlations suggest a close relationship between the constructs, it remains important to consider their unique contributions in understanding and promoting fluid management behaviours in patients on dialysis.

## Implications

The findings from this study have several implications. Firstly, the study highlights the need for tailored social support interventions that specifically address the self-regulatory needs of patients on dialysis. Healthcare providers should focus on enhancing patients' understanding of their illness (truth) and boosting their confidence in managing it (control). Strengthening support networks for patients on dialysis can be achieved through a multifaceted approach, such as encouraging active involvement from close others throughout the treatment process, establishing support groups for patients and their close others, and improving communication among all parties.

Secondly, the moderating effect of nationality on the relationship between regulatory support and fluid management underscores the importance of considering geographical and cultural differences when assessing the impact of social support on disease outcomes among patients on dialysis. Understanding how geographical region or culture influence health outcomes highlights the need for culturally sensitive interventions, which may involve adapting psychoeducational programs or support networks to better align with the socio-cultural norms and healthcare infrastructure of different regions.

Thirdly, the finding that the positive relationship between regulatory support and fluid management strengthens with age suggests the potential for targeted interventions that leverage social support networks to improve fluid management practices, especially for older patients. Healthcare providers can tailor support strategies based on patients' age demographics to maximise their effectiveness. For example, interventions promoting family involvement or enhancing support networks among older patients may yield greater benefits in terms of fluid management.

Finally, interventions should incorporate strategies to improve self-efficacy and commitment to disease management. Training programs for patients and their close others could include components on effective self-monitoring techniques and ways to foster a strong commitment to treatment adherence. This might include motivational interviewing, goal-setting workshops, and personalised feedback.

## Limitations

This study has several limitations that warrant consideration. Firstly, its cross-sectional design prevents causal inferences; longitudinal studies are needed to establish the temporal relationships between regulatory support, self-efficacy, self-monitoring, commitment to disease management, and fluid management. Secondly, the use of self-reported measures may introduce response biases. The inclusion of objective fluid management measures in future studies could enhance the validity of findings.

Lastly, the study sample primarily consisted of Nigerian residents, potentially limiting generalisability due to cultural and healthcare infrastructure influences on fluid management approaches. However, this study enriches the literature by highlighting cultural differences and suggesting how to adapt support in a culturally sensitive manner, addressing a gap in research on non-Western cultures.

## Future directions

The findings from this study highlight the need for longitudinal research to examine how the relationship between regulatory support and fluid management evolves over time across different age groups. Such studies can shed light on the changing social support needs of patients on dialysis as they age and the potential challenges they may face. Additionally, the study emphasises the importance of investigating the cultural context and the role of nationality in fluid management. Given the ethnically diverse sample in this study, future research could explore how cultural differences in social support networks impact self-regulation and health outcomes in patients on dialysis, but also why the strength of this relationship differs between nationalities and explore other potential moderators (such as education level, level of support, illness perceptions).

## Conclusion

In conclusion, this study demonstrated that regulatory support significantly impacts fluid management in patients on dialysis, primarily through its impact on self-efficacy and commitment to disease management. The results indicate that strengthening support networks which enhance patients' understanding and confidence in managing their condition, while also boosting self-efficacy and commitment to treatment adherence, can markedly improve fluid restriction compliance and overall quality of life. Tailored interventions that consider cultural, systemic, and age-related factors are crucial for optimising disease outcomes. Future research should further investigate the intricate relationship between regulatory support and fluid management, as well as the specific mechanisms through which regulatory support influences fluid management. Additionally, incorporating an objective measure of fluid adherence in future studies would be beneficial for developing more effective support strategies for patients on dialysis.

# Chapter 6

# General discussion

The objective of this thesis was to develop an understanding of the specific processes that impact upon successful self-management in chronic kidney disease (CKD). This thesis offered a distinctive view on the complex processes involved in successful self-management – by not relying on any single theoretical framework or model. This approach emerged from the recognition that self-management is a multifaceted concept, with many existing theoretical models inadequately addressing the influence of psychosocial factors and lacking a framework for conceptualising and implementing them. This flexible approach enabled a broader and more adaptable study of the various aspects of self-management.

Across four studies, I employed a variety of methodological and analytical approaches to achieve the goals of this thesis. Study 1 involved a systematic review and meta-analysis to investigate the effectiveness of controlled interventions in enhancing self-regulation of psychological, behavioural, and physiological health outcomes among patients on dialysis. Study 2 used semi-structured interviews to explore patients on dialysis' attitudes toward dietary and fluid restrictions, as well as the self-regulatory strategies they employed or found challenging whilst trying to adhere to their kidney treatment. Additionally, in Study 3 I examined the contextual factors that influence how patients on dialysis self-regulate and adhere to their treatment regime. Finally, in Study 4 using an online survey developed based on the findings from the previous studies, I investigated the relationship between social support aimed at supporting self-regulatory needs and self-reported fluid adherence.

This chapter discusses the research conducted in this thesis, organised into four sections. First, it provides an overview of the key findings from Studies 1 to 4. Next, it briefly discusses how these findings contribute to our understanding of self-regulation in CKD.

Based on this discussion, it highlights some limitations and proposes directions for future research on self-regulation in CKD.

## Summary of present findings

First, Study 1 evaluated the effectiveness of randomised controlled interventions aimed at improving self-regulation of health outcomes in dialysis patients. Through a systematic review and meta-analysis, the study assessed the impact on psychological constructs (e.g., self-efficacy, knowledge), behavioural targets (e.g., dietary, fluid, medication adherence), and physiological outcomes such as blood levels of potassium, phosphate, and interdialytic weight gain (IDWG). The study also explored the relationships between changes in these constructs and the moderation of outcomes by behaviour change techniques derived from the behaviour change taxonomy (BCT: Michie et al., 2013), and intervention duration. Results indicated moderate and significant improvements in dietary, fluid, and medication adherence, leading to moderate reductions in serum phosphate and IDWG among intervention groups, consistent with previous findings by Murali et al. (2019).

Regarding psychological intervention targets, significant effects were found on knowledge and quality of life, despite fewer studies reporting on these (e.g., Chang et al., 2021; Hare et al., 2014). Analysing the relationships between psychological, behavioural, and physiological outcomes revealed potential pathways connecting changes in knowledge and quality of life with behavioural and physiological outcomes. Improved knowledge was positively associated with better medication adherence, which, in turn, were linked to reductions in IDWG. Enhanced quality of life was also associated with decreased IDWG, aligning with previous research (Kahraman et al., 2015; Vasilopoulou et al., 2016). Moderator analyses identified five predominant behaviour change technique (BCT) categories in interventions: knowledge shaping, feedback and monitoring, natural consequences, goals and planning, and social support. Examining the effect of these BCTs on self-efficacy showed that interventions incorporating social support were more effective in promoting adherence, consistent with previous studies (e.g., Chironda & Bhengu, 2019). Additionally, longer interventions with at least four contacts with healthcare professionals were linked to greater effects on psychological wellbeing, including depression, anxiety, and quality of life. This supports research indicating that longer interventions have a more significant impact on wellbeing and depression measures (e.g., Boiler et al., 2013). However, the studies in the review did not adequately consider the role of social, environmental, and socioeconomic factors in treatment adherence among patients on dialysis. These factors are crucial because managing CKD involves strict dietary and fluid restrictions, which are significantly influenced by interactions with others and the patient's social environment (e.g., Holt-Lunstad, 2021; Nair et al., 2021). By overlooking these aspects, these studies missed important elements such as the support patients receive, their ability to afford suitable food items, and the responsibilities involved in meal preparation. Studies 2 and 3 aimed to address these gaps by exploring how patients undergoing dialysis manage their kidney disease, with a particular focus on their attitudes towards self-regulation, especially regarding dietary and fluid restrictions. This qualitative exploration provided a deeper understanding of the psychosocial and contextual factors that influence treatment adherence, offering insights that were not captured in the studies included in Study 1.

Study 2 concentrated on the self-regulatory strategies that patients either used or neglected in managing their dietary and fluid restrictions. Study 3 examined contextual factors influencing their ability to self-regulate. These objectives were investigated through a double-blinded qualitative study. To understand the "how" and "why" of specific behaviours in particular contexts, patients were categorised into high or low adherence groups based on three CKD physiological outcomes averaged over three months: IDWG, phosphate, and potassium levels.

The findings in Study 2 revealed three main themes: (1) planning, (2) behavioural strategies for adhering to restrictions, and (3) self-monitoring. These themes align with established theoretical models of self-regulation and goal attainment (e.g., Carver & Scheier, 1982; Harkin et al., 2016; Nielsen et al., 2018; Schwarzer, 2014).

Both high and low adherence groups reported using similar self-regulatory strategies, such as food substitutions, dietary portion control, cooking from scratch, and monitoring food intake. However, a key difference emerged in the frequency and type of strategies employed by each group. Low adherence patients more frequently used drink substitutions and thirst management strategies, occasional treats or cheat days, lack of active planning due to habits and self-monitored their outcomes. In contrast, high adherence patients showed a slightly higher tendency towards planning strategies aimed at passing medical tests. Comparative analysis revealed that low adherence patients engaged in multiple strategies more often than high adherence patients. Considering the observed variations in patients' use of self-regulatory strategies, it became evident that further investigation into the reasons behind these differences was warranted. Specifically, it was important to understand why some patients encountered difficulties in managing their condition, while others were able to do so effectively. This prompted the need for a follow-up study to explore the contextual factors that influenced patients self-regulation.

Using the same methodology as Study 2, including the study design and patient grouping based on adherence, the results from Study 3 identified six themes: (1) competing priorities, (2) personalised support from the healthcare team, (3) social support, (4) intrinsic and extrinsic motivation, (5) physiological feedback, and (6) outcome expectancies. A notable contrast emerged between patients with high and low adherence to kidney disease management protocols. Low adherence patients faced significantly more obstacles, particularly from competing life priorities such as childcare responsibilities and financial pressures. These challenges often hindered their ability to implement essential disease management behaviours, including dietary modifications. This finding aligns with existing research highlighting how financial constraints and parental duties can significantly impact an individual's ability to effectively self-regulate health behaviours (Alvarez-Villarreal et al., 2021; Suarilah & Lin, 2022).

Both adherence groups expressed a desire for better communication from their healthcare team, emphasising the need for clear guidance on disease management and personalised care plans tailored to their comprehension levels, capabilities, and life situations. This need was more pronounced among low adherence patients. These findings are consistent with research demonstrating the importance of tailored healthcare guidance and personalised support in effective disease management (e.g., Hessler et al., 2019; Howden et al., 2015).

Additionally, all participants acknowledged the importance of social support from family, partners, friends, healthcare providers, peers, and pets in their ability to self-regulate. However, low adherence patients often reported feeling unsupported due to insufficient social support. This aligns with research on the relationship between social support and self-regulation in dialysis patients (e.g., Chen et al., 2018; Dinh & Bonner, 2023).

Finally, Study 4 conducted a quantitative investigation based on findings from Studies 1 and 3. Study 1 showed that social support-based interventions positively affected self-efficacy in patients on dialysis, while Study 3 highlighted the significant influence of support quality and presence on patients' self-regulatory abilities. Consequently, Study 4 examined whether social support aimed at fulfilling self-regulatory needs improved fluid management in patients on dialysis, controlling for factors like age, gender, nationality, support quality, and relationship satisfaction. It also explored how self-regulatory mechanisms (self-efficacy, commitment, and self-monitoring) mediated the relationship between regulatory support and fluid management. These associations were examined across various social support relationships, including family, friends and neighbours, other patients on dialysis, and the healthcare team.

Results showed a strong positive relationship between regulatory support and fluid management, with higher support levels associated with better fluid management. Support quality and patient location significantly influenced this relationship, with stronger effects observed in patients living in Global South (e.g., India, Nigeria), and those experiencing high-strained interactions. Older patients demonstrated a stronger link between regulatory support and fluid management, while gender and relationship satisfaction did not significantly impact fluid management. Hierarchical regression analysis identified family support as the strongest predictor of fluid management, followed by support from friends and neighbours. Support from other patients on dialysis and the healthcare team did not significantly enhance fluid management prediction. These findings align with our initial hypothesis and previous research suggesting family support as most influential in managing fluid intake for dialysis patients (Jager et al., 2004; Rambod & Rafii, 2010; Silva et al., 2016).

Our analysis revealed that self-efficacy and commitment to disease management significantly mediated the relationship between regulatory support and fluid management in dialysis patients. This suggests that regulatory support enhances patients' confidence and dedication to managing their disease, leading to improved fluid management. These results complement recent studies by Gartika et al. (2021), Kartini et al. (2020), and Tao et al. (2024), highlighting the importance of self-efficacy and commitment in adhering to fluid restrictions. Interestingly, self-monitoring did not mediate this relationship, suggesting it may not be the primary mechanism at play. This aligns with mixed findings on self-monitoring's role in fluid adherence among patients on dialysis (Howren et al., 2016). However, studies combining self-monitoring with strategies like reinforcement and goal setting have shown significant reductions in IDWG (Welch & Thomas-Hawkins, 2005).

Exploratory analysis showed that better fluid management was linked to lower levels of depression, suggesting that patients who managed their fluid intake well felt less depressed. This finding aligns with existing literature on the impact of depression on disease management and outcomes (e.g., Cukor et al., 2013; Farrokhi et al., 2014). Further analysis revealed that patients from the Global South (e.g., India, Nigeria), experienced significantly lower distress levels compared to those from the Global North (e.g., Germany, UK), possibly due to stronger support networks. In many Global South cultures, a strong emphasis on family and community support provides emotional and practical assistance, helping to reduce distress levels (Pelham et al., 2022).

In summary, the research, spanning four studies, examined self-regulation among patients on dialysis. Study 1 assessed randomised controlled interventions, demonstrating moderate improvements in dietary, fluid, and medication adherence, alongside positive effects on psychological constructs like self-efficacy and knowledge. However, it highlighted the neglect of social, environmental, and socioeconomic factors influencing adherence. To address these, Studies 2 and 3 used qualitative methods to explore self-regulation strategies and contextual influences. Study 2 found differences in strategy use between high and low adherence groups, while Study 3 revealed that low adherence patients faced significant barriers, such as competing life priorities and inadequate social support, while both groups expressed a need for tailored healthcare guidance. Study 4 then quantitatively examined the impact of social support on fluid management confirming that social support positively influenced fluid management, particularly from family. It found that self-efficacy and commitment mediated this relationship, suggesting that enhanced support improves patients' confidence in managing their condition. Better fluid management was also linked to lower depression levels, with cultural differences noted in patient distress. Overall, the studies underscore the importance of considering psychosocial and contextual factors in promoting effective self-management in kidney disease.

## Implications and contributions to the literature

Patients undergoing dialysis represent a unique and complex cohort within the healthcare system. Unlike many chronic conditions, end-stage renal disease requiring dialysis offers no curative option, and inadequate self-management can lead to premature mortality. This distinctive characteristic underscores the critical need for a comprehensive, holistic approach to optimise disease outcomes in this patient population. The complexity of dialysis patients' needs renders a one-size-fits-all intervention strategy insufficient. There is a pressing need to shift away from the traditional biomedical model towards a more patient-centred and culturally sensitive approach to care. This paradigm shift should prioritise psychosocial factors, aiming to transform haemodialysis care by addressing the intricate interplay of medical, psychological, and social determinants of health. A holistic intervention strategy should encompass personalised care plans that consider individual patient circumstances and preferences, cultural competence in healthcare delivery to ensure interventions resonate with diverse patient populations, psychological support to address the emotional burden of associated with dialysis, and social interventions to enhance patients' support networks and improve quality of life. Crucially, interventions should focus on enhancing self-efficacy and commitment, two key mechanisms that drive behaviour change. By incorporating techniques that boost patients' confidence in their ability to manage their condition and strengthening their dedication to treatment goals, interventions can significantly increase the likelihood of successful and sustained behaviour change. This approach empowers patients to take an active role in their care, leading to improved adherence and better health outcomes.

The findings from this thesis not only facilitate a deeper understanding of the psychosocial and environmental influences on treatment adherence for patients on dialysis but also offer a structured approach for future research and interventions in this domain. By recognising the complex interplay of factors affecting patients on dialysis and leveraging mechanisms like self-efficacy and commitment, healthcare providers can develop more effective, patient-centred strategies to improve outcomes and quality of life. The importance of a holistic intervention approach in optimising disease outcomes for patients on dialysis cannot be overstated; it is imperative that the healthcare community continues to evolve its practices to meet the multifaceted needs of this patient population.

## Limitations of the present work

This thesis is constrained by three primary limitations. Firstly, it concentrates exclusively on the perspectives and experiences of patients on dialysis, overlooking the perceptions of their close others regarding their ability to provide support in disease management. Secondly, the generalisability of the findings to the broader CKD population is limited due to the study's focus on patients on dialysis. Lastly, the research does not fully explore the psychological burden of living with CKD, or the coping strategies patients employ to address the emotional challenges associated with their condition.

Firstly, a relatively minor limitation of this thesis is the absence of perspectives from the patients' social network, which could have provided valuable additional insights into the role of social support in disease outcomes. Understanding the motivations behind the support (or lack thereof) offered by close others, as well as their perceived ability to provide the necessary support, could have enriched the study's findings. The expectations of close others significantly influence a patient's experience and capacity to manage their disease. Positive and supportive expectations can boost motivation, self-efficacy, and social support, thereby assisting patients in navigating the complexities of kidney disease and potentially leading to improved outcomes. Conversely, unrealistic or poorly communicated expectations may undermine patient confidence and increase stress levels, potentially hindering effective disease management. Research by Koga et al. (2022) and Triesch (2001) has demonstrated that expectations from close others play a crucial role in both the progression and management of kidney disease, as well as in determining patients' quality of life. Therefore, incorporating the perspectives of close others would have provided a more comprehensive understanding of how support can be mutually beneficial.

Secondly, this thesis focused on patients undergoing dialysis, which may restrict the generalisability of its findings to the broader CKD population. While the research provides valuable insights, it is important to recognise that patients on dialysis represent only those at the most advanced stage of kidney disease. Their experiences, symptoms, and management needs are often markedly different from those of patients in earlier stages of CKD. As kidney disease progresses, there's a notable shift in both symptom severity and treatment focus. Early-stage CKD management typically centers on addressing underlying conditions, whereas later stages involve more intensive efforts to control complications and discussions about life-sustaining treatments such as dialysis and kidney transplantation. The unique challenges faced by patients on dialysis may not accurately reflect the experiences of those in earlier stages of the disease. Consequently, while the research offers valuable insights into the experiences of patients with advanced kidney disease, its applicability to the broader CKD population should be considered with careful discernment.

Thirdly, this thesis did not thoroughly investigate the psychological challenges faced by patients on dialysis. It did not thoroughly examine the mental health burdens, such as stress, anxiety, and depression, often associated with adhering to demanding treatment regimens (Palmer et al., 2013; Rahman & Pradido, 2020). Additionally, it failed to fully investigate how social support networks assist patients in managing these psychological stressors. A more comprehensive analysis of these mental health aspects could have provided pertinent understanding into patients' overall wellbeing and their ability to effectively manage their disease.

## Future directions

Psychological wellbeing significantly influences health behaviours, with studies showing that one in five dialysis patients experiences depression, a rate higher than in other chronic illnesses and the general population (Palmer et al., 2013a; Waraich et al., 2004). Depression and anxiety are prevalent among dialysis patients, ranging from 12% to 87% (Cohen et al., 2016; Rahman & Pradido, 2020). These conditions are linked to adverse psychosocial outcomes, negative health effects, and increased mortality (e.g., Cukor et al., 2013; Farrokhi et al., 2014). However, the impact of psychological factors like depression, anxiety, and self-efficacy on behaviour change and health outcomes is often overlooked, making it difficult to understand their predictive value for future behavioural changes and outcomes. To address this gap, future research should directly examine the relationships between psychological health measures, behavioural changes, and physiological outcomes. This approach would offer a more comprehensive understanding of the interplay between mental health, behaviour, and physical health in dialysis patients, potentially leading to more effective interventions and treatment strategies.

Furthermore, as a continuation of Chapters 3 and 4, there is a need for empirical studies to replicate our findings and establish a robust evidence base concerning the effectiveness of contextual factors, and self-regulatory strategies in enhancing various disease outcomes. Chapters 3 and 4 categorised patients on dialysis based on their adherence level and identified differences not only in the contextual factors that influenced their self-regulation but also in the strategies they used for effective self-regulation. For example, in Chapter 3, patients in the high adherence group preferred strategic planning to ensure they passed their medical tests. In contrast, low adherence patients employed a mix of strategies, including routine planning, drink substitutions, thirst management techniques, occasional treat indulgence, and active monitoring of their behaviours. In Chapter 4, patients in the low adherence group faced greater barriers such as parenting and financial strains, as well as insufficient social support in managing their kidney disease. While these findings provide valuable insights into factors influencing disease management success, further research is necessary to quantitatively assess the applicability and generalisability of these findings across a broader patient population. Further, to empirically evaluate whether the identified contextual factors and strategies effectively improve health outcomes in patients on dialysis. Such research would strengthen the evidence base and potentially inform more targeted and effective interventions for improving adherence and overall health outcomes in this patient population.

Lastly, as an extension of Chapter 5, one could investigate the role of healthcare system on patients' disease management. The social and economic contexts in which patients exist affect their ability to self-manage effectively and access necessary care resources. It is widely recognised that socioeconomic status significantly influences health behaviours and outcomes, leading to disparities in disease management. For instance, factors like poor living conditions, financial constraints, and limited access to healthcare contribute to accelerated disease progression and mortality in CKD patients (e.g., Morton et al., 2016). Hence, it is crucial to consider how the healthcare system influences patients' ability to make and maintain the behavioural changes which are necessary for effectively managing their disease. It would be intriguing to investigate whether there are differences in health outcomes (psychological, behavioural, and physiological) among patients on dialysis based on whether their CKD treatment is free at point of delivery or incurs personal cost. To enhance the validity of findings, future studies should incorporate objective measures of fluid management alongside self-reported measures. This approach would provide more precise data and mitigate potential response biases. Additionally, to improve the generalisability of results, research should include diverse populations from various regions and cultures. This broader scope would enable direct comparisons and help identify both universal and culture-specific factors influencing fluid management and psychological outcomes in patients on dialysis.

## Conclusion

To conclude, this thesis offers valuable insights into the complex nature of self-regulation and adherence among patients on dialysis. The findings emphasise the critical role of regulatory support in improving fluid management especially regulatory support from family including romantic partners, with self-efficacy and commitment to disease management emerging as key mediators. The findings underscore the importance of social support networks, personalised care approaches, and clear communication from healthcare providers, while emphasising the need to consider patients' individual circumstances and living environments. These results advocate for a holistic approach to CKD management that integrates medical treatment with psychological and social support. Such an approach recognises and addresses the complex interplay between physical health, psychological wellbeing, and cultural factors to optimise patient outcomes. Promoting self-regulation among patients not only reduces their mortality risks but also alleviates the strain on healthcare systems, contributing to long-term sustainability. This approach gains increasing importance as populations age and the prevalence of chronic conditions like CKD rises, offering a dual benefit of improving patient outcomes while enhancing healthcare efficiency.

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# Appendices

## **Chapter 2** Promoting self-regulation in chronic disease: A systematic review and meta-analysis of behaviour change interventions.

### Appendix A

### Assessment of risk of bias of the 46 studies included in the meta-analysis using Cochrane ROB 2

| Study | Bias arising from the randomisation process | Bias due to deviations from intended interventions | Bias due to missing outcome data | Bias in measurement of the outcome | Bias in selection of the reported result |
|---|---|---|---|---|---|
| Arad et al., (2021) | Low | Low | Low | Low | Low |
| Ashurst & Dobbie, (2003) | Some | Some | Some | Low | Some |
| Baraz et al., (2010) | Some | Low | Some | Low | Some |
| Brantley et al., (1990) | Some | Some | High | Low | Low |
| Chang et al., (2021) | Low | Low | Low | Low | Low |
| Chen W et al., (2006) | Low | Some | Some | Low | Some |
| Chen et al., (2021) | Some | Low | Low | Low | Low |
| Cho, (2013) | Some | Some | Low | Some | Low |
| Cukor et al., (2014) | Low | Some | Some | Low | Low |
| Cummings et al., (1981) | High | Some | Some | Some | Low |
| de Araujo et al., (2010) | Some | Low | Some | Low | Low |
| de Freitas et al., (2020) | Low | Some | Low | Some | Some |
| Ford et al., (2004) | Low | Some | Low | Low | Some |
| Forni Ogna et al., (2013) | Low | Some | Low | Low | Some |
| Griva et al., (2018) | Low | Some | Some | Some | Some |
| Hanifi et al., (2018) | Low | Low | Low | Low | Low |
| Hare et al., (2014) | Some | Some | Some | Some | Some |
| Haq et al., (2014) | High | Some | Low | Low | Low |
| Hou et al., (2010) | Some | Some | Some | Some | Low |
| Howren et al., (2016) | Some | Some | Some | Low | Low |

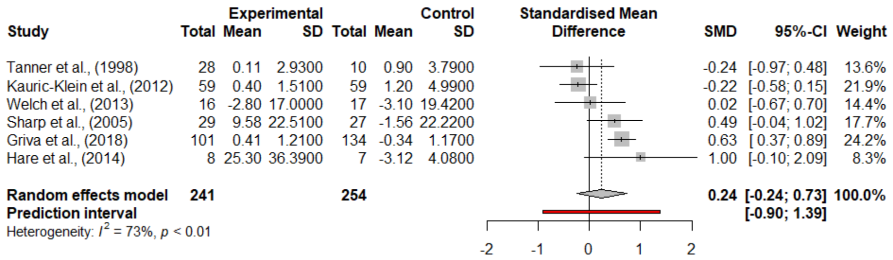
| | | | | | |
|---|---|---|---|---|---|
| Karavetian et al., (2013) | Some | Some | Some | Low | Some |
| Karavetian et al., (2015) | Some | Some | Some | Some | Some |
| Kauric-Klein et al., (2012) | Some | Some | Some | Some | Low |
| Lim et al., (2018) | Low | Low | Low | Low | Low |
| Lou et al., (2012) | High | Some | Some | Low | Low |
| Mateti et al., (2018) | Some | Some | Some | Low | Low |
| Mina et al., (2019) | Low | Low | Low | Low | Low |
| Molaison & Yadrick (2003) | High | Some | Some | Low | Low |
| Morey et al., (2008) | Low | Some | Some | Low | Low |
| Neumann et al., (2013) | Some | Some | High | Low | Low |
| Pasyar et al., (2015) | Low | Low | Some | Low | Low |
| Ramezani et al., (2018) | Some | Low | Low | Some | Some |
| Reese et al., (2015) | Some | Some | Some | Low | Some |
| Sehgal et al., (2002) | Low | Some | Low | Low | Low |
| Sharp et al., (2005) | Low | Some | Low | Some | Low |
| Shi et al., (2013) | Low | Low | Low | Low | Some |
| Skoutakis et al., (1978) | Some | Some | Some | Some | Some |
| Sullivan et al., (2009) | Low | Low | Low | Low | Low |
| Tanner et al., (1998) | High | Some | Low | Some | Some |
| Tsay et al., (2003) | Low | Low | Low | Low | Some |
| Valsaraj et al., (2020) | Low | Low | Low | Low | Low |
| Welch et al., (2013) | High | High | Some | Low | Some |
| Wileman et al., (2014) | Low | Some | Some | Some | High |
| Wileman et al., (2016) | Some | Some | Some | Some | Some |
| Wong et al., (2010) | Some | Some | Some | Some | Some |
| Yokum et al., (2008) | Some | Some | High | Low | Some |

# Appendix B

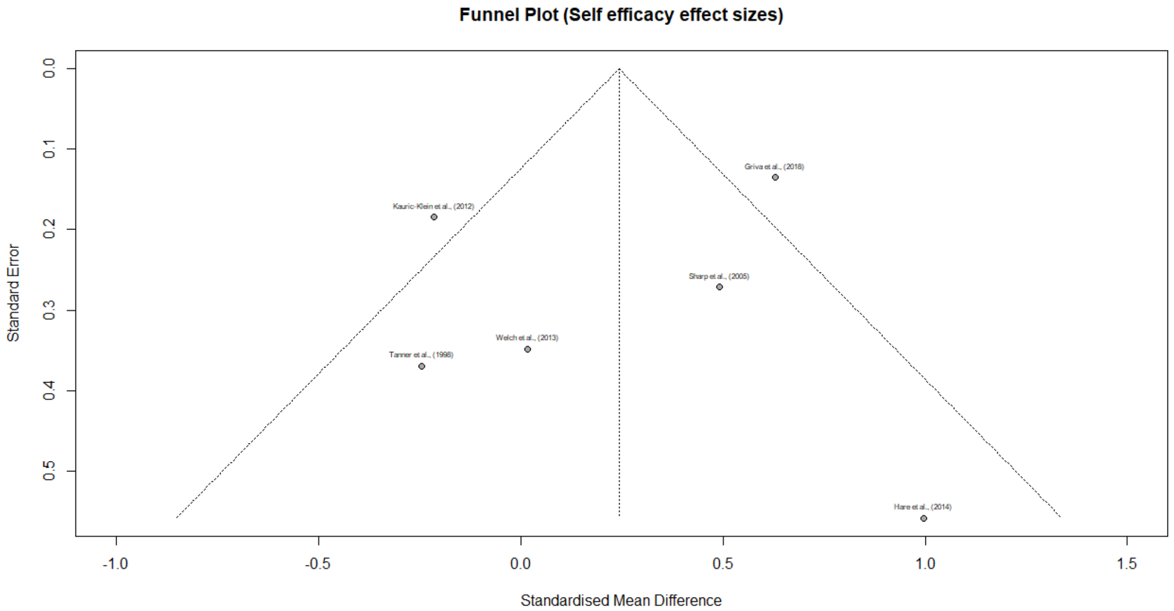
## Forest and funnel plots for psychological, behavioural, and physiological constructs

## Psychological outcomes

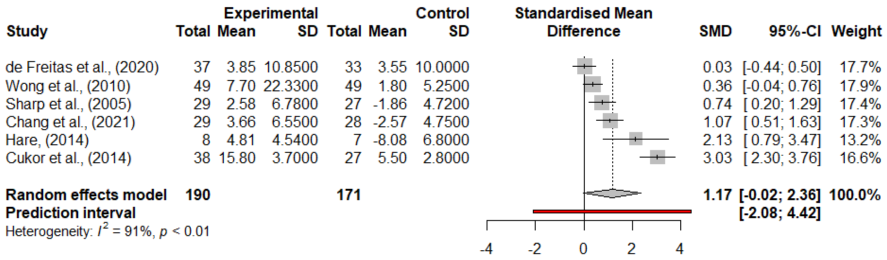
### Self-efficacy: Forest plot // pooled effect size



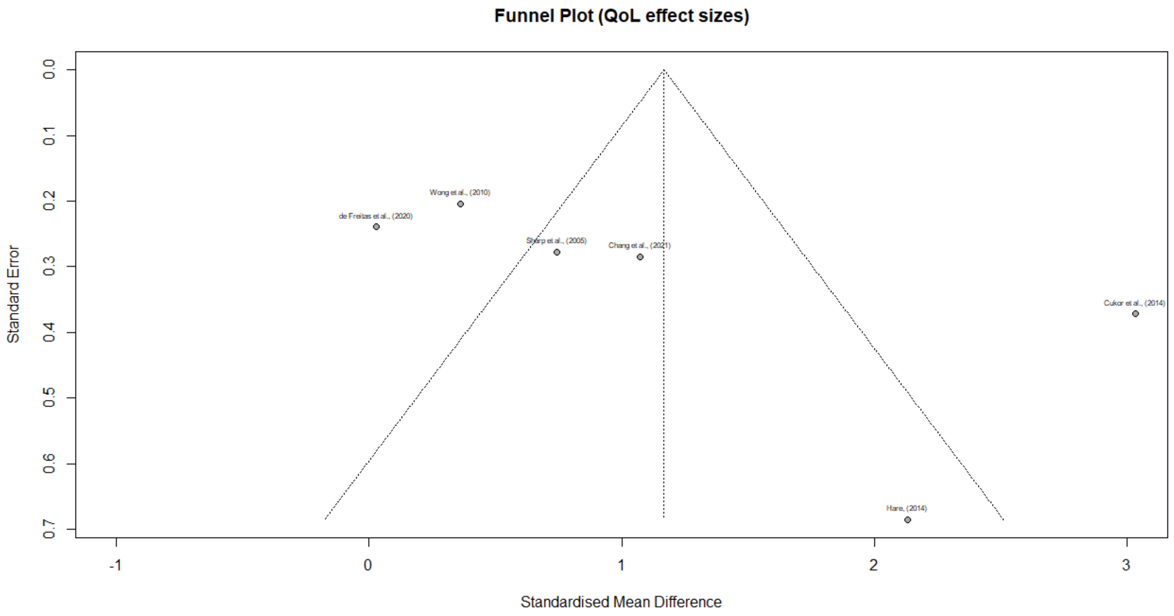
### Funnel plot



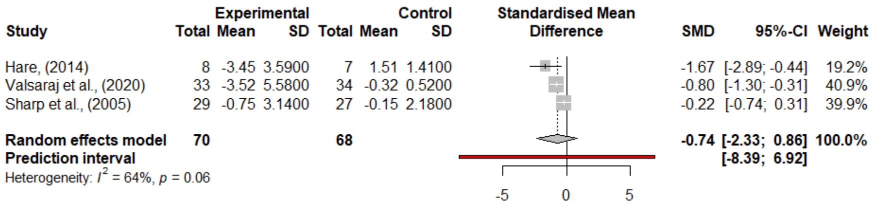
### Quality of Life: Forest plot // pooled effect size



## Funnel plot



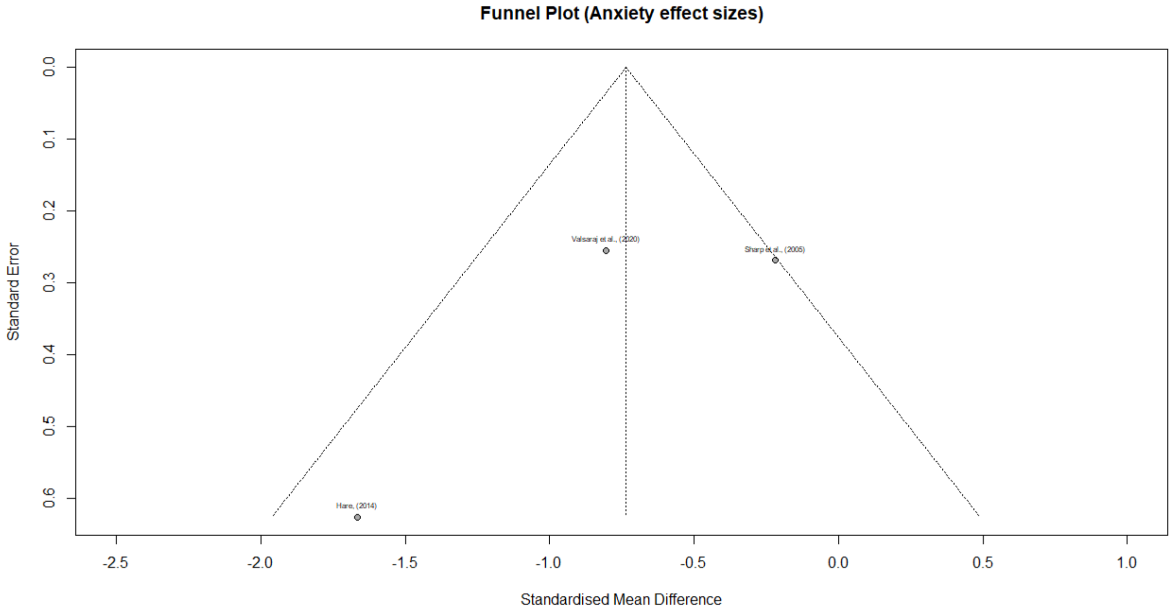
## Anxiety: Forest plot // pooled effect size



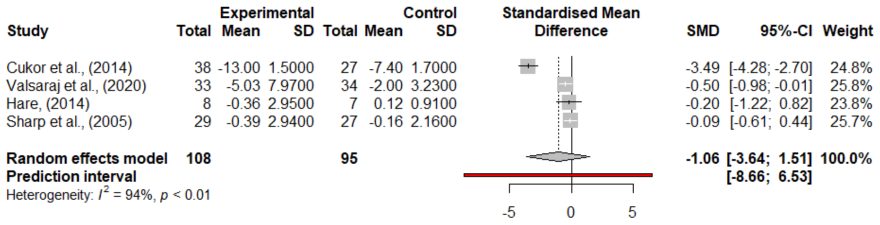
| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Hare, (2014) | 8 | -3.45 | 3.5900 | 7 | 1.51 | 1.4100 | -1.67 | [-2.89; -0.44] | 19.2% |
| Valsaraj et al., (2020) | 33 | -3.52 | 5.5800 | 34 | -0.32 | 0.5200 | -0.80 | [-1.30; -0.31] | 40.9% |
| Sharp et al., (2005) | 29 | -0.75 | 3.1400 | 27 | -0.15 | 2.1800 | -0.22 | [-0.74; 0.31] | 39.9% |
| **Random effects model** | **70** | | | **68** | | | **-0.74** | **[-2.33; 0.86]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-8.39; 6.92]** | |

Heterogeneity: $I^2 = 64\%$, $p = 0.06$

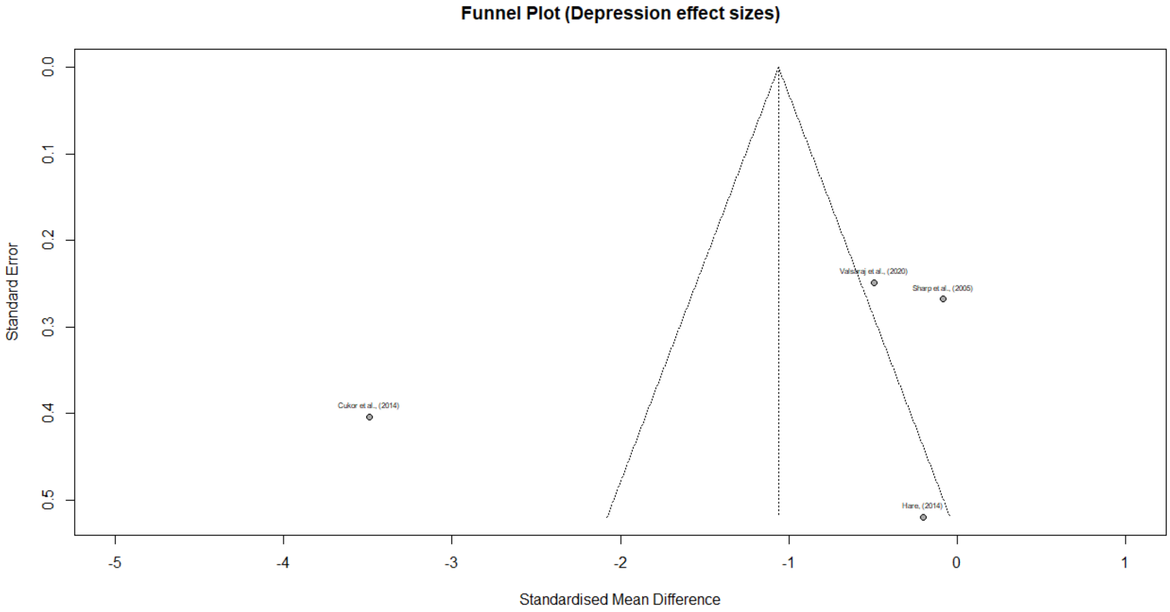
## Funnel plot



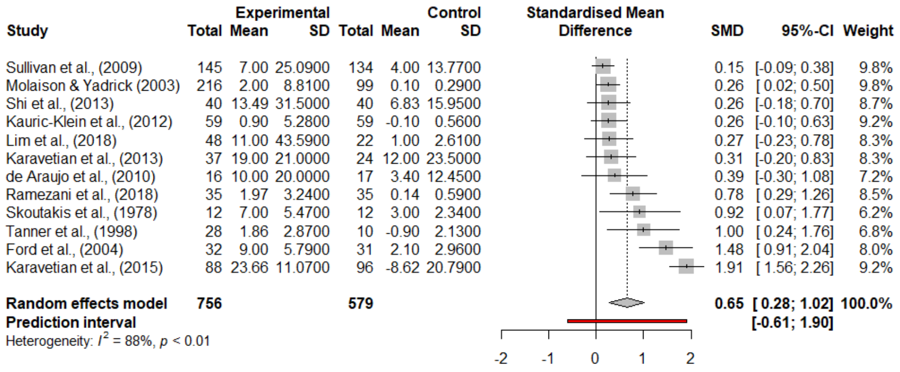
## Depression: Forest plot // pooled effect size



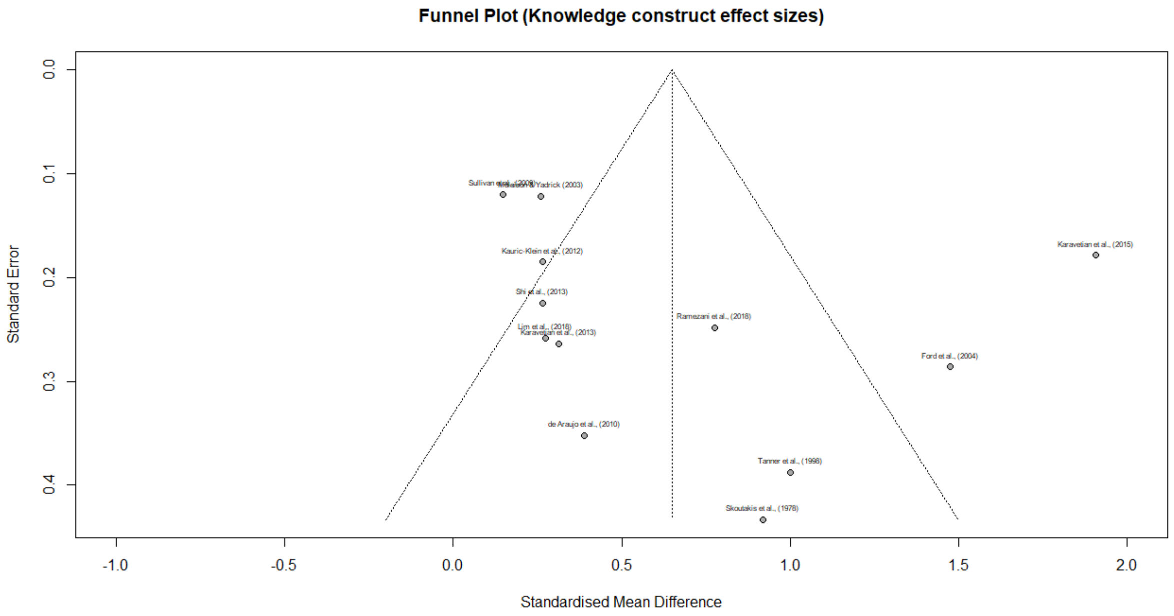
## Funnel plot



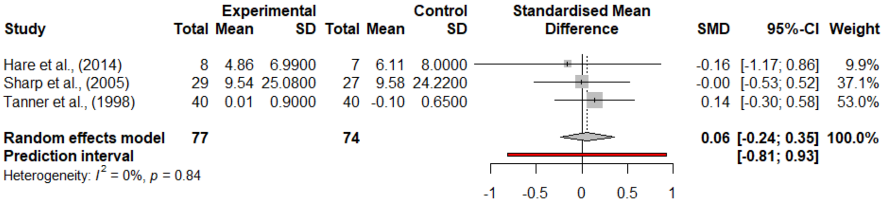
## Knowledge: Forest plot // pooled effect size



## Funnel plot



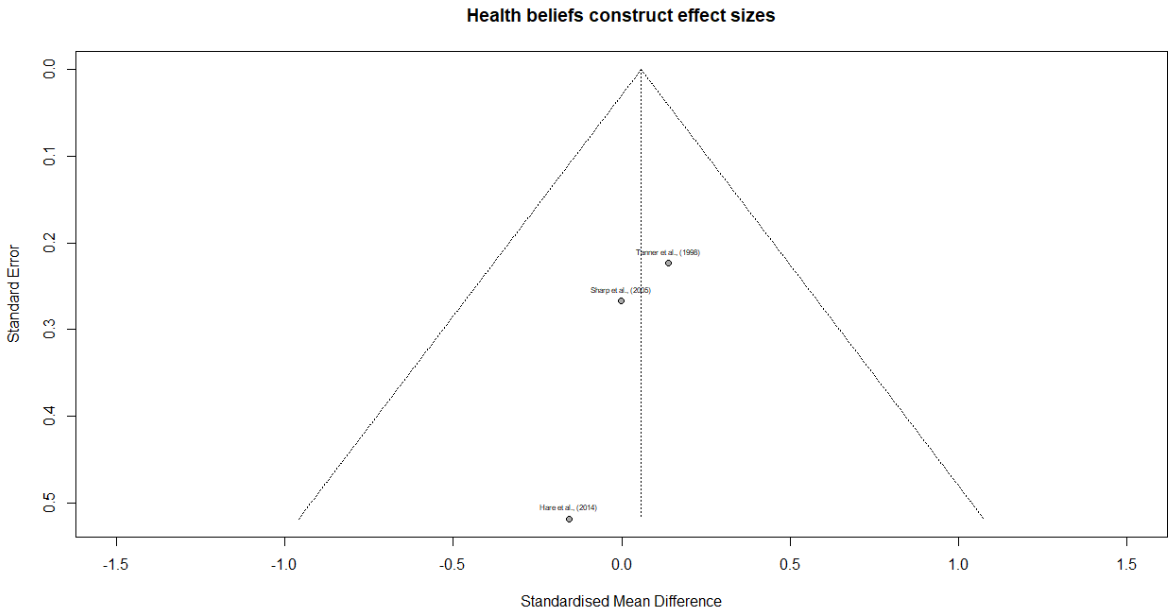
## Outcome expectancies: Forest plot // pooled effect size



| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Hare et al., (2014) | 8 | 4.86 | 6.9900 | 7 | 6.11 | 8.0000 | -0.16 | [-1.17; 0.86] | 9.9% |
| Sharp et al., (2005) | 29 | 9.54 | 25.0800 | 27 | 9.58 | 24.2200 | -0.00 | [-0.53; 0.52] | 37.1% |
| Tanner et al., (1998) | 40 | 0.01 | 0.9000 | 40 | -0.10 | 0.6500 | 0.14 | [-0.30; 0.58] | 53.0% |
| **Random effects model** | **77** | | | **74** | | | **0.06** | **[-0.24; 0.35]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-0.81; 0.93]** | |

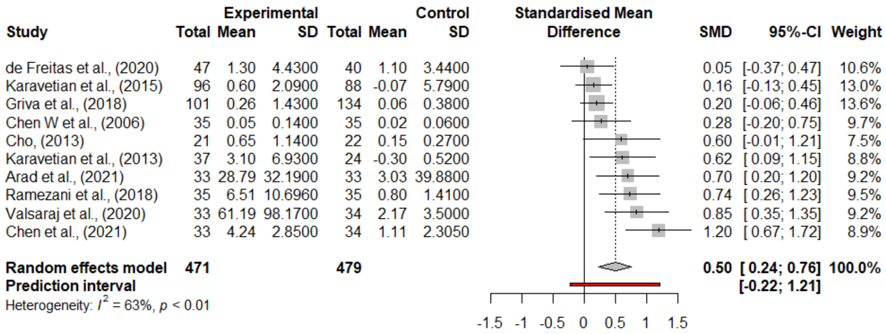
Heterogeneity: $I^2 = 0\%$, $p = 0.84$

## Funnel plot



## Behavioural outcomes

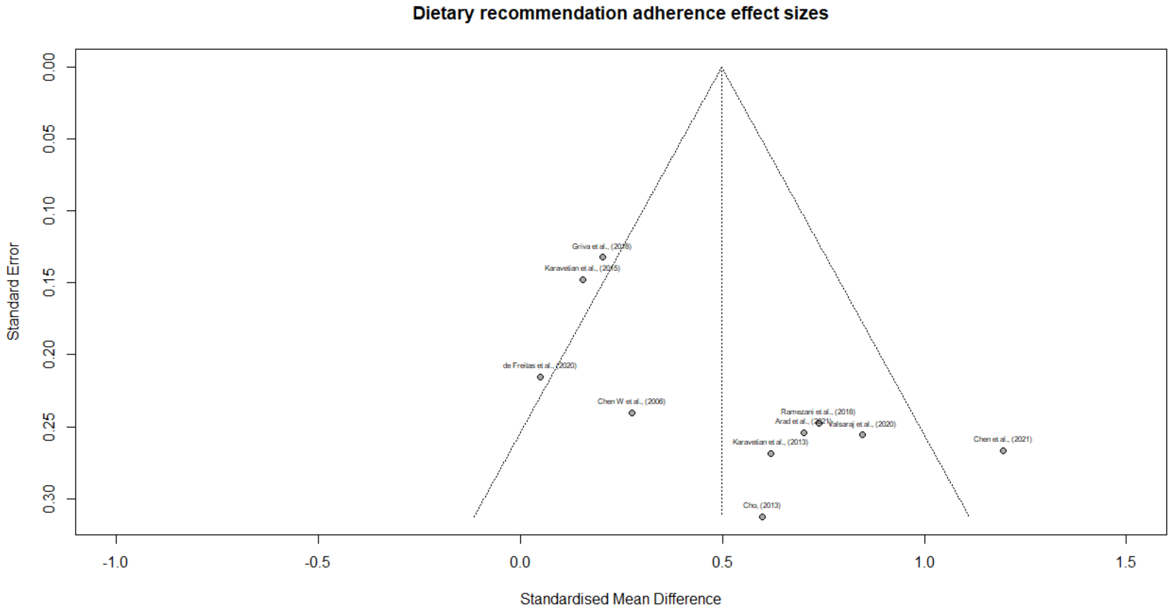
### Dietary adherence: Forest plot // pooled effect size



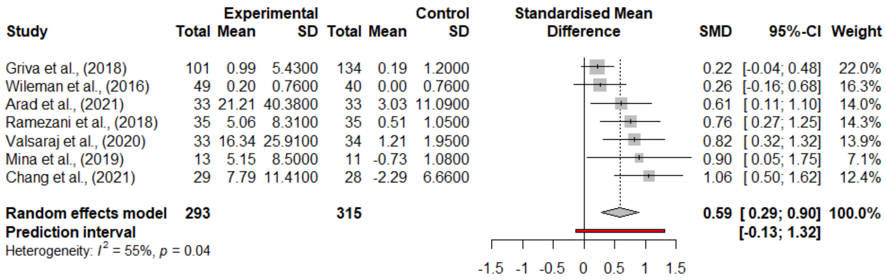
| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| de Freitas et al., (2020) | 47 | 1.30 | 4.4300 | 40 | 1.10 | 3.4400 | 0.05 | [-0.37; 0.47] | 10.6% |
| Karavetian et al., (2015) | 96 | 0.60 | 2.0900 | 88 | -0.07 | 5.7900 | 0.16 | [-0.13; 0.45] | 13.0% |
| Griva et al., (2018) | 101 | 0.26 | 1.4300 | 134 | 0.06 | 0.3800 | 0.20 | [-0.06; 0.46] | 13.6% |
| Chen W et al., (2006) | 35 | 0.05 | 0.1400 | 35 | 0.02 | 0.0600 | 0.28 | [-0.20; 0.75] | 9.7% |
| Cho, (2013) | 21 | 0.65 | 1.1400 | 22 | 0.15 | 0.2700 | 0.60 | [-0.01; 1.21] | 7.5% |
| Karavetian et al., (2013) | 37 | 3.10 | 6.9300 | 24 | -0.30 | 0.5200 | 0.62 | [ 0.09; 1.15] | 8.8% |
| Arad et al., (2021) | 33 | 28.79 | 32.1900 | 33 | 3.03 | 39.8800 | 0.70 | [ 0.20; 1.20] | 9.2% |
| Ramezani et al., (2018) | 35 | 6.51 | 10.6960 | 35 | 0.80 | 1.4100 | 0.74 | [ 0.26; 1.23] | 9.5% |
| Valsaraj et al., (2020) | 33 | 61.19 | 98.1700 | 34 | 2.17 | 3.5000 | 0.85 | [ 0.35; 1.35] | 9.2% |
| Chen et al., (2021) | 33 | 4.24 | 2.8500 | 34 | 1.11 | 2.3050 | 1.20 | [ 0.67; 1.72] | 8.9% |
| **Random effects model** | **471** | | | **479** | | | **0.50** | **[ 0.24; 0.76]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-0.22; 1.21]** | |

Heterogeneity: $I^2 = 63\%$, $p < 0.01$

### Funnel plot



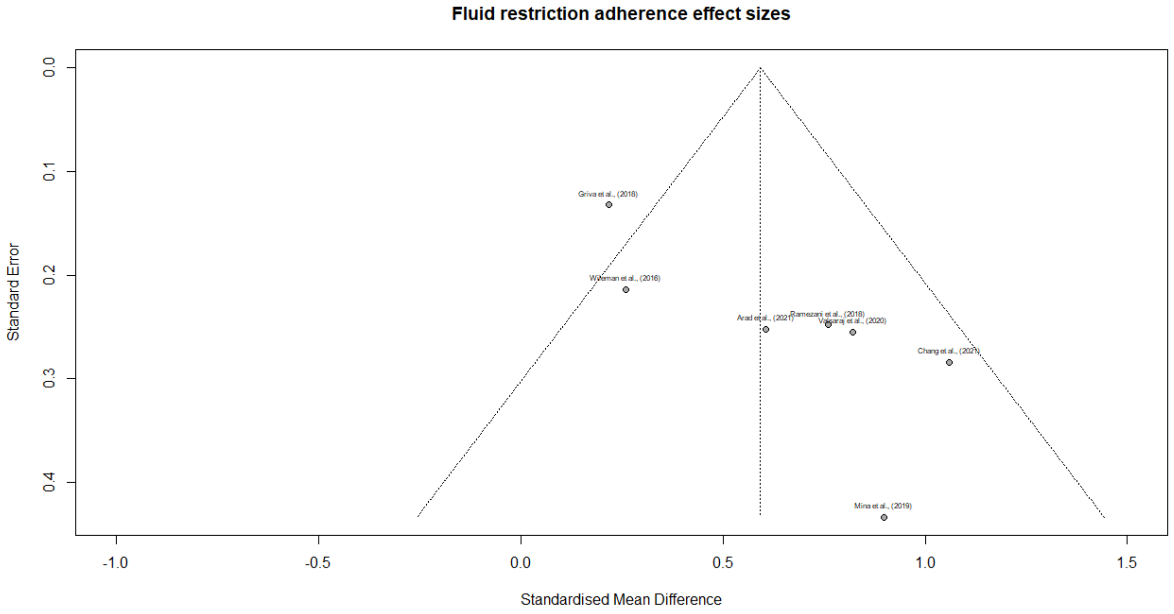
### Fluid adherence: Forest plot // pooled effect size



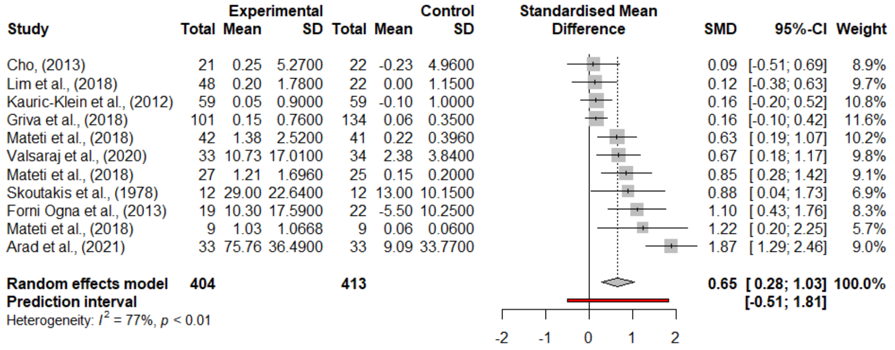
| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Griva et al., (2018) | 101 | 0.99 | 5.4300 | 134 | 0.19 | 1.2000 | 0.22 | [-0.04; 0.48] | 22.0% |
| Wileman et al., (2016) | 49 | 0.20 | 0.7600 | 40 | 0.00 | 0.7600 | 0.26 | [-0.16; 0.68] | 16.3% |
| Arad et al., (2021) | 33 | 21.21 | 40.3800 | 33 | 3.03 | 11.0900 | 0.61 | [ 0.11; 1.10] | 14.0% |
| Ramezani et al., (2018) | 35 | 5.06 | 8.3100 | 35 | 0.51 | 1.0500 | 0.76 | [ 0.27; 1.25] | 14.3% |
| Valsaraj et al., (2020) | 33 | 16.34 | 25.9100 | 34 | 1.21 | 1.9500 | 0.82 | [ 0.32; 1.32] | 13.9% |
| Mina et al., (2019) | 13 | 5.15 | 8.5000 | 11 | -0.73 | 1.0800 | 0.90 | [ 0.05; 1.75] | 7.1% |
| Chang et al., (2021) | 29 | 7.79 | 11.4100 | 28 | -2.29 | 6.6600 | 1.06 | [ 0.50; 1.62] | 12.4% |
| **Random effects model** | **293** | | | **315** | | | **0.59** | **[ 0.29; 0.90]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-0.13; 1.32]** | |

Heterogeneity: $I^2 = 55\%$, $p = 0.04$

## Funnel plot



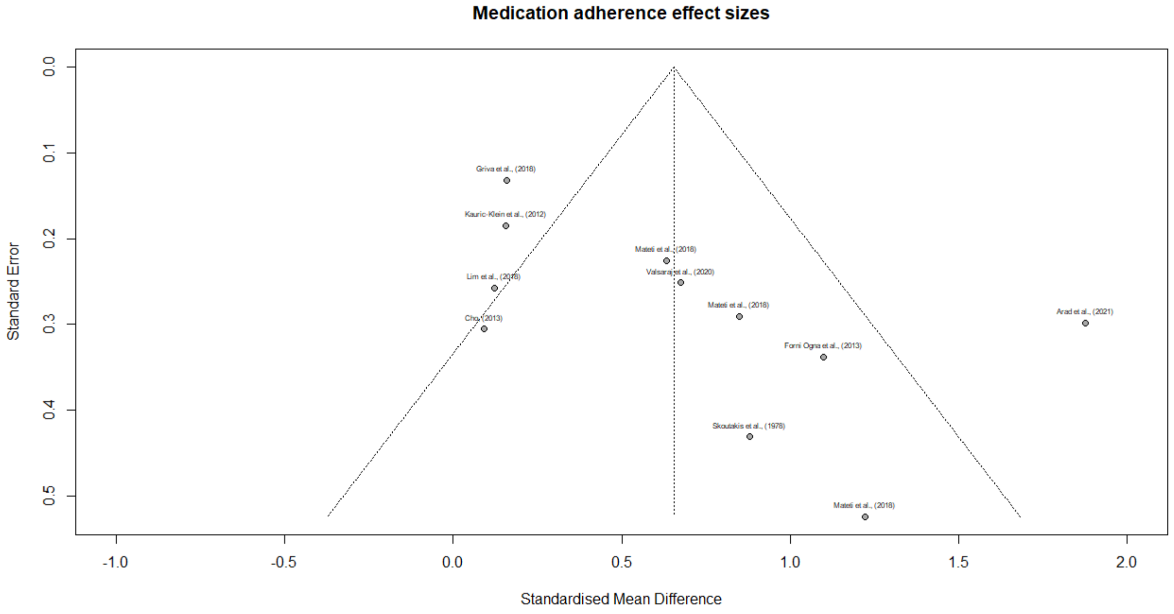
## Medication adherence: Forest plot // pooled effect size



| Study | Experimental | | | Control | | | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| | Total | Mean | SD | Total | Mean | SD | | | |
| Cho, (2013) | 21 | 0.25 | 5.2700 | 22 | -0.23 | 4.9600 | 0.09 | [-0.51; 0.69] | 8.9% |
| Lim et al., (2018) | 48 | 0.20 | 1.7800 | 22 | 0.00 | 1.1500 | 0.12 | [-0.38; 0.63] | 9.7% |
| Kauric-Klein et al., (2012) | 59 | 0.05 | 0.9000 | 59 | -0.10 | 1.0000 | 0.16 | [-0.20; 0.52] | 10.8% |
| Griva et al., (2018) | 101 | 0.15 | 0.7600 | 134 | 0.06 | 0.3500 | 0.16 | [-0.10; 0.42] | 11.6% |
| Mateti et al., (2018) | 42 | 1.38 | 2.5200 | 41 | 0.22 | 0.3960 | 0.63 | [ 0.19; 1.07] | 10.2% |
| Valsaraj et al., (2020) | 33 | 10.73 | 17.0100 | 34 | 2.38 | 3.8400 | 0.67 | [ 0.18; 1.17] | 9.8% |
| Mateti et al., (2018) | 27 | 1.21 | 1.6960 | 25 | 0.15 | 0.2000 | 0.85 | [ 0.28; 1.42] | 9.1% |
| Skoutakis et al., (1978) | 12 | 29.00 | 22.6400 | 12 | 13.00 | 10.1500 | 0.88 | [ 0.04; 1.73] | 6.9% |
| Forni Ogna et al., (2013) | 19 | 10.30 | 17.5900 | 22 | -5.50 | 10.2500 | 1.10 | [ 0.43; 1.76] | 8.3% |
| Mateti et al., (2018) | 9 | 1.03 | 1.0668 | 9 | 0.06 | 0.0600 | 1.22 | [ 0.20; 2.25] | 5.7% |
| Arad et al., (2021) | 33 | 75.76 | 36.4900 | 33 | 9.09 | 33.7700 | 1.87 | [ 1.29; 2.46] | 9.0% |
| **Random effects model** | **404** | | | **413** | | | **0.65** | **[ 0.28; 1.03]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-0.51; 1.81]** | |

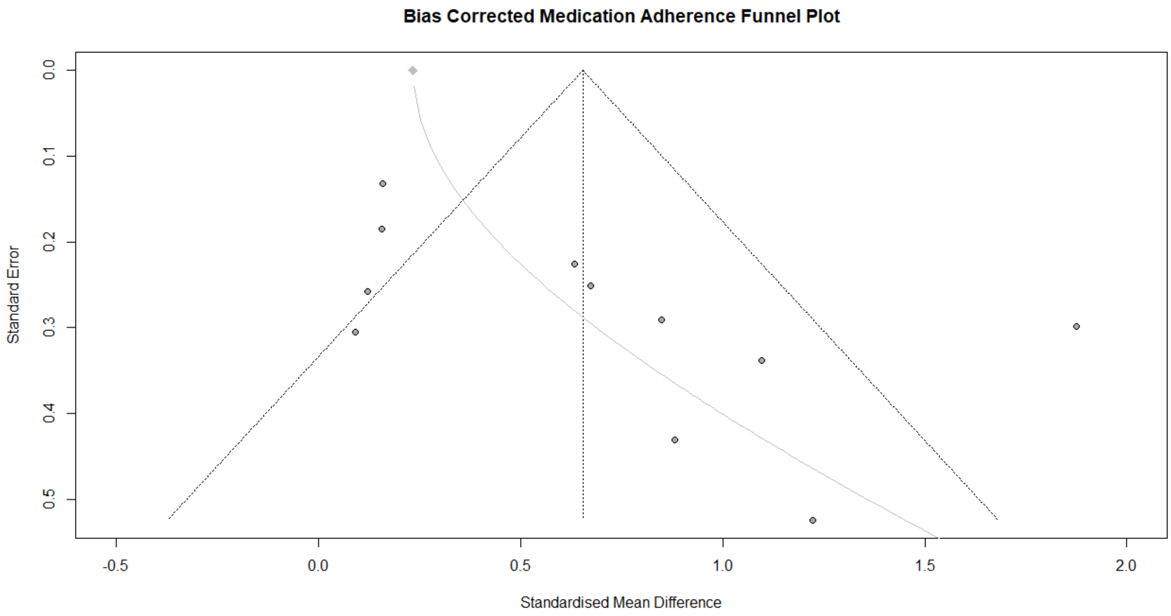
Heterogeneity: $I^2 = 77\%$, $p < 0.01$

## Funnel plot

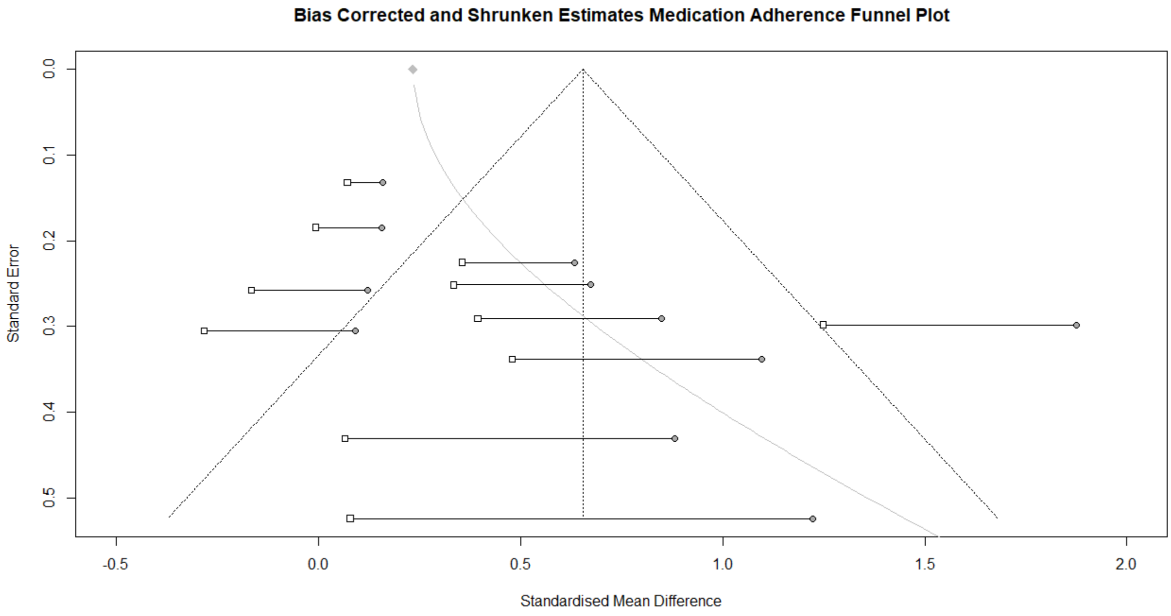


# Ruckers Limit Meta-Analysis

## Funnel plot with curve (bias corrected)

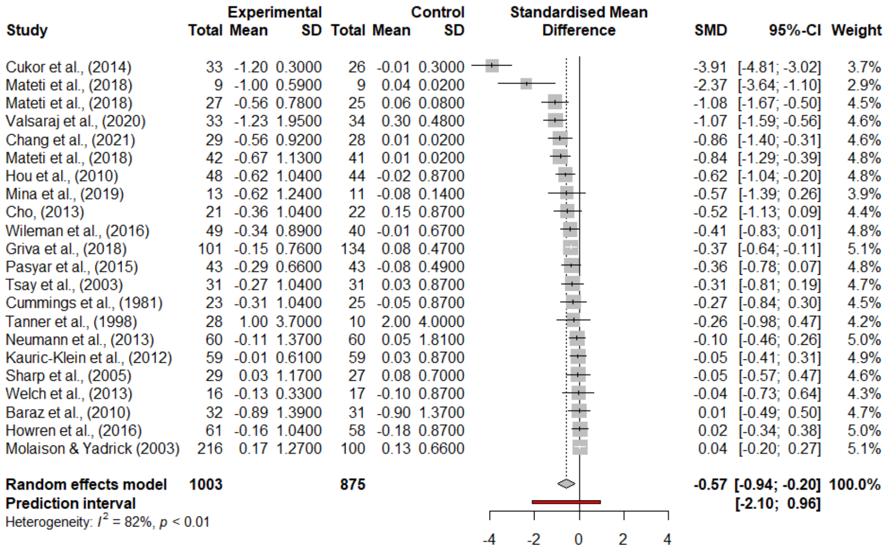


## Funnel plot with shrunken estimates



## Physiological outcomes

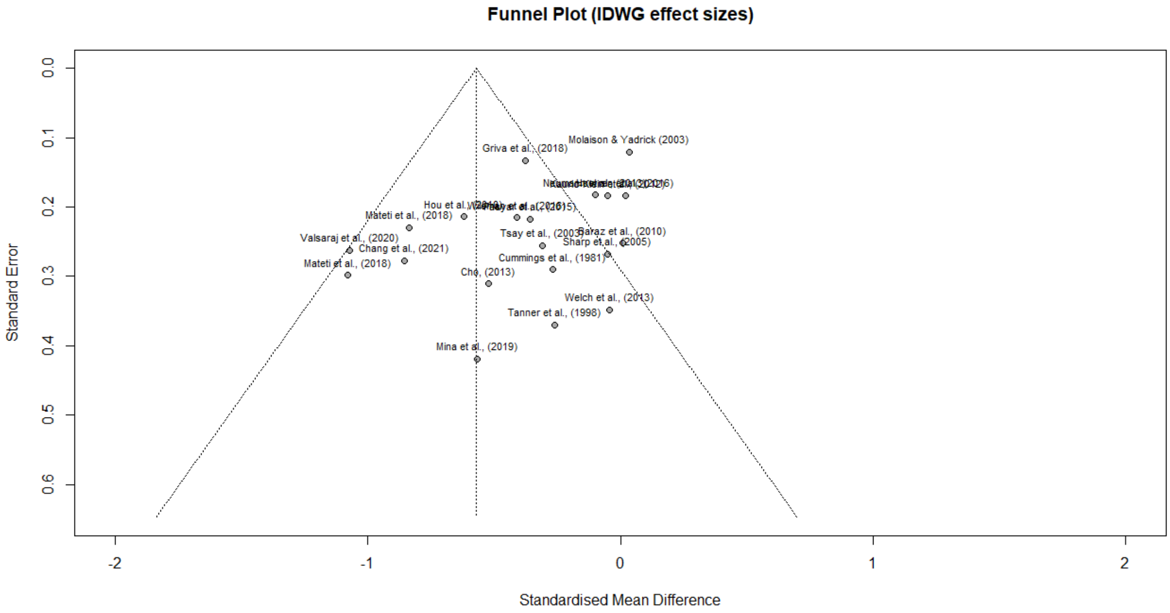
### IDWG: Forest plot // pooled effect size



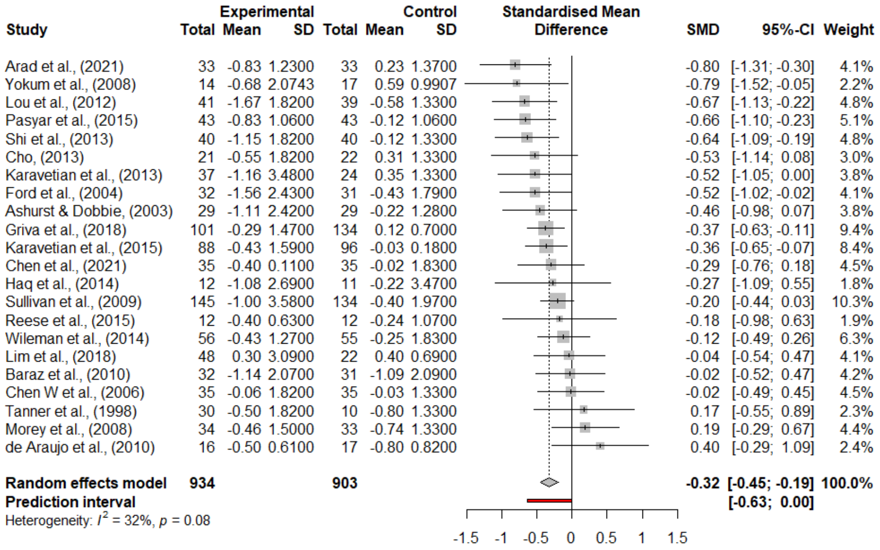
| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Cukor et al., (2014) | 33 | -1.20 | 0.3000 | 26 | -0.01 | 0.3000 | -3.91 | [-4.81; -3.02] | 3.7% |
| Mateti et al., (2018) | 9 | -1.00 | 0.5900 | 9 | 0.04 | 0.0200 | -2.37 | [-3.64; -1.10] | 2.9% |
| Mateti et al., (2018) | 27 | -0.56 | 0.7800 | 25 | 0.06 | 0.0800 | -1.08 | [-1.67; -0.50] | 4.5% |
| Valsaraj et al., (2020) | 33 | -1.23 | 1.9500 | 34 | 0.30 | 0.4800 | -1.07 | [-1.59; -0.56] | 4.6% |
| Chang et al., (2021) | 29 | -0.56 | 0.9200 | 28 | 0.01 | 0.0200 | -0.86 | [-1.40; -0.31] | 4.6% |
| Mateti et al., (2018) | 42 | -0.67 | 1.1300 | 41 | 0.01 | 0.0200 | -0.84 | [-1.29; -0.39] | 4.8% |
| Hou et al., (2010) | 48 | -0.62 | 1.0400 | 44 | -0.02 | 0.8700 | -0.62 | [-1.04; -0.20] | 4.8% |
| Mina et al., (2019) | 13 | -0.62 | 1.2400 | 11 | -0.08 | 0.1400 | -0.57 | [-1.39; 0.26] | 3.9% |
| Cho, (2013) | 21 | -0.36 | 1.0400 | 22 | 0.15 | 0.8700 | -0.52 | [-1.13; 0.09] | 4.4% |
| Wileman et al., (2016) | 49 | -0.34 | 0.8900 | 40 | -0.01 | 0.6700 | -0.41 | [-0.83; 0.01] | 4.8% |
| Griva et al., (2018) | 101 | -0.15 | 0.7600 | 134 | 0.08 | 0.4700 | -0.37 | [-0.64; -0.11] | 5.1% |
| Pasyar et al., (2015) | 43 | -0.29 | 0.6600 | 43 | -0.08 | 0.4900 | -0.36 | [-0.78; 0.07] | 4.8% |
| Tsay et al., (2003) | 31 | -0.27 | 1.0400 | 31 | 0.03 | 0.8700 | -0.31 | [-0.81; 0.19] | 4.7% |
| Cummings et al., (1981) | 23 | -0.31 | 1.0400 | 25 | -0.05 | 0.8700 | -0.27 | [-0.84; 0.30] | 4.5% |
| Tanner et al., (1998) | 28 | 1.00 | 3.7000 | 10 | 2.00 | 4.0000 | -0.26 | [-0.98; 0.47] | 4.2% |
| Neumann et al., (2013) | 60 | -0.11 | 1.3700 | 60 | 0.05 | 1.8100 | -0.10 | [-0.46; 0.26] | 5.0% |
| Kauric-Klein et al., (2012) | 59 | -0.01 | 0.6100 | 59 | 0.03 | 0.8700 | -0.05 | [-0.41; 0.31] | 4.9% |
| Sharp et al., (2005) | 29 | 0.03 | 1.1700 | 27 | 0.08 | 0.7000 | -0.05 | [-0.57; 0.47] | 4.6% |
| Welch et al., (2013) | 16 | -0.13 | 0.3300 | 17 | -0.10 | 0.8700 | -0.04 | [-0.73; 0.64] | 4.3% |
| Baraz et al., (2010) | 32 | -0.89 | 1.3900 | 31 | -0.90 | 1.3700 | 0.01 | [-0.49; 0.50] | 4.7% |
| Howren et al., (2016) | 61 | -0.16 | 1.0400 | 58 | -0.18 | 0.8700 | 0.02 | [-0.34; 0.38] | 5.0% |
| Molaison & Yadrick (2003) | 216 | 0.17 | 1.2700 | 100 | 0.13 | 0.6600 | 0.04 | [-0.20; 0.27] | 5.1% |
| **Random effects model** | **1003** | | | **875** | | | **-0.57** | **[-0.94; -0.20]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-2.10; 0.96]** | |

Heterogeneity: $I^2 = 82\%$, $p < 0.01$

### Funnel plot



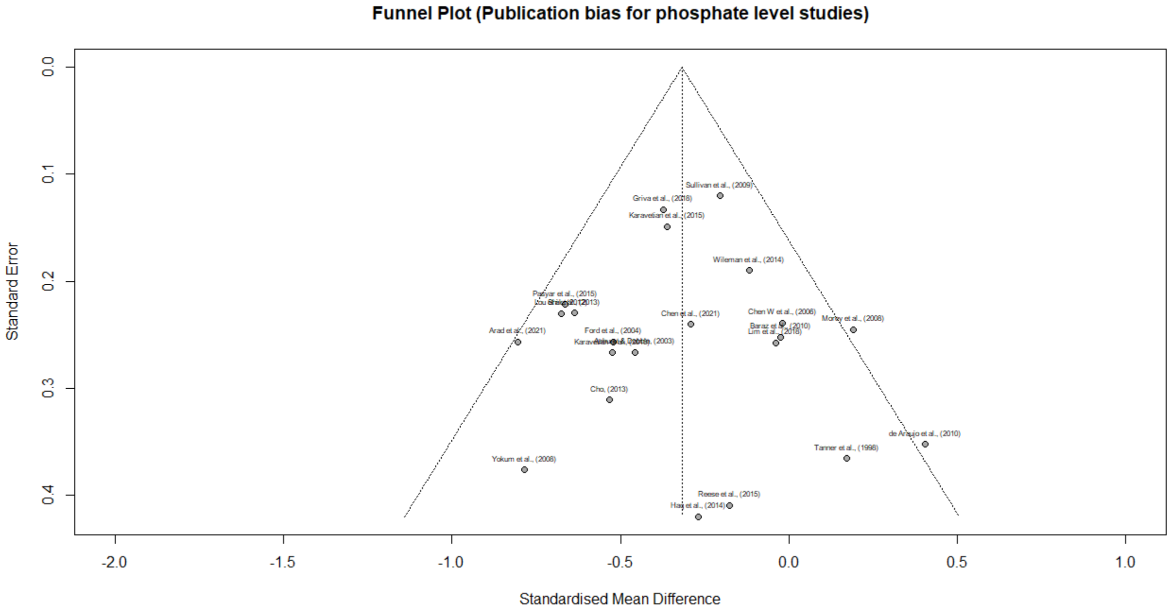
## Phosphate serum level: Forest plot // pooled effect size



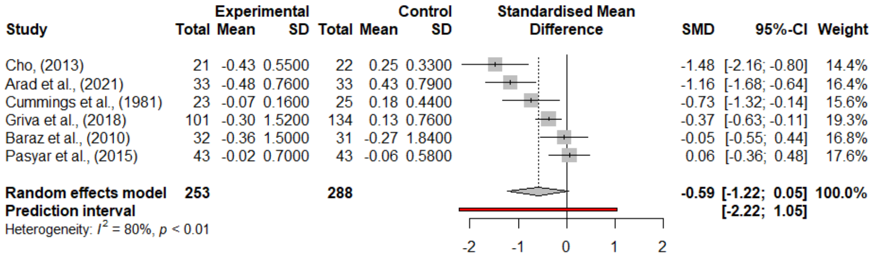
| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Arad et al., (2021) | 33 | -0.83 | 1.2300 | 33 | 0.23 | 1.3700 | -0.80 | [-1.31; -0.30] | 4.1% |
| Yokum et al., (2008) | 14 | -0.68 | 2.0743 | 17 | 0.59 | 0.9907 | -0.79 | [-1.52; -0.05] | 2.2% |
| Lou et al., (2012) | 41 | -1.67 | 1.8200 | 39 | -0.58 | 1.3300 | -0.67 | [-1.13; -0.22] | 4.8% |
| Pasyar et al., (2015) | 43 | -0.83 | 1.0600 | 43 | -0.12 | 1.0600 | -0.66 | [-1.10; -0.23] | 5.1% |
| Shi et al., (2013) | 40 | -1.15 | 1.8200 | 40 | -0.12 | 1.3300 | -0.64 | [-1.09; -0.19] | 4.8% |
| Cho, (2013) | 21 | -0.55 | 1.8200 | 22 | 0.31 | 1.3300 | -0.53 | [-1.14; 0.08] | 3.0% |
| Karavetian et al., (2013) | 37 | -1.16 | 3.4800 | 24 | 0.35 | 1.3300 | -0.52 | [-1.05; 0.00] | 3.8% |
| Ford et al., (2004) | 32 | -1.56 | 2.4300 | 31 | -0.43 | 1.7900 | -0.52 | [-1.02; -0.02] | 4.1% |
| Ashurst & Dobbie, (2003) | 29 | -1.11 | 2.4200 | 29 | -0.22 | 1.2800 | -0.46 | [-0.98; 0.07] | 3.8% |
| Griva et al., (2018) | 101 | -0.29 | 1.4700 | 134 | 0.12 | 0.7000 | -0.37 | [-0.63; -0.11] | 9.4% |
| Karavetian et al., (2015) | 88 | -0.43 | 1.5900 | 96 | -0.03 | 0.1800 | -0.36 | [-0.65; -0.07] | 8.4% |
| Chen et al., (2021) | 35 | -0.40 | 0.1100 | 35 | -0.02 | 1.8300 | -0.29 | [-0.76; 0.18] | 4.5% |
| Haq et al., (2014) | 12 | -1.08 | 2.6900 | 11 | -0.22 | 3.4700 | -0.27 | [-1.09; 0.55] | 1.8% |
| Sullivan et al., (2009) | 145 | -1.00 | 3.5800 | 134 | -0.40 | 1.9700 | -0.20 | [-0.44; 0.03] | 10.3% |
| Reese et al., (2015) | 12 | -0.40 | 0.6300 | 12 | -0.24 | 1.0700 | -0.18 | [-0.98; 0.63] | 1.9% |
| Wileman et al., (2014) | 56 | -0.43 | 1.2700 | 55 | -0.25 | 1.8300 | -0.12 | [-0.49; 0.26] | 6.3% |
| Lim et al., (2018) | 48 | 0.30 | 3.0900 | 22 | 0.40 | 0.6900 | -0.04 | [-0.54; 0.47] | 4.1% |
| Baraz et al., (2010) | 32 | -1.14 | 2.0700 | 31 | -1.09 | 2.0900 | -0.02 | [-0.52; 0.47] | 4.2% |
| Chen W et al., (2006) | 35 | -0.06 | 1.8200 | 35 | -0.03 | 1.3300 | -0.02 | [-0.49; 0.45] | 4.5% |
| Tanner et al., (1998) | 30 | -0.50 | 1.8200 | 10 | -0.80 | 1.3300 | 0.17 | [-0.55; 0.89] | 2.3% |
| Morey et al., (2008) | 34 | -0.46 | 1.5000 | 33 | -0.74 | 1.3300 | 0.19 | [-0.29; 0.67] | 4.4% |
| de Araujo et al., (2010) | 16 | -0.50 | 0.6100 | 17 | -0.80 | 0.8200 | 0.40 | [-0.29; 1.09] | 2.4% |
| **Random effects model** | **934** | | | **903** | | | **-0.32** | **[-0.45; -0.19]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-0.63; 0.00]** | |

Heterogeneity: $I^2 = 32\%$, $p = 0.08$

## Funnel plot



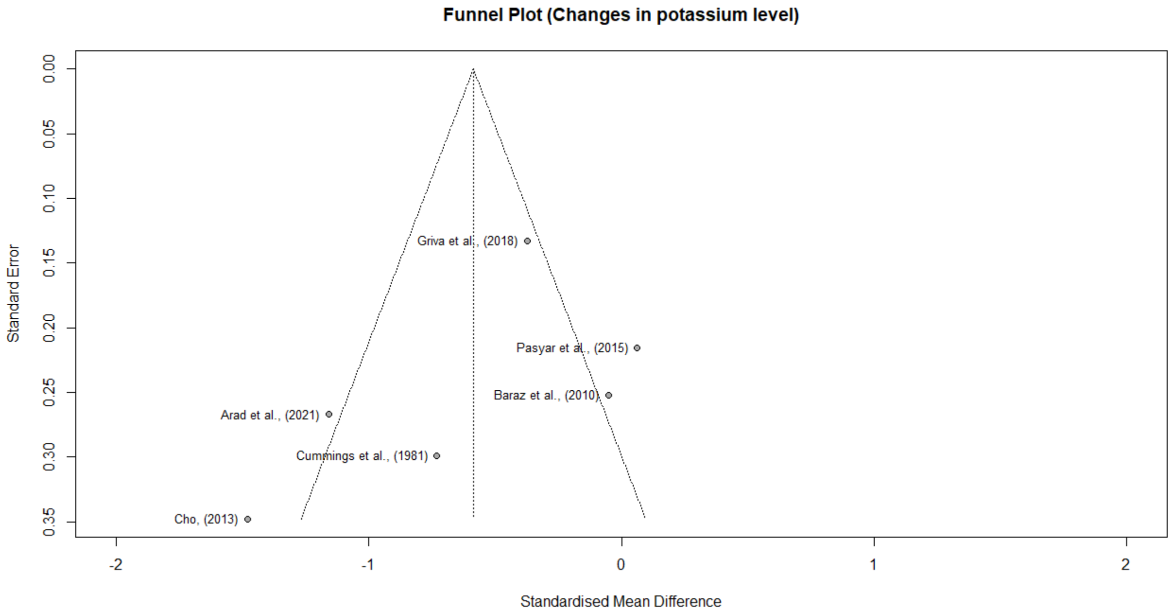
## Potassium serum level: Funnel plots/ pooled effect



| Study | Experimental Total | Experimental Mean | Experimental SD | Control Total | Control Mean | Control SD | SMD | 95%-CI | Weight |
|---|---|---|---|---|---|---|---|---|---|
| Cho, (2013) | 21 | -0.43 | 0.5500 | 22 | 0.25 | 0.3300 | -1.48 | [-2.16; -0.80] | 14.4% |
| Arad et al., (2021) | 33 | -0.48 | 0.7600 | 33 | 0.43 | 0.7900 | -1.16 | [-1.68; -0.64] | 16.4% |
| Cummings et al., (1981) | 23 | -0.07 | 0.1600 | 25 | 0.18 | 0.4400 | -0.73 | [-1.32; -0.14] | 15.6% |
| Griva et al., (2018) | 101 | -0.30 | 1.5200 | 134 | 0.13 | 0.7600 | -0.37 | [-0.63; -0.11] | 19.3% |
| Baraz et al., (2010) | 32 | -0.36 | 1.5000 | 31 | -0.27 | 1.8400 | -0.05 | [-0.55; 0.44] | 16.8% |
| Pasyar et al., (2015) | 43 | -0.02 | 0.7000 | 43 | -0.06 | 0.5800 | 0.06 | [-0.36; 0.48] | 17.6% |
| **Random effects model** | **253** | | | **288** | | | **-0.59** | **[-1.22; 0.05]** | **100.0%** |
| **Prediction interval** | | | | | | | | **[-2.22; 1.05]** | |

Heterogeneity: $I^2 = 80\%$, $p < 0.01$

## Funnel plot



## **Chapters 3 and 4** Qualitative study of patients on dialysis experience of kidney disease

## Appendix C

### Qualitative interview schedule

1. To start, in your own words, what does having kidney disease mean to you?

    **P**- What does your condition mean to you?
    **P**- If it has restricted thing- what kind of things
    **p**- how has it impacted on your life- has it affected your social/family life?

2. Has anyone ever advised you to make changes to your lifestyle because of kidney disease?

    **P**- probe the sources of advice information- who? nurses, dietitians, doctor, what been given- printed sheets, books etc. Looked things up

3. Can you explain to me the type of things you are expected to do (e.g., the foods to avoid etc)?

    **P**- Can you tell me the foods you are allowed to eat / avoid (fluids- how much you are supposed to drink)
    **P**- Do you know what you should be doing?

4. What do you think would happen if you do not do these things?

    **P**- If you were not careful about your diet (what you eat) or ate food on the avoid list/ drank too much, what do you think would happen to you?

5. Overall, how much does it matter to you to do these things in your daily life?

    **P**- why is it/ why is it not important to you to follow these things?
    **P**- do you try hard/ or not?

6. Do you find it easy or difficult to follow the advice you have been given (e.g., nurses or whoever gave advice?
    **P**- how much do you believe that you can follow their advice?

    **P**- if difficult- what makes it difficult, if easy- what makes it easy? If someone else makes food etc- where do they get the information from, what do they do, do you do it together?

7. Can you tell me some of the ways that you try to do these things?

    **P**- (have a plan [what is on this plan], write down what I eat, drink, check my weight, have a cup with the amount of water I can drink, keeping a record, getting someone else to do it)

What have you found useful - has it improved any of your outcomes (IDWG, potassium etc)? If you were helping a new patient to follow these things- what would you tell them?

8. Do you have support from friends and family (share the same meals, adjust their habit, you felt understood)?

**Monitoring by the Clinic**

I understand that once a month when you come here to the clinic, they test your blood and weigh you before dialysis.

9. How did you feel today before coming to this dialysis session?
10. Does it bother you when your monthly bloods are coming up?
11. Why do you think you have your bloods taken monthly?
12. When your monthly blood results come back as 'high'/ 'within target range', how does that make you feel?

    **P-** If happy what impact does this have on personal efforts- try harder (what does this mean) or celebrate with a blow-out. If gloomy how does this affect your efforts going forward?

13. You were weighed today, what was the feedback you received from staff?

    **P-** How did it make you feel?
    **P-** How did your care team react?

I would like to ask you a few questions about how having kidney disease make you feel

**Self-Identity and esteem**

14. How does it make you feel about yourself as a person?

    **P-** Has this changed since your diagnosis?

**Connection to others**

15. How has having kidney disease affected your relationship with close others?

    **P-** friends, family, partners

**Mood**

16. Do you ever feel really down in yourself?

    **P-** are you feeling like that now, how often do you feel like this?

**Future**

17. If you got a transplant tomorrow, how would your life change?

**P-** Do you think you will get a transplant? What does it depend upon? If yes, is there anything you are trying to do to help you to get one? (self-management)

18. Generally, how do you view the future?
    Just in case you end on a very sad note, use a mood manipulation at the end of the interview- tell me about sometime when you felt happy.

**Dissemination**

Once the results of this study have been completed, what is the best way for us to share our findings with others?

Who should we tell this information?

Finally, I just want to say that sometimes when people take part in interviews, it might cause them to feel a certain kind of way. So, if after I leave or you go home and you feel a certain type of way and want to talk to someone, I have a number here for the hospitals Crisis Action Team (CAT) (**0300 123 2425**).

Do you have any questions for me before we end?

That will be all, thank you so much for your time. Crisis card: give to all.

## **Chapter 5** The role of regulatory support on fluid management among patients on dialysis

## Appendix D

### Qualtrics regulatory support full study questionnaire

### Your views on how you manage your kidney disease survey

| | |
|---|---|
| **SECTION 1** | **THESE QUESTIONS ARE ABOUT YOU. ALL ANSWERS WILL BE TREATED WITH STRICT CONFIDENCE. PLEASE ANSWER ALL THE QUESTIONS.** |

**What is your age? Please write a number here (e.g., 62)** ______________

**What is your gender?** (Please tick √ one box)

☐ Male ☐ Female ☐ Other gender identity ☐ Prefer not to say

**How would you describe your ethnicity?** If more than one category applies, please select the one with which you most strongly identify. (Please tick √ one box)

☐ White (e.g., Caucasian, European, Irish, Gypsy or Irish Traveller)
☐ Asian (e.g., Chinese, Singaporean, Indian, Bangladeshi, Pakistani, Asian British)
☐ Middle-Eastern (e.g., Saudi-Arabian, Iranian, Lebanese, Turkish)
☐ Black (e.g., African, Caribbean, African-American, Black British)
☐ Mixed/Multiple Ethnic Groups
☐ Other (Please Specify) ________________________________________________

**Which of the following classifications best describes your relationship status?** (Please tick √ one box)

☐ Single (not in a romantic relationship) ☐ Casually dating ☐ Exclusively dating/In a committed dating relationship

☐ Married/Civil Partnership/Common-Law ☐ Widowed ☐ Engaged

**Do you have a child/ children?**

☐ Yes ☐ No

**Which of the following best describes your current living situation?** (Please tick √ one box)

☐ I live alone ☐ I live with my partner and/or family members (e.g., spouse, children) ☐ I live in an assisted/ supported living accommodation

☐ I live with people who are not related to me (e.g., shared accommodation) ☐ Other (Please Specify) ________________________

**What is the highest level of education you have completed?** (Please tick √ one box)

☐ No formal education ☐ Primary school ☐ Secondary school

☐ College/Sixth form ☐ Apprenticeships ☐ Undergraduate

☐ Postgraduate ☐ Specialist/ professional training ☐ Other __________

**What is your current employment status?** Please tick √ the one answer that best applies to you.

☐ Unemployed ☐ Part time paid employment ☐ Full time paid employment

☐ Student ☐ Retired from paid employment ☐ Looking after home and family

☐ Other (please specify) __________________

**Which of the following best captures your annual HOUSEHOLD income before deductions (including all members of your household)?**

☐Under £10,000 ☐£10,000 to £17,999 ☐£18,000 to £25,999 ☐£26,000 to £35,999

☐£36,000-£55,999 ☐£56,000 to £89,999 ☐£90,000 to £149,999 ☐£150,000 and over

**Have you been told that you have problems with your kidneys?**

☐Yes ☐ No

If yes, how long ago were you told? (Please enter the number of months e.g., 12 (display logic) ________________

**Have you received information about dietary restrictions?**

☐Yes ☐ No

**Have you received information about fluid restrictions?**

☐Yes ☐No

**Have you been prescribed any medication since your diagnosis of kidney disease?**

☐Yes ☐No

**Do you know what your GFR is? (This is a measurement of how well your kidneys are working)**

☐Yes ☐ No

If yes, what is your GFR number? E.g., 19 (display logic) ________________

**To look after my kidneys, it is important for me to:** (use sliding scale on Qualtrics and display logic for stage 3AB)

☐Restrict what I drink as much as possible everyday to avoid straining my kidneys.
☐Somewhat restrict what I drink as much as possible everyday to avoid straining my kidneys.
☐Don’t make any changes to how much I drink everyday.
☐Drink somewhat more than usual everyday to flush out my kidneys.

☐ Drink as much as possible everyday to flush out my kidneys.

**What stage is your chronic kidney disease?**

☐ Stage 1 ☐ Stage 2
☐ Stage 3 ☐ Stage 4
☐ Stage 5 ☐ I do not have chronic kidney disease

**Are you on dialysis?**

☐ Yes, haemodialysis (HD) ☐ Yes, peritoneal dialysis (PD)
☐ No

**Do you have diabetes?**

☐ Yes ☐ No

**Have you ever been diagnosed with any other chronic health conditions alongside your kidney disease?**

☐ Yes (please list them here) ________________________________ ☐ No

**Are you currently waiting or eligible for a kidney transplant?** (Please tick √ the box that applies).

☐ My disease is not currently at a point where I need to consider a kidney transplant.

☐ My disease has progressed to a point where I am waiting to be put on the kidney transplant list.

☐ My disease has progressed to a phase where I am currently on a kidney transplant list.

☐ My kidneys are failing but I am not eligible for a kidney transplant.

☐ I have received a kidney transplant in the past.

☐ I previously had a kidney transplant but need a new one.

**Do you receive healthcare that is free at point of service (e.g., single payer or national healthcare), or are you expected to pay out of pocket or through a private insurance provider?**

☐ My healthcare is free at point of service (e.g., I don't receive a bill from my doctor).

☐ My healthcare is paid for (e.g., I pay out of pocket, or it is covered by a private insurance provider)

| | |
|---|---|
| **SECTION 2** | **THIS SECTION IS ABOUT THE PEOPLE IN YOUR LIFE.**<br>**Please answer all the questions.** |

Please think about **how many people you could reach out to in your life** if you needed help. This will include the people in your family (including a spouse/partner, children, parents, siblings, grandchildren, etc), your friends, neighbours, or people in your community. **Please write the number of people you can reach out to here ____________**

| | | | | | | |
|---|---|---|---|---|---|---|
| **SECTION 3: IN THIS SECTION WE WILL ASK YOU ABOUT YOUR FAMILY.**<br>**Please read each statement carefully and draw a circle on each response line. An example of how to do this is below.** | | | | | | |
| **For example, my family tries to help me manage my kidney disease.**<br>**If you slightly agree with this statement, you will draw a circle like this:** | Strongly Disagree | Disagree | Slightly Disagree | [✓ Slightly Agree] | Agree | Strongly Agree |
| The help my family gives me leaves me with a better understanding of how to manage my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my family gives me helps me to think more positively about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my family gives me helps me to get a different point of view on managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my family gives me makes me feel I can manage the course of my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| | | | | | | |
|---|---|---|---|---|---|---|
| The help my family gives me helps me to stay on track with managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my family gives me makes me feel more confident about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family understand the way I feel about things. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family often make too many demands on me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family really cares about me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family often criticise me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can rely upon my family to help if I have a serious problem. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family often let me down when I am counting on them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can open up to my family if I need to talk about my worries. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My family often gets on my nerves. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| **Overall, how satisfied are you with the relationship you have with your family?** | | | | | | |
| I am satisfied with the relationship I have with my family. **Please circle a response.** | Extremely Unsatisfied | Very Unsatisfied | Slightly Unsatisfied | Slightly Satisfied | Very Satisfied | Extremely Satisfied |

| SECTION 4: NOW THINK ABOUT YOUR FRIENDS AND/OR NEIGHBOURS.<br>Please read each statement carefully and draw a circle on each response line. An example of how to do this is below. | | | | | | |
|---|---|---|---|---|---|---|
| **For example, my friends/ neighbours try to help me manage my kidney disease.<br>If you slightly agree with this statement, you will draw a circle like this:** | Strongly Disagree | Disagree | Slightly Disagree | [✓ Slightly Agree] | Agree | Strongly Agree |
| The help my friends/ neighbours give me leaves me with a better understanding of how to manage my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my friends/ neighbours give me helps me to think more positively about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my friends/ neighbours give me helps me to get a different point of view on managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my friends/ neighbours give me makes me feel I can manage the course of my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my friends/ neighbours give me helps me to stay on track with managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my friends/ neighbours give me makes me feel more confident about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours understand the way I feel about things. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours often make too many demands on me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours really care about me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours often criticise me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| | | | | | | |
|---|---|---|---|---|---|---|
| I can rely upon my friends/ neighbours to help if I have a serious problem. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours often let me down when I am counting on them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can open up to my friends/ neighbours if I need to talk about my worries. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My friends/ neighbours often get on my nerves. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| **Overall, how satisfied are you with the relationship you have with your friends/neighbours?** | | | | | | |
| I am satisfied with the relationship I have with my friends and/ or neighbours.<br>**Please circle a response.** | Extremely Unsatisfied | Very Unsatisfied | Slightly Unsatisfied | Slightly Satisfied | Very Satisfied | Extremely Satisfied |

| | | | | | | |
|---|---|---|---|---|---|---|
| **SECTION 5: NOW THINK ABOUT OTHER PEOPLE WITH KIDNEY DISEASE (e.g., support groups, treatment centres, etc)**<br>**Please read each statement carefully and draw a circle on each response line. An example of how to do this is below.** | | | | | | |
| **For example, other people with kidney disease try to help me manage my kidney disease.**<br>**If you slightly agree with this statement, you will draw a circle like this:** | Strongly Disagree | Disagree | Slightly Disagree | [✓ Slightly Agree] | Agree | Strongly Agree |
| The help other people with kidney disease give me leaves me with a better understanding of how to manage my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help other people with kidney disease give me helps me to think more positively about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help other people with kidney disease give me helps me to get a different point of view on managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help other people with kidney disease give me makes me feel I can manage the course of my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| | | | | | | |
|---|---|---|---|---|---|---|
| The help other people with kidney disease give me helps me to stay on track with managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help other people with kidney disease give me makes me feel more confident about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease understand the way I feel about things. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease often make too many demands on me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease really care about me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease often criticise me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can rely upon other people with kidney disease to help if I have a serious problem. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease often let me down when I am counting on them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can open up to other people with kidney disease if I need to talk about my worries. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people with kidney disease often get on my nerves. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| **Overall, how satisfied are you with the relationship you have with other people with kidney disease?** | | | | | | |
| I am satisfied with the relationship I have with other people with kidney disease.<br>**Please circle a response.** | Extremely Unsatisfied | Very Unsatisfied | Slightly Unsatisfied | Slightly Satisfied | Very Satisfied | Extremely Satisfied |

| | | | | | | |
|---|---|---|---|---|---|---|
| **SECTION 6: NOW THINK ABOUR YOUR KIDNEY HEALTHCARE TEAM (e.g., Doctors, Nurses, Dietician).**<br>**Please read each statement carefully and draw a circle on each response line. An example of how to do this is below.** | | | | | | |
| **For example, my healthcare team try to help me manage my kidney disease.**<br>**If you slightly agree with this statement, you will draw a circle like this:** | Strongly Disagree | Disagree | Slightly Disagree | [✓ Slightly Agree] | Agree | Strongly Agree |
| The help my healthcare team gives me leaves me with a better understanding of how to manage my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my healthcare team gives me helps me to think more positively about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my healthcare team gives me helps me to get a different point of view on managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my healthcare team gives me makes me feel I can manage the course of my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my healthcare team gives me helps me to stay on track with managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| The help my healthcare team gives me makes me feel more confident about managing my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My healthcare team understand the way I feel about things. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My healthcare team often make too many demands on me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My healthcare team really cares about me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My healthcare team often criticise me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can rely upon my healthcare team to help if I have a serious problem. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| | | | | | | |
|---|---|---|---|---|---|---|
| My healthcare team often let me down when I am counting on them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I can open up to my healthcare team if I need to talk about my worries. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| My healthcare team often gets on my nerves. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| **Overall, how satisfied are you with the relationship you have with your kidney healthcare team?** | | | | | | |
| I am satisfied with the relationship I have with my kidney healthcare team. **Please circle a response.** | Extremely Unsatisfied | Very Unsatisfied | Slightly Unsatisfied | Slightly Satisfied | Very Satisfied | Extremely Satisfied |

| **SECTION 7: Please rate the extent to which you agree or disagree with each of the following statements about the people in your life. Please read each statement carefully and circle your response for each line.** | | | | | | |
|---|---|---|---|---|---|---|
| Other people tempt me to eat things I have been advised to avoid. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people tempt me to drink things I have been advised to avoid. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people try not to offer me food/drinks I have been advised to avoid. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people give me food I have been advised to avoid because they know I like them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people give me drinks I have been advised to avoid because they know I like them. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| Other people help me by eating and drinking the same things I have been advised to eat and drink. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| | |
|---|---|
| **SECTION 8** | **THIS IS A QUESTION ABOUT YOUR KIDNEY HEALTHCARE TEAM.**<br>**Please read the scenario below and tick the response you most agree with.** |

**Scenario:** Thinking about your kidney care team, imagine that they tell you that your dry weight is out of target (high). **Which type of support would you prefer from them in this scenario? Please tick √ one box.**

- ☐ I would prefer that the kidney healthcare team gives me some tips/ suggestions of what I can do to stop this happening again.
- ☐ I would prefer that the kidney healthcare team gives me a strict personalised plan to follow that tells me when to drink to avoid this happening again.
- ☐ I would prefer that the kidney healthcare team leaves it to me to work out on my own.

**SCENARIO FOR STAGE 3 CKD**

**Scenario:** Thinking about your healthcare team, imagine that they tell you that your kidney disease is getting worse.
**Which type of support would you prefer from them in this scenario? Please tick √ one box.**

- ☐ I would prefer that my healthcare team gives me some suggestions of what I can do to stop my kidney disease from getting worse.
- ☐ I would prefer that the kidney healthcare team gives me a strict guidance to follow to stop my kidney disease from getting worse.
- ☐ I would prefer that my healthcare team leaves me alone to figure it out.

**SECTION 9: Next we would like to ask you about different aspects of your life. Please rate how much you agree or disagree with each statement. Please read each statement carefully and draw a circle on your response for each line.**

| | | | | | | |
|---|---|---|---|---|---|---|
| I often feel that I lack companionship. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I often feel left out. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I often feel isolated from others. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

**SECTION 10: HOW HAVE YOU BEEN FEELING IN THE PAST WEEK?**
**Please circle the box beside the reply that is closest to how you have been feeling in the past week.**
**Don’t take too long over you replies: your immediate is best.**

| | | | | |
|---|---|---|---|---|
| I feel tense or ‘wound up’. | Most of the time | A lot of the time | From time to time, occasionally | Not at all |
| I still enjoy the things I used to enjoy. | Definitely as much | Not quite as much | Only a little | Hardly at all |
| I get a sort of frightened feeling as if something awful is about to happen. | Very definitely and quite badly | Yes, but not too badly | A little, but it doesn't worry me | Not at all |
| I can laugh and see the funny side of things. | As much as I always could | Not quite so much now | Definitely not so much now | Not at all |
| Worrying thoughts go through my mind. | A great deal of the time | A lot of the time | From time to time, but not too often | Only occasionally |
| I feel cheerful. | Not at all | Not often | Sometimes | Most of the time |
| I can sit at ease and feel relaxed. | Definitely | Usually | Not often | Not at all |
| I feel as if I am slowed down. | Nearly all the time | Very often | Sometimes | Not at all |
| I get a sort of frightened feeling like 'butterflies' in the stomach. | Not at all | Occasionally | Quite often | Very often |
| I have lost interest in my appearance. | Definitely | I don't take as much care as I should | I may not take quite as much care | I take just as much care as ever |
| I feel restless as if I have to be on the move. | Very much indeed | Quite a lot | Not very much | Not at all |
| I look forward with enjoyment to things. | As much as I ever did | Rather less than I used to | Definitely less than I used to | Hardly at all |
| I get sudden feelings of panic. | Very often indeed | Quite often | Not very often | Not at all |
| I can enjoy a good book or radio or TV program. | Often | Sometimes | Not often | Very seldom |

**SECTION 11: Please rate how much you agree or disagree with each of the following statements when it comes to the following behaviours associated with managing your kidney disease.**

**Please read each statement carefully and select a response from each line.**

| | | | | | | |
|---|---|---|---|---|---|---|
| I feel confident that I can manage my kidney disease. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can limit my fluid intake. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can keep to my target weight. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can avoid getting thirsty. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can keep to my fluid restriction when socialising. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can keep to my fluid restriction when away from home. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can adjust how much I drink if I had too much or too little the day before. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can manage my salt intake. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can find information about managing my kidney disease. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can speak to my healthcare team about any worries or questions. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can avoid drinking more when I am upset. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident I can keep to my fluid allowance when it gets too hot. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |

**SECTION 11: STAGE 3 CKD Please rate how much you agree or disagree with each of the following statements when it comes to the following behaviours associated with managing your kidney disease.**

**Please read each statement carefully and select a response from each line.**

| | | | | | | |
|---|---|---|---|---|---|---|
| I feel confident that I can manage my kidney disease. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can manage my salt intake. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can find information about managing my kidney disease. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |
| I feel confident that I can speak to my healthcare team about any worries or questions. | Extremely unconfident | Very unconfident | Quite unconfident | Quite confident | Very confident | Extremely confident |

**SECTION 12: Please rate how much you agree or disagree with each of the following statements about managing your kidney disease.**

**Please read each statement carefully and select a response from each line.**

| | | | | | | |
|---|---|---|---|---|---|---|
| I am committed to sticking to my fluid allowance. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to keeping my dry weight within the target range set for me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to limiting my daily fluid intake. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to doing what my healthcare team advise me to do (when it comes to fluid intake) | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

**SECTION 12: STAGE 3 CKD Please rate how much you agree or disagree with each of the following statements about managing your kidney disease.**

**Please read each statement carefully and select a response from each line.**

| | | | | | | |
|---|---|---|---|---|---|---|
| I am committed to doing what I can to manage my kidney disease | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to doing what my healthcare team advise me to do to manage my kidney disease. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to doing what I can to stop my kidney disease from getting worse. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| I am committed to doing what my kidney healthcare team tells me to do. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

**SECTION 13: DO YOU DO ANY OF THESE TO MANAGE YOUR FLUID INTAKE?**

**Please read each statement carefully and circle one box.**

| | | | | | |
|---|---|---|---|---|---|
| I weigh myself at home using a scale. | Never | Occasionally | Sometimes | Often | Frequently |
| I check my blood pressure with a monitor. | Never | Occasionally | Sometimes | Often | Frequently |
| I check my blood sugar levels with a pin prick. | Never | Occasionally | Sometimes | Often | Frequently |
| I weigh my food. | Never | Occasionally | Sometimes | Often | Frequently |
| I keep a record of what I'm drinking. | Never | Occasionally | Sometimes | Often | Frequently |
| I measure how much fluid I consume | Never | Occasionally | Sometimes | Often | Frequently |
| I keep a record of my urine output. | Never | Occasionally | Sometimes | Often | Frequently |
| I watch out for swelling of the hands, feet, face and legs. | Never | Occasionally | Sometimes | Often | Frequently |

| **SECTION 14: HERE IS A LIST OF THINGS THAT SOME PEOPLE SAY THEY DO TO MANAGE THEIR FLUID INTAKE. DO YOU DO ANY OF THESE? Please answer all the questions and draw a circle in each response line.** | | | | | | |
|---|---|---|---|---|---|---|
| I suck on ice cubes or frozen fruit to avoid drinking. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I sip rather than gulp drinks. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I fill a container (e.g., jug, bottle) with all I am allowed to drink for the day. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I use a small cup to drink out of. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I make my drinks super-hot to drink slowly. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I only drink when I take my medication. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I suck mints to make my mouth moist, so I don’t get thirsty and drink. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I drink packaged drinks (cans, bottles, cartons) so I know how much I’ve drunk. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |

| | | | | | | |
|---|---|---|---|---|---|---|
| I swirl my mouth out with cold water. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I only drink hot drinks (e.g., tea, coffee). | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I suck on ice lollies or ice poles. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I drink with a straw. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I don't cook with or add salt to my food. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I ask my dialysis nurse to take more fluids off when I am on dialysis so I can drink more later. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| I sit in front of a fan or in an air-conditioned room to keep cool, so I don't get thirsty. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |
| When I have hot drinks, I only drink half of the content. | No, I have never tried this | I have tried this once or twice | I have tried this a few times | Yes, I do this occasionally | Yes, I do this quite often but not all the time | Yes, I do this all the time |

| SECTION 15: HOW ARE YOU DOING REGARDING YOUR DRY WEIGHT?<br>Please read each statement carefully and draw a circle on each response line. | | | | | | |
|---|---|---|---|---|---|---|
| In general, I keep my dry weight within the target range set for me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I stick to my daily fluid allowance. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I manage my fluid allowance pretty well. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, my dry weight is outside the target set for me. | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I keep my thirst levels under control | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I manage my thirst levels well | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I succeed in regulating my fluid intake | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I manage my urge to drink too much | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I drink more than my daily allowance | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |
| In general, I manage my hydration levels pretty well | Strongly Disagree | Disagree | Slightly Disagree | Slightly Agree | Agree | Strongly Agree |

| SECTION 16: TO ASSESS FLUID MANAGEMENT, IT IS HELPFUL TO KNOW HOW MUCH URINE YOU PASS<br>Please draw a circle around the response that is nearest to how much urine you pass each day. | | | |
|---|---|---|---|
| Do you pass urine?<br>If so, how much approximately? | I don't pass urine | Less than 500ml/day (about 2 cups or less) | More than 500ml/day (more than 2 cups) |

Please give the completed booklet back to a member of staff.
Thank you for your help.