

**The Psychosocial Consequences of Gastrointestinal Symptoms and Dietary Changes in Patients Receiving Peritoneal Dialysis for End-Stage Renal Disease: A Qualitative Study**

**Emily Duncanson**

*This report is submitted in partial fulfillment of the degree of Master of Psychology (Health)*

School of Psychology, Faculty of Health and Medical Sciences

University of Adelaide


October 2017

Word count: 11,938 (not including abstracts, reference lists, figures, or appendices)

### **Declaration**

I certify that this report does not contain material that has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this report contains no material previously published or written by another person except where due reference is made.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the School to restrict access for a period of time.



Emily Duncanson



October, 2017

## Acknowledgements

I would like to express my sincere gratitude to my supervisor Professor Anna Chur-Hansen for her knowledge, guidance, and constant support throughout all stages of the development of my thesis.

I would like to thank Dr Shilpa Jesudason and other staff of the Central and Northern Adelaide Renal and Transplantation Service (CNARTS) Clinical Research Group for supporting me in what was a wonderful research opportunity. Thank you to the renal nurses and administrative staff of the Hampstead Dialysis Centre and the Renal Unit at the Royal Adelaide Hospital for their help with recruiting participants and accommodating me whilst I used their facilities to conduct interviews. Thank you to the Hospital Research Foundation for sharing news of the project via the Kidney, Transplant and Diabetes Research Australia website (see Appendix A). I would also like to sincerely thank the individuals who volunteered to share their experiences for this research.

Finally, I am extremely grateful to my partner, family, and friends for their encouragement and support throughout the past two years.

## Table of Contents

Declaration.....	ii
Acknowledgements.....	iii
List of Figures.....	vii
List of Appendices.....	viii
<b>Literature Review.....</b>	<b>1</b>
Abstract.....	2
The Quality of Life, Psychological Wellbeing, and Gastrointestinal Health of Patients Receiving Peritoneal Dialysis for End-Stage Renal Disease: A Narrative Literature Review.....	3
Chronic Kidney Disease.....	4
Peritoneal Dialysis in Australia.....	4
Quality of Life and Psychological Wellbeing.....	5
The physical, psychological, and quality of life effects of end-stage renal disease and peritoneal dialysis.....	6
The Gastrointestinal Health of Patients Receiving Peritoneal Dialysis.....	11
Common gastrointestinal problems.....	11
The relationship between gastrointestinal symptoms and psychosocial wellbeing.....	11
Dietary management.....	13
The mind-gut axis and chronic kidney disease.....	14
Discussion.....	16
Conclusion.....	18
References.....	20

<b>Research Report.....</b>	<b>31</b>
Abstract.....	32
Index Words.....	33
Introduction.....	34
Methods.....	38
Study Setting and Participants.....	38
Data Collection.....	40
Data Analysis.....	41
Results.....	42
Loss of Autonomy.....	42
Interference to daily life.....	42
Dialysis process and sleep.....	43
Impacts on relationships.....	43
Powerlessness.....	44
Frustration.....	45
Food aversion.....	45
Restriction.....	46
Friendships and social life.....	47
Impacts on partner.....	47
Partner as a carer.....	48
Attempts to Gain Autonomy.....	48
Coping well.....	48
Pragmatism.....	49
Maintaining normality.....	49
Discussion.....	50

Acknowledgements.....	58
References.....	59
Appendices.....	67
American Journal of Kidney Diseases Information for Authors and Editorial Policies....	84

## List of Figures

### Research Report

Figure 1. Concept map illustrating the main themes and sub-themes identified from the qualitative data.....	66
---	----

## List of Appendices

### Research Report

Appendix A. Article Published on the Kidney, Transplant and Diabetes Research Australia (KTDR) Website.....	67
Appendix B. Presentation Slides of Final Results and Concept Map Presented at CNARTS Clinical Research Group Meeting .....	69
Appendix C. Journal Article from American Journal of Kidney Diseases.....	74



## **Literature Review**

The Quality of Life, Psychological Wellbeing, and Gastrointestinal Health of Patients  
Receiving Peritoneal Dialysis for End-Stage Renal Disease: A Narrative Literature Review

Emily Duncanson

School of Psychology

University of Adelaide

Word count: 5,007 (not including abstract or reference list)

### Abstract

Patients receiving renal replacement therapies for end-stage renal disease experience markedly poorer quality of life than healthy individuals. Patients undergoing peritoneal dialysis experience mood disorders, body image disturbance, and changes in lifestyle and relationships. Research has also shown that gastrointestinal symptoms are common among this patient group, however, the literature exploring their relation to patients' psychosocial wellbeing is yet to be summarised. This narrative review will therefore discuss the relevant quantitative and qualitative research regarding the impacts of peritoneal dialysis on patients' psychological wellbeing and quality of life, including evidence suggesting the negative role of GI dysfunction in these issues.

The Quality of Life, Psychological Wellbeing, and Gastrointestinal Health of Patients Receiving Peritoneal Dialysis for End-Stage Renal Disease: A Narrative Literature Review

Chronic kidney disease (CKD) is characterised by the irreversible decline of renal function, which is eventually fatal unless substituted by kidney transplantation or dialysis therapy (Abbasi, Chertow, & Hall, 2010). Peritoneal dialysis (PD) is a home-based therapy for end-stage renal disease (ESRD) that offers patients advantages including lifestyle flexibility and autonomy in managing their condition (Ellam & Wilkie, 2015; Wuerth, et al., 2002). Despite this, patients undergoing PD often live with great physical and psychosocial burden. Research has demonstrated that sleep disturbance, fatigue, and pain are common (Almutary, Bonner, & Douglas, 2016), as well as gastrointestinal (GI) symptoms such as constipation, diarrhoea, reflux, and eating dysfunction (Almutary et al., 2016; Cano et al., 2007; Dong, Guo, Ding, Zhou, & Wu, 2014). From the patient's perspective, PD is also intrusive on daily life and relationships and has psychological consequences including body image disturbance and impaired self-esteem (Tong et al., 2013). It is therefore unsurprising that depression, anxiety, and sexual dysfunction are also prevalent among this patient group and that they experience markedly poorer quality of life compared to healthy individuals (Lew & Piraino, 2005; Merkus, et al., 1999).

Despite the vast amount of research on quality of life in CKD populations, the relationships between physical symptoms and psychological wellbeing among patients receiving PD are not well understood. This narrative review will first provide an overview of the physical and psychosocial effects of ESRD and PD therapy. An examination of the research regarding GI symptoms, dietary management, and their relation to psychological wellbeing and quality of life in ESRD follows, as well as a discussion of emerging evidence concerning the connection between brain and GI health, or the so-called mind-gut axis. Relevant qualitative studies exploring the lived experiences of patients receiving PD are

reviewed throughout. Gaps and limitations to the current literature are identified and suggestions for future research are made.

### **Chronic Kidney Disease**

CKD is a life-limiting condition characterised by the progressive and irreversible decline of kidney function. It is classified into five stages according to the level of kidney impairment, as measured by one's glomerular filtration rate via a blood test. Glomerular filtration rate is an estimate of the amount of blood that passes through the small filters of the kidneys, or the glomeruli, whose function is to clear the blood of waste and toxic products. In the final stage of CKD (Stage 5), or ESRD, patients require kidney transplantation or dialysis to survive (Abbasi et al., 2010). The accumulation of toxins in the progression to and during ESRD results in uremic syndrome or uremia, which manifests in various neural, muscular, endocrine, and metabolic symptoms (Meyer & Hostetter, 2007). Uremia, uremic syndrome, and renal failure are terms often used synonymously with ESRD.

### **Peritoneal Dialysis in Australia**

In the last two decades in Australia, the number of individuals receiving renal replacement therapies for ESRD has steadily increased (Australia and New Zealand Dialysis and Transplant Registry (AZDATA Registry), 2017a). At the end of 2015 there were approximately 23,000 dialysis and renal transplant patients, with roughly 2,500 undergoing PD (ANZDATA Registry, 2017b). Patients who are recommended PD are first required to undergo surgery to place a catheter into the peritoneal membrane in the lower abdomen. During dialysis exchanges, dialysate is infused into the peritoneum, which acts as a filter to absorb toxins, waste products, and water from the patient's blood (Ellam & Wilkie, 2015). These are then drained into an external bag attached to the catheter that the patient discards at the end of therapy. Two forms of PD exist. Both are self-administered therapies that occur in the patient's home. In the pre-dialysis phase, patients receive education about PD and training

in how to perform dialysis exchanges. Patients receiving continuous ambulatory peritoneal dialysis (CAPD) perform four to six manual dialysis exchanges throughout the day, a process that takes approximately thirty minutes. Automated peritoneal dialysis (APD) requires the patient to connect to a machine for approximately ten hours during the night, which performs dialysis exchanges automatically whilst the person sleeps (Ellam & Wilkie, 2015). APD is the more common form of PD in Australia (approximately 67% of PD patients) (ANZDATA, 2017b) and whilst there is no clear evidence indicating its clinical superiority over CAPD (Rabindranath et al., 2007), it likely offers patients greater psychosocial benefits including independence from therapy during the day and thus decreased interference on occupational and social functioning (Tong et al., 2013).

### **Quality of Life and Psychological Wellbeing**

Quality of life is a subjective and multifaceted construct, which poses challenges to its definition and assessment. However, agreement exists that it encompasses a number of intersecting domains including physical, material, social and emotional wellbeing, and development and activity (Felce & Perry, 1995). Quality of life has been defined as an individual's perception of their position in life in relation to their cultural context, values, goals, expectations, standards, and concerns (Finkelstein, Wuerth, & Finkelstein, 2009). Psychological wellbeing may be considered both an independent concept and a key component of quality of life. Ryff (1989) argued that psychological wellbeing encompasses the six domains of self-acceptance, positive relations with others, autonomy, environmental safety, purpose in life, and personal growth. Health-related quality of life has been defined as the extent to which an individual perceives a medical condition and its treatment affects the physical, social, emotional, and therapeutic dimensions of their usual or expected functioning and wellbeing (Finkelstein et al., 2009; Guney et al., 2010). Although different in nature, many chronic diseases are common in their long-term trajectory and deleterious physical,

economic, and psychosocial consequences for individuals and their families. Quality of life is therefore considered a critical issue in the assessment and management of patients with such conditions and has been extensively investigated in research, including among patients with varying stages of CKD (Edgell et al., 1996).

**The physical, psychological, and quality of life effects of end-stage renal disease and peritoneal dialysis.** Whilst dialysis therapy offers patients the prolonging of life, it does not restore kidney function to normal. This has significant emotional and psychosocial consequences for patients, many of whom have to cope with the disease and its daily treatment for a number of years. It is therefore unsurprising that they experience poorer psychological wellbeing and quality of life compared to transplant recipients and healthy individuals (Maglakelidze, Pantsulaia, Technokhnelidze, Managadze, & Chkotua, 2011). For patients receiving PD, quality of life generally declines with time on dialysis in both physical and psychological arenas (Bakewell, Higgins, & Edmunds 2002; Lim, Yu, Kang, Foo, & Griva, 2016). The compromised psychological wellbeing of patients receiving PD may be the result of limited physical and functional capacity, symptom burden, medication side-effects, and treatment complications (peritonitis or catheter exit site infections) and subsequent surgeries. Patients also face a number of direct psychosocial difficulties as a consequence of the daily PD therapy regime, including lifestyle restrictions, sleep disturbance, changes in relationships, and social isolation (Guney et al., 2010; Tong et al., 2013). Thus, patients' poor quality of life is likely explained by reciprocal interactions between a number of physiologic and psychosocial influences. The relationships between these factors are worthy of further research effort and clinical consideration in nephrology, as poor psychological status and quality of life are strongly associated with clinical outcomes in ESRD, including treatment nonadherence, morbidity, and mortality (Farrokhi, Abedi, Beyene, Kurdyak, & Jassal, 2014; Lew & Pirano, 2005).

Symptom burden has been established as a strong predictor of poor psychological status and lower health-related quality of life in patients with CKD (Almutary, Bonner, & Douglas, 2013; Almutary et al., 2016; Davis, Phillips, Naish, & Russell, 2002; Davison & Jhangri, 2010). In those receiving dialysis, multiple physical symptoms are suspected to result from uremia itself, as well as the secondary impacts of dialysis on physiology (Skroeder, Jacobson, Lins, & Kjellstrand, 1994). Research has shown that symptom burden is high among patients receiving PD, who consistently report fatigue, itching, muscle cramps, pain (Almutary et al., 2016; Figueiredo et al., 2012; Murtagh, Addington-Hall, & Higginson, 2007) and a variety of GI symptoms (Cano et al., 2007) (to be discussed further later in this review). A literature review by Almutary et al. (2013) investigated total symptom burden of patients at CKD Stage 4 (pre-dialysis), Stage 5 (patients receiving hemodialysis (HD) or PD) and Stage 5 (conservative management). Findings revealed that compared to other CKD groups, the physical and psychological symptom burden of PD patients is understudied and not well understood, representing a significant gap in the literature. The same investigators (Almutary et al., 2016) therefore conducted a cross-sectional study comparing the multidimensional symptom experience (prevalence, severity, distress, and frequency) of patients either receiving HD or PD and those at Stage 4 not undergoing dialysis, using the CKD Symptom Burden Index. They found that symptom distress was significantly higher among the dialysis group than the non-dialysis group and that patients receiving PD reported an average of ten CKD-related symptoms. Furthermore, in all groups, fatigue was one of the most burdensome symptoms, but mostly so for those receiving PD. Whilst the prevalence of many symptoms is well-established in the CKD literature, less is known about their role in impairments to patients' psychosocial wellbeing. As suggested by Almutary et al. (2016), level of symptom severity and associated distress contribute greatly to total symptom burden. Arguably, it may be these factors that have the greatest implications for patients' mental

health and quality of life, highlighting that investigation of the patient's symptom experience, particularly from their perspective, warrants further investigation.

Patients undergoing PD experience psychological disorders more commonly than healthy individuals. It is estimated that the prevalence of depression is three to four times higher in CKD and ESRD groups compared to the general population (Lew & Piraino, 2005; Shirazian et al., 2017), with one systematic review and meta-analysis yielding estimates between 22.8% and 39.3% (Palmer et al., 2013). In patients receiving PD, depression is associated with inadequate nutrition, increased hospitalisations, lower quality of life, and possibly premature death (Lew & Piraino, 2005). The mechanisms underlying depression in ESRD are complex. High rates may be explained by similarities in somatic symptoms of depression and uremia, such as lack of energy, decreased appetite, and sleep disturbance (Christensen & Ehlers, 2002), in addition to the many psychosocial changes that accompany the progression to the final stage of renal failure and dialysis therapy. Delayed sleep onset, nighttime awakenings, and restless leg syndrome are also frequently reported by patients undergoing PD (Murtagh et al., 2007; Santos & Almondes, 2015) and are in turn, associated with depression and poorer quality of life (Guney et al., 2010).

Although not as widely studied as depression, research has demonstrated that other psychological problems are commonly experienced by patients receiving PD. Prevalence estimates for symptoms of anxiety in dialysis patients range between 12% and 52% (Murtagh et al., 2007). For PD patients, worries about restrictions in daily life, changes in physical appearance, and fear of decline in physical function are common (Ye et al., 2008), as is body image disturbance (Partridge & Robertson, 2011). Physical appearance concerns are likely related to the visible bodily changes that result from dialysis including weight gain, abdominal stretching and bloating, and the permanent catheter, which may further exacerbate the sexual dysfunction many patients experience (Vecchio, Palmer, Tonelli, Johnson, &



Strippoli, 2012). Common sexual problems reported by both male and female patients include decreased interest in sex, low levels of sexual satisfaction, and difficulties with arousal and in achieving orgasm (Finkelstein, Shirani, Wuerth, & Finkelstein, 2007; Steele et al., 1996). Qualitative evidence has also revealed negative changes in patients' attitudes towards sex in the presence of their disease and treatment (Vecchio et al., 2012; see also Yilmaz & Özaltm, 2011). Both married and single patients on PD express concerns regarding the impacts of the therapy on body image and sexual functioning, and perceive these as obstacles to current or potential future relationships (Yilmaz, 2010; Yilmaz & Özaltm, 2011). Sexual dysfunction in CKD is likely the consequence of biological and psychological aetiology, including hormonal abnormalities associated with renal failure, medications, and depression. For patients undergoing PD, changes in partner roles and relationships as a result of living with ESRD and undergoing therapy in the home may also contribute to these problems. In particular, for those who undergo APD whilst in bed, the machine, connecting cord, and catheter may pose particular intrusion on sexual relationships and physical intimacy.

A number of qualitative studies have explored patients' experiences and perceptions of living with ESRD and PD, revealing their varied psychosocial impacts. Tong et al. (2013) carried out a comprehensive thematic synthesis of 39 qualitative studies exploring patients' experiences, beliefs, and attitudes about PD therapy. Studies included in the review predominantly explored topics including decision-making in dialysis treatment, advanced care planning, and treatment in the home environment. The authors identified seven major themes: resilience and confidence, support structures, overwhelming responsibility, control, freedom, sick identity, and disablement. For some patients, the control and independence offered by home PD was greatly valued and related to a sense of resilience and self-efficacy, particularly for those who perceived strong family, peer, and medical support. However, for

others, PD was seen as an overwhelming responsibility, intrusive, burdensome for families, and led to a sense of worthlessness. Patients also described impaired physical functioning, general fatigue, and damages to self-esteem and body image. Using the consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007), the authors concluded that the comprehensiveness of reporting and quality of the studies included varied greatly. They also highlighted that 23 of the 39 studies reviewed omitted details of the PD modality of the study sample. This detail is important and should be considered in future study samples, as patients' psychosocial concerns may vary depending on PD modality, particularly as CAPD and APD involve different routines at different times in the patient's day-to-day life.

The review discussed above highlights that the majority of qualitative studies conducted with patients receiving PD have assessed their broader opinions of the therapy. Only a small number have explored the interaction between physical processes or symptoms and patients' psychosocial wellbeing. The findings of these studies support that of the quantitative literature, suggesting that sleep disturbance is a significant concern for PD patients. In a phenomenological study by Yngman-Uhlin, Friedrichsen, Gustavsson, Fernström, and Edéll-Gusafsson (2010) involving 14 patients on PD (nine CAPD and five APD), poor sleep not only resulted in daytime physical tiredness but patients also related this to mental drowsiness, irritability, stress, decreased mood, worry, and existential thinking. These factors interacted in a bi-directional manner with tiredness, which was described as a prolonged and ever-present feeling. Another study found that pre-dialysis, HD, and PD patients experienced fatigue in both mental and physical domains as central to their limited functional capacity, and described persistent lack of energy and strength (Heiwe, Clyne, Dahlgren, 2003).

### **The Gastrointestinal Health of Patients Receiving Peritoneal Dialysis**

**Common gastrointestinal problems.** As previously mentioned, GI problems are common in ESRD. In particular, between 32% and 85% of patients on dialysis report experiencing GI symptoms (Ariffin et al., 2016; Dong & Guo, 2010; Salamon, Woods, Paul, & Huggins, 2013; Shirazian & Radhakrishnan, 2010; Strid et al., 2002). Despite this variation in prevalence estimates, likely due to inconsistencies in symptom definitions and assessment tools used in the literature, GI symptoms are a well recognised feature of the symptomatic profile of patients undergoing PD. Constipation, diarrhoea, nausea, and abdominal pain are particularly common (Cano et al., 2007; Dong et al., 2014; Figueiredo et al., 2012), with some evidence suggesting these patients may be more susceptible to malnutrition and more severe gastroesophageal reflux and eating dysfunction than those undergoing HD (Ariffin et al., 2016; Dong et al., 2014; Strid et al., 2002). Irritable bowel syndrome is also common, affecting up to one third of PD patients (Shirazian & Radhakrishnan, 2010). Such GI complications among patients on dialysis are multifactorial problems, resulting from uremia, diet, medication side-effects, and the impact of dialysis itself on GI function (Dong & Guo, 2010; Yasuda et al., 2002).

#### **The relationship between gastrointestinal symptoms and psychosocial wellbeing.**

Although GI problems are a well-recognised feature of the ESRD patient's experience, their relation to quality of life has been the subject of only few studies. A clear inverse association between gastrointestinal symptoms and psychological wellbeing and quality of life exists in the general population and patients with ESRD (Strid et al., 2002; Tougas, Chen, Hwang, Liu, & Eggleston, 1999). In dialysis groups, the connection between GI symptoms and quality of life has predominately been examined in observational research. For example, Strid et al. (2002) assessed the GI symptoms and general psychological wellbeing of 233 HD, PD, and pre-dialytic patients (Chronic Renal Failure (CRF) group) compared to healthy controls,

via the Gastrointestinal Symptom Rating Scale (GSRS) and the Psychological General Well-Being index (PGWB index). Results showed that total GSRS scores were significantly higher among individuals with CRF than those without and that PD patients suffered from more severe reflux and eating dysfunction than other groups. Pre-dialysis and PD patients had similar PGWB index scores to healthy controls, however, a negative correlation between GSRS scores and the PGWB index was found. The authors concluded that in addition to the psychosocial consequences of dialysis, patients with high GI symptom profiles may be at increased risk of poor psychological outcomes. Another study, by Zhang et al. (2013), measured the incidence of constipation and its effects on the health-related quality of life of 78 HD and 127 PD patients. Compared to those without constipation, patients who reported this symptom had significantly lower health-related quality of life scores, as measured by the 12-item short form (SF-12) General Health Survey, and higher scores on the Beck Depression Inventory. Furthermore, although constipation was experienced by a greater number of HD patients, those undergoing PD with constipation had significantly worse health-related quality of life in both physical and mental domains. In contrast, Almutary et al.'s (2016) recent study found that PD patients had the highest incidence of constipation when compared to HD and pre-dialysis patients, and experienced the greatest distress with this symptom and decreased appetite.

Research has further demonstrated that dialysis patients employ various strategies in an attempt to alleviate troublesome GI symptoms, which may have both physical and psychosocial consequences. Salamon et al.'s (2013) cross-sectional study assessed the prevalence of GI symptoms and their impact on food intake in 122 PD and 172 HD patients via a structured 10-minute interview conducted by a dietician. Patients responded "yes" or "no" to the question "do you suffer from any of the following symptoms?", with reference to a range of GI symptoms including nausea, vomiting, early satiety, constipation, and diarrhea.

Results showed that not only were symptoms more prevalent in PD patients than HD patients (85% and 51% respectively), a significantly greater number receiving PD attributed the commencement of dialysis to the onset or worsening of GI symptoms (54.9%) and reported a decrease in food intake and dietary changes to improve them (33.6%). Participants reported strategies including substantially reducing fluid intake with meals, missing meals (particularly breakfast) or consuming plainer or softer foods, however, it is not clear how these data were assessed or analysed. Anorexia, classified by the authors as a GI symptom, was also reported in more than twice the number of PD than HD patients (48% and 22% respectively).

**Dietary management.** To maintain health and manage comorbidities, patients receiving dialysis are often required to adhere to a prescribed renal diet and significantly restrict fluid intake. In conjunction with this, many experience decreased appetite and distorted taste (dysgeusia) (Affrin et al., 2016). Diet and fluid instructions can be met with difficulty and frustration by patients on dialysis, resulting in reduced adherence to the recommended diet (Palmer et al., 2015). Morris, Love, van Aar, Liles, and Roskell (2015) conducted semi-structured in-depth interviews with 10 PD patients to understand their experiences of following dietary advice provided by renal dietitians. A major theme, difficulty outside the home, originated from the data, revealing that patients' described following dietary advice as particularly challenging when in public or social settings. Patients described eating foods reluctantly rather than disclosing their dietary needs to other people, a sense of frustration and restriction in dietary choice, and difficulties in dealing with social judgments about their dietary requirements. In extreme cases, some described declining invitations to social events at which they knew food would be present to avoid attention and judgment from others. These findings are consistent with that of Hollingdale, Sutton, and Hart's (2008) study, which involved focus groups with ten pre-dialysis and ten dialysis

patients. Themes of self-discipline, low motivation, and confusion regarding dietary advice were also found, and patients reported their partners had also adopted the diet out of ease of preparing meals. In line with Salamon et al.'s (2013) quantitative study, patients reported self-imposed dietary changes in response to symptoms, such as refraining from eating foods that did not 'agree' with them. Given the evidence discussed, and that the preparation and consumption of food is at the center of many social interactions, dietary changes and co-occurring GI problems could pose particular threat to the psychosocial wellbeing of patients on PD. In conjunction with other consequences of PD including changes in weight, physical appearance, and body image disturbance, these issues represent a complex group of factors that may lead to psychological outcomes for patients including depression and possibly, disordered eating.

**The mind-gut axis and chronic kidney disease.** Growing evidence suggests a bi-directional relationship between the gastrointestinal system, or the gut, and the brain, commonly referred to as the mind-gut axis. This axis involves communication between the central and the enteric nervous system by means of neural and hormonal links, influenced by the trillions of microbial cells harbored in the gut, or the gut microbiome (Carabotti, Scirocco, Maselli, & Severi, 2015). Not only are mind-gut interactions vital in the maintenance of gastrointestinal homeostasis, emerging research suggests they may also contribute to the coordination of one's physical and emotional state, thus influencing the risk of various disorders (Foster & Neufeld, 2013; Mayer, Padua, & Tillisch, 2014). Experimental research in animal models supports the modulating effect of gut microbiota on the mind-gut axis, as reflected in an increase in stress reactivity and anxiety-like behaviour (Bravo et al., 2011; Lou et al., 2014). In humans, associations have been established between microbial imbalance, or dysbiosis, and autism (Mayer et al., 2014; Song, Liu, & Finegold, 2004) and stress, anxiety, and depressive symptoms (Foster & Neufeld, 2013).

Gut microbiome are modified by a number of physical, psychological, and environmental factors, including diet, antibiotic medication, and stress (Foster & Neufeld, 2013; Wing, Patel, Ramezani, & Raj, 2016). Disruptions to mind-gut communications have been found in patients with gastrointestinal disorders. In particular, extensive research has shown the occurrence of dysbiosis in patients with irritable bowel syndrome, up to 94% of whom experience a comorbid psychiatric disorder, namely major depression and generalised anxiety disorder (DuPont, 2014; Whitehead, Palsson, & Jones, 2002). Similarly, emerging evidence also indicates modifications to the structure, diversity, and abundance of the gut microbiome of patients with CKD (Vaziri et al., 2012; Wing et al., 2016). This is attributable to the impacts of kidney failure itself and dialysis therapy, including lesions to intestinal barriers, secretion of ammonia and urea into the gastrointestinal tract, and decreased digestive capacity (Ramezani & Raj, 2014). In turn, unbalanced gut microbiota are said to contribute to the progression of CKD and associated comorbidities (Felizardo, Castoldi, Andrade-Oliveira, & Câmara, 2016).

As seen in other populations, associations between irritable bowel syndrome, GI symptoms, and psychiatric disorders have been established in ESRD patients. Kahvecioglu et al. (2005) assessed this among 93 HD and 35 PD patients and 51 healthy controls who completed a series of questionnaires evaluating upper GI symptoms, irritable bowel syndrome, and psychological status. The prevalence of irritable bowel syndrome and psychiatric disorders was significantly higher among dialysis patients than controls, and among dialysis patients, significantly increased in the presence of anxiety and depression. In Cano et al.'s (2007) study, 100 HD and 48 PD patients completed the standardized Rome II questionnaire (Thompson, Irvine, Pare, Ferrazzi, & Rance, 2002), the results of which were compared with that of 148 medical outpatients and 148 healthy controls without renal failure. The prevalence of GI symptoms and irritable bowel syndrome was higher among dialysis

patients than other groups. The association between GI symptoms and anxiety and depression in PD patients was not examined, likely due to small numbers, however, irritable bowel syndrome rates were significantly higher among PD patients than medical outpatients. This stands as an important finding given the established association between irritable bowel syndrome and anxiety and mood disorders (Whitehead et al., 2002), as previously discussed.

### **Discussion**

It is well documented that ESRD and renal replacement therapies have significant deleterious consequences for patients' psychological wellbeing and quality of life. As demonstrated in the aforementioned literature, in patients receiving PD, these issues have largely been examined in quantitative research employing various self-report measures. The fixed nature of such tools represent limitations to their assessment of wellbeing and quality of life, which are, inherently, subjective constructs. Data obtained by these generic instruments may therefore not reflect the patient's priorities and experiences of dysfunction (Pugh-Clarke, Koufaki, Rowley, Mercer, & Naish, 2002). Furthermore, discrepancies between objective clinical variables and patient reported symptoms have been found in PD cohorts, for example, GI symptoms and levels of serum haemoglobin, albumin, urea and creatinine, fatigue and haemoglobin, and itchy skin and phosphorous (Affrin et al., 2016; Figueiredo et al., 2012; Thong et al., 2009). This may suggest that clinical interventions aimed at improving quality of life may not relate meaningfully to the patient's experience (Murtagh et al., 2007) and that health professionals may be unaware of or underestimate the role of particular pathophysiology on patient wellbeing. Furthermore, whilst quantitative evidence has consistently shown that particular symptoms are highly prevalent among patients on PD, it may not be these that cause the greatest impairments to psychosocial wellbeing and functioning.



The literature reviewed also emphasises GI problems as a potential mechanism by which the psychological wellbeing and quality of life of PD patients are negatively impacted. Much remains to be learned about the consequences of altered gut microbiome in CKD, however, the emerging evidence of mind-gut axis communications suggests that this may be yet another mechanism placing patients with this condition at risk of poor psychological outcomes. In addition, the review highlights that dialysis patients report difficulties following dietary advice and attempt to control symptoms through changes in diet and eating behaviour. It is plausible to suggest that these behaviours may have additional negative consequences for patients' lifestyle, relationships, nutritional status, and mental health. Given investigation in the theme of the mind-gut axis is in its infancy, more research is needed to further understandings of the role of GI and bowel health in CKD and accompanying psychological comorbidities (Ramezani & Raj, 2014).

Despite the findings of the literature reviewed and the well-recognised prevalence of GI symptoms and psychological problems among patients receiving dialysis, the relationship between GI health, mental health, and quality of life remains unclear. Little is known about if and how GI complications play a role in impairments to dialysis patients' mental and emotional wellbeing and impact their day-to-day lives. The paucity of qualitative studies on these topics may be one explanation for this gap in knowledge. At present, research employing quantitative methods dominates the literature in these areas, which can reveal associations but not an in-depth understanding of the patient's experience. Most qualitative studies conducted with PD patients have investigated topics such as treatment decision-making and advanced care planning, with few exploring patients' multidimensional symptom experience and psychosocial wellbeing. Moreover, few of these qualitative studies have been conducted with patients on HD and PD separately, which may limit the transferability of findings to particular groups. Although evidence suggests there are no significant differences

in the health-related quality of life of patients receiving HD or PD (Ho & Li, 2016), qualitative exploration may reveal unique differences in the psychosocial concerns and needs of these individuals, which may not be detectable via quantitative methods.

To address the discussed gaps and limitations of the current literature, it is suggested that qualitative methods be employed in future research with patients undergoing PD and other ESRD groups. This research would provide an in-depth understanding of what patients consider to be the most important issues in relation to their psychological wellbeing and quality of life. Given growing support for patient-centered care in nephrology (Tong & Craig, 2016), the findings of qualitative research could provide great insight into patients' experiences, values, and priorities to better inform shared-decision making and reveal potential areas of unmet need.

### **Conclusion**

The present review demonstrates that although patients' lives are maintained by dialysis, this often comes at significant psychosocial costs. However, further research is needed to explore *how* PD results in impairments to patients' psychological wellbeing and quality of life. To the author's knowledge, no qualitative study has explored the experiences, perceptions, and attitudes of PD patients regarding the impact of PD therapy on psychological wellbeing and quality of life, particularly focusing on the links between mental health, GI health, diet, and quality of life. Future qualitative research should attempt to contribute to the current CKD literature and the emerging field of mind-gut axis research by asking questions such as 'what are the psychological consequences and quality of life impacts of PD?' and 'what are the psychosocial consequences of dietary changes and GI symptoms in patients receiving PD?' This information would be useful for both health care professionals and patients, to integrate patient preferences with best available clinical evidence in the management of this life-limiting illness, particularly in its advanced stages. Given the

prolonged course of CKD and the profound psychosocial consequences of renal replacement therapies for patients and their families (Tong, Winkelmayr, & Craig, 2014), such research is crucial to promote patient wellbeing and quality of life.

## References

- Abbasi, M., Chertow, G. M., & Hall, Y.N. (2010). End-stage renal disease. *American Family Physician*, 82(12), 1512–1514. Retrieved from <https://www-clinicalkey-com-au.proxy.library.adelaide.edu.au/#!/content/journal/1-s2.0-S0002838X10605047>
- Affrin, N. F. M., Naing, L., Pisharam, J., Khalil, M. A. M., Tamin, N., Chong, V. H., & Tan, J. (2016). Appetite and gastrointestinal symptoms in end stage renal disease patients. *Journal of Clinical & Experimental Nephrology*, 1(2), 1–6. Retrieved from <http://clinical-experimental-nephrology.imedpub.com/appetite-and-gastrointestinal-symptoms-in-end-stage-renal-disease-patients.php?aid=9441>
- Almutary, H., Bonner, A., & Douglas, C. (2013). Symptom burden in chronic kidney disease: A review of recent literature. *Journal of Renal Care*, 39, 140–150. doi:10.1111/j.1755-6686.2013.12022.x
- Almutary, H., Bonner, A., & Douglas, C. (2016). Which patients with chronic kidney disease have the greatest symptom burden? A comparative study of advanced CKD stage and dialysis modality. *Journal of Renal Care*, 42, 73–82. doi: 10.1111/jorc.12152
- Australia and New Zealand Dialysis and Transplant Registry (AZDATA Registry). (2017). *Chapter 2: Prevalence of End Stage Kidney Disease (39<sup>th</sup> Annual Report)*. Retrieved from ANZDATA website: [http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c02\\_prevalence\\_v2.1\\_20170418.pdf](http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c02_prevalence_v2.1_20170418.pdf)
- Australia and New Zealand Dialysis and Transplant Registry (AZDATA Registry). (2017). *Chapter 5: Peritoneal Dialysis (39<sup>th</sup> Annual Report)*. Retrieved from ANZDATA website [http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c05\\_peritoneal\\_v2.0\\_20170418.pdf](http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c05_peritoneal_v2.0_20170418.pdf)

- Bakewell, A. B., Higgins, R. M., & Edmunds, M. R. (2002). Quality of life in peritoneal dialysis patients: Decline over time and association with clinical outcomes. *Kidney International*, *61*(1), 239–248. Retrieved from <http://www.kidney-international.org/action/doSearch?searchType=quick&searchText=Quality+of+life+in+peritoneal+dialysis+patients%3A+decline+over+time+and+association+with+clinical+outcomes+&occurrences=all&journalCode=kint&searchScope=fullSite>
- Bravo, J. A., Forsythe, P., Chew, M. V., Escaravage, E., Savignac, H. M., Dinan, T. G., . . . Cryan, J. F. (2011). Ingestion of *Lactobacillus* strain regulates emotional behavior and central GABA receptor expression in a mouse via the vagus nerve. *Proceedings of the National Academy of Sciences of the United States of America*, *108*, 16050–16055. doi: 10.1073/pnas.1102999108
- Cano, A. E., Neil, A. K., Kang, J. Y., Barnabas, A., Eastwood, J. B., Nelson, S. R., . . . Maxwell, D. (2007). Gastrointestinal symptoms in patients with end-stage renal disease undergoing treatment by hemodialysis or peritoneal dialysis. *American Journal of Gastroenterology*, *102*, 1990–1997. doi: 10.1111/j.1572-0241.2007.01321.x
- Carabotti, M., Scirocco, A., Maselli, M. A., & Severi, C. (2015). The gut-brain axis: Interactions between enteric microbiota, central and enteric nervous systems. *Annals of Gastroenterology*, *28*(2), 203–209. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4367209/>
- Christensen, A. J., & Ehlers, S. L. (2002). Psychological factors in end-stage renal disease: An emerging context for behavioral medicine research. *Journal of Consulting and Clinical Psychology*, *70*, 712–724. doi: 10.1037//0022-006X.70.3.712

- Davis, S. J., Phillips, L., Naish, P. F., & Russell, G. I. (2002). Quantifying comorbidity in peritoneal dialysis patients and its relationship to other predictors of survival. *Nephrology Dialysis Transplantation*, *17*, 1085–1092. doi: 10.1093/ndt/17.6.1085
- Davison, S., & Jhangri, G. (2010). Impact of pain and symptom burden on the health-related quality of life of hemodialysis patients. *Journal of Pain & Symptom Management*, *39*, 477–485. doi:10.1016/j.jpainsymman.2009.09.008
- Dong, R., & Guo, Z. Y. (2010). Gastrointestinal symptoms in patients undergoing peritoneal dialysis: Multivariate analysis of correlated factors. *World Journal of Gastroenterology*, *16*, 2812–2817. doi: 10.3748/wjg.v16.i22.2812
- Dong, R., Guo, Z. Y., Ding, J. R., Zhuo, Y. Y., & Wu, H. (2014). Gastrointestinal symptoms: A comparison between patients undergoing peritoneal dialysis and hemodialysis. *World Journal of Gastroenterology*, *20*, 11370–11375. doi: 10.3748/wjg-v20-i31-11370
- DuPont, H. L. (2014). Review article: Evidence for the role of gut microbiota in irritable bowel syndrome and its potential influence on therapeutic targets. *Alimentary Pharmacology and Therapeutics*, *39*, 1033–1042. doi: 10.1111/apt.12728
- Edgell, E. T., Coons, S. J., Carter, W. B., Kallich, J. D., Mapes, D., Damush, T. M., & Hays, R. D. (1996). A review of health-related quality-of-life measures used in end-stage renal disease. *Clinical Therapeutics*, *18*(5), 887–938. Retrieved from [http://ac.els-cdn.com/S014929189680049X/1-s2.0-S014929189680049X-main.pdf?\\_tid=fb101b4c-6c23-11e7-be48-00000aab0f02&acdnat=1500428925\\_b06f89923ec8544a95dbb5829345b2c1](http://ac.els-cdn.com/S014929189680049X/1-s2.0-S014929189680049X-main.pdf?_tid=fb101b4c-6c23-11e7-be48-00000aab0f02&acdnat=1500428925_b06f89923ec8544a95dbb5829345b2c1)
- Ellam, T., & Wilkie, M. (2015). Peritoneal dialysis. *Medicine*, *43*, 484–488. doi: 10.1016/j.mpmed.2015.05.001

- Farrokhi, F., Abedi, N., Beyene, J., Kurdyak, P., & Jassal, S. V. (2014). Association between depression and mortality in patients receiving long-term dialysis: A systematic review and meta-analysis. *American Journal of Kidney Disease*, *63*, 623–635. doi: 10.1053/j.ajkd.2013.08.024
- Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*, 51 – 74. doi: 10.1016/0891-4222(94)00028-8
- Felizardo, R. J. F., Castoldi, A., Andrade-Oliveira, V., & Câmara, N. O. S. (2016). The microbiota and chronic kidney disease: A double-edged sword. *Clinical & Translational Immunology*, *5*, 1–9. doi: 10.1038/cti.2016.36
- Figueiredo, A., E., Goodlad, C., Clemenger, M., Haddoub, S. S., McGrory, J., Pryde, K., . . . Brown, E. A. (2012). Evaluation of physical symptoms in patients on peritoneal dialysis. *International Journal of Nephrology*, *2012*, 1–4. doi: 10.1155/2012/305424
- Finkelstein, F. O., Shirani, S., Wuerth, D., & Finkelstein, S. H. (2007). Therapy insight: sexual dysfunction in patients with chronic kidney disease. *Nature Clinical Practice Nephrology*, *3*, 200–207. doi:10.1038/ncpneph0438
- Finkelstein, F. O., Wuerth, D., & Finkelstein, S. H. (2009). Health related quality of life and the CKD patient: Challenges for the nephrology community. *International Society of Nephrology*, *76*, 946–952. doi:10.1038/ki.2009.307
- Foster, J. A., & Neufeld, K-A. M. (2013). Gut-brain axis: How the microbiome influences anxiety and depression. *Trends in Neurosciences*, *36*, 305–312. doi: 10.1016/j.tins.2013.01.005
- Gerogianni, S. K., & Babatsikou, F. P. (2014). Psychological aspects in chronic renal failure. *Health Science Journal*, *8*(2), 205–214. Retrieved from <http://hypatia.teiath.gr/xmlui/bitstream/handle/11400/1495/826.pdf?sequence=1>

Guney, I., Solak, Y., Atalay, H., Yazici, R., Altintepe, L., Kara, F., . . . Turk, S. (2010).

Comparison of effects of automated peritoneal dialysis and continuous automated peritoneal dialysis on health-related quality of life, sleep quality, and depression.

*Hemodialysis International*, 14, 515–522. doi: 10.1111/j.1542-4758.2010.00465.x

Heiwe, S., Clyne, N., & Dahlgren, M. A. (2003). Living with chronic renal failure: patients' experiences of their physical and functional capacity. *Physiotherapy Research International*, 8, 167–177. doi: 10.1002/pri.287

Ho, Y-F., & Li, I-C. (2016). The influence of different dialysis modalities on the quality of life of patients with end-stage renal disease: A systematic literature review.

*Psychology & Health*, 31, 1435–1465. doi:10.1080/08870446.2016.1226307

Hollingdale, R., Sutton, D., & Hart, K. (2008). Facilitating dietary changes in renal disease: Investigating patients' perspectives. *Journal of Renal Care*, 34, 136–142. doi:

10.1111/j.1755-6686.2008.00034.x

Kahvecioglu, S., Akdag, I., Kiyici, M., Gullulu, M., Yavuz, M., Ersoy, A., . . . Yurtkuran, M.

(2005). High prevalence of irritable bowel syndrome and upper gastrointestinal symptoms in patients with chronic renal failure. *Journal of Nephrology*, 18(1), 61–66.

Retrieved from

[https://www.researchgate.net/profile/Murat\\_Kiyici/publication/7961795\\_High\\_prevalence\\_of\\_irritable\\_bowel\\_syndrome\\_and\\_upper\\_gastrointestinal\\_symptoms\\_in\\_patients\\_with\\_chronic\\_renal\\_failure/links/0c96053731654e1d5e000000.pdf](https://www.researchgate.net/profile/Murat_Kiyici/publication/7961795_High_prevalence_of_irritable_bowel_syndrome_and_upper_gastrointestinal_symptoms_in_patients_with_chronic_renal_failure/links/0c96053731654e1d5e000000.pdf)

Lew, S. Q., & Piraino, B. (2005). Quality of life and psychological issues in peritoneal dialysis patients. *Seminars in Dialysis*, 18, 119–123. doi: 10.1111/j.1525-

139X.2005.18215.x



- Lim, H. A., Yu, Z., Kang, A. W. C., Foo, M. W. Y., & Griva, K. (2016). The course of quality of life in patients on peritoneal dialysis: A 12-month prospective observational cohort study. *International Journal of Behavioral Medicine, 23*, 507–514. doi: 10.1007/s12529-015-9521-z
- Lou, J., Wang, T., Liang, S., Hu, X., Li, W., & Jing, F. (2014). Ingestion of *Lactobacillus* strain reduces anxiety and improves cognitive function in the hyperammonemia rat. *Science China, 57*, 327–335. doi: 10.1007/s11427-014-4615-4
- Maglakelidze, N., Pantsilaia, T., Tchokhanelidze, I., Managadze, L., & Chkhotua, A. (2011). Assessment of health-related quality of life in renal transplant recipients and dialysis patients. *Transplant Proceedings, 43*, 376–379. doi: 10.1016/j.transproceed.2010.12.015
- Mayer, E. A., Padua, D., & Tillisch, K. (2014). Altered brain-gut axis in autism: Comorbidity or causative mechanisms? *Bioessays, 39*, 933–939. doi:10.1002/bies.201400075
- Merkus, M. P., Jager, K. J., Dekker, F. W., de Haan, R. J., Boeschoten, E. W., & Krediet, R. T. (1999). Physical symptoms and quality of life in patients on chronic dialysis: Results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). *Nephrology Dialysis Transplantation, 14*(5), 1163–1170. Retrieved from <https://academic.oup.com/ndt/article/14/5/1163/1816221/Physical-symptoms-and-quality-of-life-in-patients>
- Meyer, T. W., & Hostetter, T. H. (2007). Uremia. *The New England Journal of Medicine, 257*, 1316–1325. doi: 10.1056/NEJMra071313
- Morris, A., Love, H., van Aar, Z., Liles, C., & Roskell, C. (2015). The problematic world of following a renal diet outside the home. *Journal of Renal Care, 41*, 253–259. doi: 10.1111/jorc.12134

- Murtagh, F. E. M., Addington-Hall, J., & Higginson, I. J. (2007). The prevalence of symptoms in end-stage renal disease: A systematic review. *Advances in Chronic Kidney Disease, 14*, 82–99. doi: 10.1053/j.ackd.2006.10.001
- Palmer, S. C., Hanson, C. S., Craig, J. C., Strippoli, G. F. M., Ruospo, M., Campbell, K., . . . Tong, A. (2015). Dietary and fluid restrictions in CKD: A thematic synthesis of patient views from qualitative studies. *American Journal of Kidney Disease, 65*, 559–573. doi: 10.1053/j.ajkd.2014.09.012
- Palmer, S., Vecchio, M., Craig, J. C., Tonelli, M., Johnson, D. W., Nicolucci, A., . . . Strippoli, G. F. M. (2013). Prevalence of depression in chronic kidney disease: Systematic review and meta-analysis of observational studies. *Kidney International, 84*, 179–191. doi:10.1038/ki.2013.77
- Partridge, K. A., & Robertson, N. (2011). Body-image disturbance in adult dialysis patients. *Disability and Rehabilitation, 33*, 504–510. doi: 10.3109/09638288.2010.498556
- Pugh-Clarke, K., Koufaki, P., Rowley, V., Mercer, T., Naish, P. (2002). Improvement of quality of life of dialysis patients during six months of exercise. *Journal of Renal Care, 28*, 11–12. doi: 10.1111/j.1755-6686.2002.tb00189.X
- Rabindranath, K. S., Adams, J., Ali, T. Z., MacLeod, A. M., Vale, L., Cody, J. D., . . . Daly, C. (2007). Continuous ambulatory peritoneal dialysis versus automated peritoneal dialysis for end-stage renal disease. *Cochrane Database of Systematic Reviews 2007*, 1–29. Art. No.: CD006515. doi: 10.1002/14651858.CD006515
- Ramezani, A., & Raj, D. S. (2014). The gut microbiome, kidney disease and targeted interventions. *Journal of The American Society of Nephrology, 45*, 657–670. doi: 10.1681/ASN.2013080905

- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, *57*, 1069–1081. doi: 10.1037/0022-3514.57.6.1069
- Salamon, K., Woods, J., Paul, E., & Huggins, C. (2013). Peritoneal dialysis patients have higher prevalence of gastrointestinal symptoms than hemodialysis patients. *Journal of Renal Nutrition*, *23*, 114–118. doi: 10.1053/j.jrn.2012.02.007
- Santos, T. T. D., & Almondes, K. M. D. (2015). Sleep quality in chronic kidney disease patients: A systematic review. *Biological Rhythm Research*, *46*, 833–845. doi: 10.1080/09291016.2015.1056436
- Shirazian, S., Grant, C. D., Aina, O., Mattana, J., Khorassani, F., & Ricardo, A. C. (2017). Depression in chronic kidney disease: similarities and differences in diagnosis, epidemiology, and management. *Kidney International Reports*, *2*, 94–107. doi: 10.1016/j.ekir.2016.09.005
- Shirazian, S., & Radhakrishnan, J. (2010). Gastrointestinal disorders and renal failure: exploring the connection. *Nature Reviews Nephrology*, *6*, 480–492. doi: 10.1038/nrneph.2010.84
- Skroeder, N. R., Jacobson, D. H., Lins, L-E., & Kjellstrand, C. M. (1994). Acute symptoms during and between hemodialysis: the relative role of speed, duration and biocompatibility of dialysis. *Artificial Organs*, *18*(12), 880–887. Retrieved from <http://onlinelibrary.wiley.com.proxy.library.adelaide.edu.au/doi/10.1111/j.1525-1594.1994.tb03339.x/abstract;jsessionid=AE6D2B726F2AE3ABDAC3226B8DA66A3A.f02t01>
- Song, Y., Liu, C., & Finegold, S. M. (2004). Real-time PCR Quantitation of clostridia in feces of autistic children. *Applied and Environmental Microbiology*, *70*, 6459–6465. doi: 10.1128/AEM.70.11.6459 – 6465.2004

- Steele, T. E., Wuerth, D., Finkelstein, S., Juergensen, D., Juergensen, P., Kliger, A. S., & Finkelstein, F. O. (1996). Sexual experience of the chronic peritoneal dialysis patient. *Journal of the American Society of Nephrology*, 7(8), 1165–1168. Retrieved from <http://jasn.asnjournals.org/content/7/8/1165>
- Strid, H., Simrén, M., Johansson, A-C., Svedlund, J., Samuelsson, O., & Björnsson, E. S. (2002). The prevalence of gastrointestinal symptoms in patients with chronic renal failure is increased and associated with impaired psychological general well-being. *Nephrology Dialysis Transplantation*, 17, 1434–1439. doi: 10.1093/ndt/17.8.1434
- Thompson, W. G., Irvine, E. J., Pare, P., Ferrazzi, S., & Rance, L. (2002). Functional gastrointestinal disorders in Canada: First population-based survey using Rome II Criteria with suggestions for improving the questionnaire. *Digestive Diseases and Sciences*, 47, 225–235. doi: 10.1023/A:10.13208713670
- Thong, M. S. Y., van Dijk, S., Noordzij, M., Boeschoten, E. W., Krediet, R. T., Dekker, F. W., & Kaptein, A. A. (2009). Symptom clusters in incident dialysis patients: Associations with clinical variables and quality of life. *Nephrology Dialysis Transplantation*, 24, 255–230. doi: 10.1093/ndt/gfn449
- Tong, A., & Craig, J. C. (2016). Tuning into qualitative research – a channel for the patient voice. *Clinical Journal of the American Society of Nephrology*, 11, 1128–1130. doi: 10.2215/CJN.05110516
- Tong, A., Lesmana, B., Johnson, D. W., Wong, G., Campbell, D., & Craig, J. C. (2013). The perspectives of adults living with peritoneal dialysis: Thematic synthesis of qualitative studies. *American Journal of Kidney Diseases*, 61, 873–888. doi: 10.1053/j.ajkd.2012.08.045
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups.

- International Journal for Quality in Health Care*, 19, 349–357. doi: 10.1093/intqhc/mzm042
- Tong, A., Winkelmayr, W. C., & Craig, J. C. (2014). Qualitative research in CKD: An overview of methods and applications. *American Journal of Kidney Diseases*, 64, 338–346. doi: 10.1053/j.ajkd.2014.02.026
- Tougas, G., Chen, Y., Hwang, P., Liu, M. M., & Eggleston, A. (1999). Prevalence and impact of upper gastrointestinal symptoms in the Canadian population: Findings from the DIGEST Study. *The American Journal of Gastroenterology*, 94, 2845–2854. doi: 10.1111/j.1572-0241.1999.01427.x
- Vaziri, N. D., Wong, J., Pahl, M., Piceno, Y. M., Yuan, J., DeSantis, T. Z. . . . Andersen, G. L. (2012). Chronic kidney disease alters intestinal microbial flora. *Kidney International*, 83, 308–315. doi: 10.1038/ki.2012.345
- Vecchio, M., Palmer, S. C., Tonelli, M., Johnson, D. W., & Strippoli, G. F. M. (2012). Depression and sexual dysfunction in chronic kidney disease: A narrative review of the evidence in areas of significant unmet need. *Nephrology Dialysis Transplant*, 27, 3420–3428. doi: 10.1093/ndt/gfs135
- Whitehead, W. E., Palsson, O., & Jones, K. R. (2002). Systematic review of the comorbidity of irritable bowel syndrome with other disorders: What are the causes and implications?. *Gastroenterology*, 122, 1140–1156. doi: 10.1053/gast.2002.32392
- Wing, M. R., Patel, S. S., Ramezani, A., & Raj, D. S. (2016). Gut microbiome in chronic kidney disease. *Experimental Physiology*, 101, 471–477. doi: 10.1113/EPO85283
- Wuerth, D. B., Finkelstein, S. H., Schwetz, O., Carey, E., Klinger, A. S., & Finkelstein, F. O. (2002). Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis. *Peritoneal Dialysis International*, 22(2), 184–190. Retrieved from <http://www.pdiconnect.com/content/22/2/184.short>

- Yasuda, G., Shibata, K., Takizawa, T., Ikeda, Y., Tokita, Y., Umemura, S., & Tochikubo, O. (2002). Prevalence of constipation in continuous ambulatory peritoneal dialysis patients and comparison with hemodialysis patients. *American Journal of Kidney Diseases*, 39(6), 292–299. Retrieved from <http://www.sciencedirect.com/science/article/pii/S0272638602621997>
- Ye, X-Q., Chen, W-Q., Lin, J-X., Wang, R-P., Zhang, Z.H., Yang, X., & Yu, X-Q. (2008). Effect of social support on psychological-stress-induced anxiety and depressive symptoms in patients receiving peritoneal dialysis. *Journal of Psychosomatic Research*, 65, 157–164. doi: 10.1016/j.jpsychores.2008.04.007
- Yilmaz, M. (2010). Opinions of unmarried patients receiving peritoneal dialysis treatment about sexuality. *Sexuality and Disability*, 28, 213–221. doi: 10.1007/s11195-010-9174-4
- Yilmaz, M., & Özaltın, G. (2011). The sexual behaviours of patients receiving peritoneal dialysis treatment. *Sexuality and Disability*, 29, 1573–6717. doi: 10.1007/s11195-011-9199-3
- Yngman-Uhlin, P., Friedrichsen, M., Gustavsson, M., Fernström, A., & Edéll-Gusafsson, U. (2010). Circling around in tiredness: perspectives of patients on peritoneal dialysis. *Nephrology Nursing Journal*, 37(4), 407–413. Retrieved from <http://web.a.ebscohost.com.proxy.library.adelaide.edu.au/ehost/pdfviewer/pdfviewer?vid=1&sid=81469fde-6091-452f-ab7d-abcf6fb234a3%40sessionmgr4010>
- Zhang, J., Huang, C., Li, Y., Chen, J., Shen, F., Yao, Q., . . . & Yao, X. (2013). Health-related quality of life in dialysis patients with constipation: A cross-sectional study. *Patient Preference and Adherence*, 7, 589–594. doi: 10.2147/PPA.S4547

**The Psychosocial Consequences of Gastrointestinal Symptoms and Dietary Changes in Patients Receiving Peritoneal Dialysis for End-Stage Renal Disease: A Qualitative Study**

Emily Duncanson

Master of Psychology (Health)

School of Psychology, Faculty of Health and Medical Sciences

University of Adelaide

Address correspondence to: Emily Duncanson, School of Psychology, Faculty of Health and Medical Sciences, University of Adelaide, South Australia 5005, Australia.



Abstract: 290 words

Manuscript Word Count: 6,931 words (not including abstract, figures, reference list, acknowledgements, or appendices)

The author acknowledges the 3,500 word limit as per the American Journal of Kidney Diseases requirements, which will be adhered to for submission of the final manuscript.

## Abstract

**Background:** Patients receiving peritoneal dialysis (PD) for end-stage renal disease (ESRD) experience markedly poorer quality of life than healthy individuals. Gastrointestinal (GI) symptoms, including nausea, constipation, and diarrhoea, are prevalent and associated with poor psychosocial wellbeing among this patient group. Despite this, patients' experiences of GI symptoms and their psychosocial consequences are yet to be explored.

**Study Design:** Qualitative study. **Setting & Participants:** Participants were recruited through a Renal Unit at a public hospital in South Australia. Ten patients receiving automated PD (5 females, 5 males) aged 31 to 77 years ( $M = 59.3$ ) participated in a single one-on-one qualitative interview. **Methodology:** Qualitative interviews were audio recorded and transcribed verbatim. **Analytical Approach:** Interview transcripts were analysed using thematic analysis. **Results:** A central theme of Autonomy emerged from the data representing participants' experiences of the psychosocial consequences of dialysis, GI symptoms, and dietary changes. This overarched two main themes of Loss of Autonomy (Sub-themes: Interference to Daily Life (Dialysis Process and Sleep, Impacts on Relationships), Powerlessness, Frustration, Food Aversion, and Restriction (Friendships and Social Life, Impacts on Partner)) and Attempts to Gain Autonomy (Sub-themes: Coping Well, Pragmatism, and Maintaining Normality). A related sub-theme of Partner as a Carer emerged as part of Loss of Autonomy. **Limitations:** Recruitment of patients of particularly poor health status was difficult and may therefore limit the transferability of findings. **Conclusions:** GI symptoms have psychosocial consequences resulting in various losses of autonomy for patients, which are linked to that of diet and fluid restrictions. Patients employ various strategies to attempt to regain autonomy in the face of these issues. Dietary education and symptom management advice should aim to enhance patient autonomy within the confines of PD therapy and thus aim to reduce its impact on psychosocial wellbeing.



*INDEX WORDS:* End-stage renal disease (ESRD); peritoneal dialysis (PD); psychosocial wellbeing; gastrointestinal (GI) symptoms; dietary management; qualitative research

## Introduction

Chronic kidney disease is a life-limiting illness characterised by the progressive and irreversible decline of kidney function.<sup>1</sup> In its advanced stages, termed end-stage renal disease (ESRD), patients may choose a palliative care pathway or require kidney transplantation or dialysis therapy to survive. At the end of 2015, approximately 12,400 adults were receiving dialysis for ESRD in Australia, a figure that has steadily increased in the last two decades.<sup>2</sup> Whilst dialysis offers patients an increase in life length, it does not restore kidney function to normal and thus, may not completely revoke symptoms of the disease. In addition, dialysis itself can have profound physical and psychosocial consequences for patients, many of whom will have to maintain therapy for a number of years in the absence of accessible kidney transplantation. Problems resulting from ESRD and dialysis can include pain, poor gastrointestinal (GI) health, sleep disturbance, sexual dysfunction, psychological depression, and changes in lifestyle and relationships.<sup>3, 4, 5, 6, 7</sup>

In ESRD, quality of life can be defined as the patient's perception of the impacts of the disease and dialysis therapy on their physical, social, and emotional functioning and wellbeing.<sup>8,9</sup> Psychosocial wellbeing may be viewed as an independent construct and as having significant influence on an individual's quality of life. For patients receiving dialysis, factors relevant to psychosocial wellbeing include psychological status and relationships with individuals, family, and community.<sup>10</sup> Whilst it is well recognised that patients receiving dialysis experience markedly poorer quality of life compared to renal transplant recipients and healthy individuals,<sup>5,11</sup> greater exploration of the relationships between physical symptoms and psychosocial factors that contribute to quality of life decrements is required.

Peritoneal dialysis (PD) is a home-based therapy for ESRD currently received by approximately 2,500 individuals in Australia.<sup>12</sup> PD involves the infusion of dialysate fluid into the peritoneal membrane, or lining of the abdominal cavity, via a catheter in the patient's

lower abdomen. The peritoneum acts as a filter during dialysis exchanges, performing the kidneys' typical function of diffusing excess water and small solutes, such as urea and creatinine, from the patient's blood.<sup>13</sup> Two forms of PD exist. Patients receiving continuous ambulatory peritoneal dialysis (CAPD) manually perform four to six dialysis exchanges throughout the day, a process that takes approximately thirty minutes. Patients receiving automated peritoneal dialysis (APD) connect to a dialysis machine for approximately 10 hours each night that automatically performs a series of cycling exchanges whilst the person sleeps.<sup>13</sup> APD is the more common form of PD in Australia (67% of patients receiving PD for ESRD).<sup>12</sup>

Previous qualitative research has explored patients' experiences with and opinions of PD therapy, revealing its varied impacts on psychosocial wellbeing.<sup>7</sup> For some patients, the home-based and self-administered nature of PD leads to a sense of control, self-efficacy, and freedom.<sup>7, 14</sup> However, it can also disrupt their home environment, lifestyle, and partner relationships.<sup>7</sup> In addition, the permanent abdominal catheter has negative impacts on patients' body image, self-esteem, and sexual functioning.<sup>7, 15</sup> It is plausible to suggest that these psychosocial difficulties may be particularly pronounced for patients undergoing APD, given that therapy occurs at night whilst the patient is in bed, which may be shared with an intimate partner.

GI symptoms are common in ESRD. In particular, patients receiving PD frequently experience constipation, nausea, diarrhoea, vomiting, and abdominal pain,<sup>4, 16, 17</sup> as well as decreased appetite and dysgeusia (distorted taste).<sup>18</sup> One third are also estimated to be affected by irritable bowel syndrome.<sup>19</sup> Such GI complications are multifactorial problems, resulting from medication side-effects, diet, and the impacts of dialysis itself on the gastrointestinal tract.<sup>20, 21</sup> Quantitative research has demonstrated that GI symptoms are negatively associated with psychological wellbeing and quality of life among patients

receiving dialysis.<sup>3, 22, 23</sup> A study by Zhang et al.<sup>23</sup> assessed the incidence of constipation and health-related quality of life of 78 hemodialysis (HD) and 127 PD patients and found that those who reported experiencing this symptom had significantly poorer health-related quality of life and higher levels of depression than those who did not. Moreover, patients receiving PD with constipation had significantly worse quality of life in both physical and mental domains than those undergoing HD. Similarly, Strid et al.'s<sup>22</sup> study found an inverse association between gastrointestinal symptoms and general psychological wellbeing among a sample of dialysis and pre-dialytic patients. Other research has shown that constipation and decreased appetite are associated with high levels of distress in patients receiving PD.<sup>3</sup> Whilst GI problems are well recognised among this patient group, research suggests that their multidimensional symptom experience is understudied and less understood compared to that of other chronic kidney disease patients.<sup>3</sup> As symptom burden has been identified as a predictor of poor psychological status and lower quality of life in chronic kidney disease,<sup>24, 25, 26, 27</sup> the patient's experience of symptoms is therefore worthy of further investigation.

Dietary modification is an important aspect of the management of chronic kidney disease. Official guidelines recommend that patients receive expert dietary advice, with the aim of reducing protein, salt, phosphate, and potassium intake, appropriate to their level of renal function and associated comorbidities.<sup>28</sup> Whilst diet and fluid restrictions are necessary for effective dialysis therapy, patients perceive them as burdensome and to have negative implications for their social life and relationships.<sup>29, 30, 31, 32</sup> For example, in a recent study by Morris et al.<sup>30</sup>, patients on PD expressed frustration at their limited dietary choice and reported difficulties in dealing with judgments from others about their dietary needs. This led some patients to decline invitations to social events. Another study by Hollingdale et al.<sup>29</sup>, involving focus groups with patients in the pre-dialysis phase and patients receiving dialysis, yielded similar findings. Some participants in this study also described ceasing eating

particular foods in response to symptoms (i.e. those that did not ‘agree’ with them) and that their partners had adopted the same renal-specific diet out of ease of preparing meals. Other research has found that patients on PD employ self-imposed dietary and eating strategies in an attempt to avoid or improve GI symptoms.<sup>33</sup> Given this research, it is plausible to suggest that diet and fluid restrictions, co-occurring GI symptoms, and subsequent changes in eating behaviour may be closely related and have deleterious consequences for patients’ physical health *and* psychosocial wellbeing.

The mind-gut axis represents another potential mechanism by which GI symptoms may be linked to poor psychological status among patients with ESRD. The mind-gut axis consists of a bi-directional relationship between the central and enteric nervous system via various endocrine, immunologic, and hormonal networks.<sup>34</sup> It has been proposed that the mind-gut axis influences not only hemostasis of the GI system, but also affect and stress-related behaviours.<sup>34, 35, 36</sup> Emerging evidence suggests that mind-gut axis interactions are predominantly influenced by the trillions of microbial cells, known as the gut microbiome, distributed in the human GI tract.<sup>34</sup> These are susceptible to alteration from a number of factors including environmental stress, antibiotic medication, and diet.<sup>35, 37</sup> Research has revealed microbial imbalance, or dysbiosis, in patients with irritable bowel syndrome, up to 94% of whom experience comorbid psychological problems.<sup>38, 39</sup> Whilst limited, more recent evidence has shown similar patterns in the microbial landscape of the intestines of individuals with chronic kidney disease.<sup>37, 40</sup> In line with the mind-gut axis, research suggests that psychological distress, namely anxiety and depression can influence the onset and severity of GI symptoms.<sup>41, 42</sup> In patients with irritable bowel syndrome, gastrointestinal-specific anxiety, which includes worry about and vigilance and sensitivity to GI sensations and symptoms, has been established as a predictor of symptom severity and overall quality of

life.<sup>43</sup> These patients also describe constant anticipation of the next symptom episode and have identified stressful situations as a trigger for their occurrence.<sup>44</sup>

Despite the existing evidence, a gap remains in the literature as to *if* and *how* GI symptoms contribute to impairments in the psychosocial wellbeing of patients receiving dialysis. The dearth of qualitative research into this topic may account for this gap in knowledge. Numerous qualitative studies have explored patients' experiences and perceptions of PD therapy,<sup>7</sup> however, to the author's knowledge, none have explored their experience of GI symptoms and their potential psychosocial consequences. Qualitative exploration would elicit rich and detailed information of patients' experiences, opinions, and perceptions, to reveal how dialysis contributes to decrements in quality of life.

The aim of this study is to explore the perspectives, attitudes, and experiences of patients with ESRD undergoing PD, with a particular focus on the links between diet, gastrointestinal health, and psychosocial wellbeing. Through qualitative methods, this study asks the question: *What are the psychosocial consequences of peritoneal dialysis, the renal diet, and gastrointestinal symptoms in patients with end-stage renal disease?* Given patients' desire for holistic care<sup>32</sup> and the association between low quality of life and clinical outcomes,<sup>5, 45, 46</sup> this area of investigation is of applied interest to patients as well as health professionals working in nephrology.

## Methods

### Study Setting and Participants

This study was conducted through a Renal and Transplantation Service and Nephrology Unit at a tertiary public hospital in South Australia. The unit provides inpatient and outpatient treatment for individuals with chronic kidney disease, including kidney transplantation and dialysis therapy (HD and PD), across metropolitan and country areas of

South Australia. Participants were recruited from a Nephrology Unit and Dialysis Centre in South Australia through a purposive sampling strategy. Potential participants were those receiving PD (either CAPD or APD) for ESRD. Nephrologists initially nominated a list of suitable patients as potential participants. Nurses then approached potential participants at outpatient appointments or via telephone, to invite them to participate in the study and provided them with a participant information sheet and consent form. If interested, participants' verbal consent was obtained for the author (primary researcher) to contact them to discuss the study in more detail and arrange an interview. If the patient was initially approached via telephone, the participant information sheet and consent form were posted to them by the author after telephone contact was made. During this phone call the author assured participants of confidentiality, emphasised that participation was voluntary and would in no way affect their current or future medical care, and of their right to withdraw from the study at any time. In total, 14 patients were invited to participate in the study. Four declined, with two indicating they were too time poor and burdened by health and treatment commitments and one provided no reason. One participant withdrew from the study after arranging an interview due to a decline in their health.

Participants ( $N = 10$ ) were five men and five women whose ages ranged between 31 and 77 years ( $M = 59.3$ ). All participants were undergoing APD. The length of time since commencing their current therapy ranged from one month to two years. Three participants had received previous renal replacement therapies, including HD, CAPD, and kidney transplant. Nine participants were married and one was single. Nine of the ten participants had children, ranging from preschool to older adult age. Two participants were working and eight were not in the paid workforce. Two participants had previously diagnosed psychological disorder, managed with psychotropic medications.

## Data Collection

A single one-on-one qualitative interview was conducted by the author with each participant between April and June 2017. The author was a female provisional psychologist receiving training in conducting qualitative research and had no prior relationship with the participants. Nine interviews were conducted face-to-face in a private consulting room at the Nephrology Unit or Dialysis Centre and one was conducted via telephone due to the participant living far away from these locations. Interviews only occurred once the participant's written informed consent was obtained via the consent form. The interview guide was informed by previous research examining the gastrointestinal health, psychological wellbeing, and quality of life of patients receiving dialysis. A preliminary interview took place with a renal dietician acting as a patient, to assess the relevance of the interview questions in relation to the study aim. Participants were first asked basic questions about their demographic details and disease and treatment history. They were then asked "Can you tell me about how peritoneal dialysis has impacted your life?". All participants were asked "Do you experience gastrointestinal, or gut, symptoms, such as nausea, diarrhoea, and constipation?". The remaining questions and prompts were determined by the participant's responses and included topics related to quality of life, relationships, diet, and mental and emotional wellbeing. Interviews lasted between 57 and 99 minutes ( $M = 72.3$ ) and were audio recorded with the participant's consent. All interviews were transcribed verbatim. To protect participant anonymity and confidentiality, all identifiable information was removed from the transcripts and they were each assigned a number. All participants were offered a copy of their interview transcript to make corrections or comment if they desired. Data were collected until theoretical saturation was reached; when no new emerging themes were attained from the data.<sup>47</sup>



## **Data Analysis**

The data were analysed using the Framework approach, a variant of thematic analysis.<sup>48</sup> Framework analysis allows the identification of themes in the data through inductive and deductive methods. The researcher engages in a fluid process of analysis across five stages, during which constant comparisons are made within and across the interview transcripts. As outlined by Pope et al.<sup>48</sup> the first stage, familiarisation, begins at data collection as each interview is conducted, transcribed, and re-read, to allow the point of saturation to be identified. Second, the researcher begins identifying the thematic framework, applying emerging codes, themes, and concepts to the transcripts. Third, the researcher indexes all of the themes by systematically applying the thematic framework to the data. Fourth, the data are rearranged and synthesised into a chart by subject area and theme. Finally, the chart is used to develop a concept map, demonstrating associations between themes and to support their interpretation in relation to the research question. An audit trail was maintained throughout all stages of data collection and analysis to ensure rigor and trustworthiness. This detailed the author's thoughts and reflections on each interview, emerging themes, any changes to the thematic framework, and explanations of decisions made throughout the data analysis process. For consistency, all interview transcripts and identified themes were reviewed by a supervising researcher who had experience in conducting qualitative research and using thematic analysis. The final findings and concept map were peer reviewed by the research group of the hospital's Nephrology Unit, consisting of nephrologists, nurse practitioners, dieticians, and researchers (see Appendix B).

Ethics approval to conduct this study at the relevant hospital and dialysis center was obtained from the hospital's Research Ethics Committee (HREC Reference number: HREC/16/RAH/523) and the University of Adelaide Human Research Ethics Committee. Whilst staff of the hospital identified potential participants and two of the co-investigators of

the project were treating nephrologists, these people were not involved in the interviews nor had access to any form of the interview transcripts.

## Results

A central theme of Autonomy emerged from the data representing participants' experiences of the psychosocial consequences of dialysis, GI symptoms, and diet and fluid restrictions. This overarched two main themes of Loss of Autonomy and Attempts to Gain Autonomy. Loss of Autonomy encompassed sub-themes of Interference to Daily Life (Dialysis Process and Sleep, Impacts on Relationships), Powerlessness, Frustration, Food Aversion, and Restriction (Friendships and Social Life, Impacts on Partner). Restriction and Interference to Daily Life were related to another sub-theme; Partner as a Carer. Attempts to Gain Autonomy encompassed sub-themes of Coping Well, Pragmatism, and Maintaining Normality. The associations between sub-themes identified in the data are demonstrated in the concept map in Figure 1.

### Loss of Autonomy

**Interference to daily life.** Participants reported experiencing GI symptoms of nausea, diarrhoea, vomiting, reflux, constipation, excessive flatulence, stomach cramps, and dry retching. Some expressed uncertainty about what preceded these symptoms, whilst others attributed them to the consumption of foods high in sugar, fiber, or fat. Participants described GI symptoms as an additional dialysis-related burden and disruptive to their day-to-day activities. Some described planning their day in anticipation of potential diahorrea, or taking longer to get ready in the morning due to nausea and vomiting. Another participant described frequent bowel movements as limiting to their ability to participate in and gain pleasure from particular activities, due to the recurrent need to go to the toilet and fear of not finding one when in public.

*“I really-, like I can’t go shopping really. I can’t wander around the shops. I have to, I have to know where every public toilet is wherever I go because I know I’ll be visiting it. And you know, like, where were we somewhere the other day, and I said ‘Oh I’ve got to go’ and [partner] goes ‘Not again!’ and I’m going ‘Yeah, again!’” (P3, Line 154)*

**Dialysis process and sleep.** Participants described recurrent bowel openings, reflux, and constipation as disruptive to the dialysis therapy. One participant reported abdominal pain had at times been severe enough to preclude them from sleeping and others described their bowel functions as inhibiting to the dialysis exchanges. Patients reported that when their bowels were not sufficiently empty, this would cause the dialysis machine to beep repeatedly and thus, disrupt their sleep. For one participant, their unpredictable bowel openings in the evenings meant that they often had to re-commence the time-consuming routine of preparing and connecting to the dialysis machine, including hand washing processes.

*“But there’s other issues too I think, I’m not quite sure, you know, you’ve got to make sure that your bowels are completely empty before you go on the [dialysis] machine otherwise it doesn’t work properly. So, you’ve got to think of these things so you make sure that everything is right-, the conditions are right for dialysis to work.” (P1, Line 150)*

**Impacts on relationships.** Participants also perceived negative impacts of GI symptoms on other people, including friends and partners. Some described feeling like an impost to other people due to their unpredictable GI symptoms and frequent need to use the

toilet during outings. Others were conscious of restraining symptoms, namely flatulence, out of fear of embarrassment or offending others.

*“You’ve got to be very careful. Restrain yourself in a lot of ways and be careful. [...]It gets very, very hard. [...]Well, you can’t-, you’ve got to be a bit more respectful towards other people.” (P5, Lines 456, 458, & 460)*

One participant described the anticipation of GI symptoms, in addition to the abdominal catheter, as contributing to their decreased interest in sex since commencing APD.

*“I mean, my whole body image... it’s [catheter] this horrible thing in my stomach and um, you know, am I going to need to go the toilet in the middle of sex - oh that’s really nice isn’t it?! No. Not good.” (P3, Line 364)*

**Powerlessness.** Participants perceived a loss of autonomy and control within what was described as a confusing web of consequences resulting from ESRD and PD, including diet and fluid restrictions, GI symptoms, changes in body shape, weight gain, fluid retention from dialysis, and an inability to exercise. These problems were perceived to be interlinked and affected one another in a cumulative manner. Participants reported attempts to gain influence over one or more of these issues, however, frequently became frustrated and discouraged when their efforts resulted in further problems or they received subsequent blood test results that were unfavourable. Participants felt they were confined by the limits of their condition and powerless to effectively gain control over these issues, with some describing themselves as servants or bystanders to PD. Some participants described feeling

uncomfortable in their bodies and perceived themselves as physically unattractive as a result of these issues.

*“So, I’m probably more mindful of um, trying to have a reasonable diet to just manage the weight cos I feel like I’m not really in control of my weight anymore. [...] That’s probably the one thing that’s um, a frustration, more than anything else, cos I can’t really-, I don’t feel like I’ve got control over it. It’s like I’m a bystander to whatever happens with dialysis, just results in X, Y, Z.” (P4, Lines 120 & 122)*

**Frustration.** As a result of their various losses of autonomy, participants described a strong sense of frustration. Some experienced GI symptoms as particularly annoying. Many felt frustrated at their repeated efforts to monitor their bowel health and successfully manage GI symptoms, particularly given the strong emphasis placed on these issues by dialysis nurses. Despite experiencing frequent and distressing GI symptoms, one participant had not sought medical advice to improve these as they reported managing other symptoms and health issues was burdensome enough.

*“I don’t know what’s up with them, but it’s really annoying. But then the girls [nurses] will say ‘Don’t get constipated, don’t get constipated’, so I don’t get constipated. I eat lots of roughage. I mean, I’ve been to the toilet twice today already, I know I’ll go again this afternoon and again this evening. I just get sick of it. [...] Yep. Sick, sick, sick of it.” (P3, Lines 124 & 126)*

**Food aversion.** Participants described a loss of autonomy over food preferences and choices. This was perceived to be a result of a complex interaction of factors including

changes in the taste, texture and smell of foods, loss of appetite, and GI symptoms, namely nausea, vomiting, and gagging. Participants described aversions to foods high in protein and fat, which were associated with a strong sense of disgust, feeling nauseous, and the urge to vomit. Participants' appetite and interest in foods frequently changed. Some therefore described a discrepancy between their psychological desire for particular foods and their body's ability to comfortably consume them. Changes in tastes for foods and food aversions were strong and inexplicable. For some participants, this led to a loss of pleasure in eating experiences and a sense of disappointment.

*“So, I used to love nothing more than a really nice rump steak with a red wine-, um. [...] Annoyed is not the word. Disappointed. Something I liked so much which I can't even stand the- ((Leans away and grimaces)). But lots of foods are doing that to me at the moment. Um, I couldn't hardly eat last night either, for feeling like that and it's usually only in the mornings I feel like that but-, but last night I just noticed that I couldn't-, I wasn't coping with the meal that was in front of me and there was nothing wrong with it.” (P8, Lines 359 & 363)*

**Restriction.** Participants described feeling restricted by the renal diet requirements. They perceived limited freedom to choose what they could eat and drink, which resulted in negative emotions including anger and frustration.

*“Um, it's... it's the worst thing ever. I really hate it [fluid restriction]. When I went on this [APD] they said 'Oh you won't be on a fluid restriction', but within-, I wouldn't be on a fluid restriction and that was fine. Cause I'm a big drinker. I like drinking. And, I just find it's the worst thing, that's what really, really pisses me off,*

*more than my guts, is that fact that I can't have a nice, big, cold glass of cordial and just chug it down and think 'Yeah that was nice' and have another one if I wanted." (P3, Line 186)*

**Friendships and social life.** Some participants described adhering to the renal diet as particularly challenging when eating in public with other people. This affected one participant greatly, who reported their dietary requirements had at times prohibited them from accepting invitations to eat out with friends.

*"Yeah, sometimes when my friends call me to go out I just don't, I can't be bothered sometimes. I feel that because they basically can have a drink of wine or stuff like that, and I basically can't. Or they might go out certain places where they can eat certain foods and I can't, it's like-, well sometimes I think like, 'Why am I bothering?', like 'Why should I go out for?'" (P6, Line 150)*

**Impacts on partner.** Participants in a relationship described the negative impacts their renal diet requirements had on their partners. Many reported that their partners had adopted the same diet out of ease of preparing and cooking meals. Participants perceived adhering to the renal diet as an unfair inconvenience and restricting for their partners as well as themselves.

*"So there's a bit of fiddling around for her [partner]. And I don't like greasy foods, uh, yeah. And she said I'm not a pleasure to cook for. [...] Her diet is based around mine basically. [...] Boring for her, yep. She'd like uh, yeah, she'd like [to], you*

*know, cook up a curry or stuff she likes but she's restricted." (P2, Lines 185, 247, & 249)*

**Partner as a carer.** Participants described their Partner as a carer and assistant to the PD therapy. Some participants reported that their partners had adopted the responsibility of monitoring their food intake and preparing biochemically appropriate foods since commencing dialysis. Participants described their partners' additional designated "jobs", such as ordering treatment supplies and medications, lifting heavy fluid boxes, organising appointments, and cleaning and preparing the dialysis machine for use at night. Two participants described themselves as passive recipients to dialysis therapy that their partners 'did for' them and being unaware of the specific equipment or fluids involved in their treatment.

*"You name it, you can't eat it. You know, that's-, it's very much-, as I said, if it wasn't for [partner] ((Chuckles)), for the food, I'd be as fat as a pig and probably dead by now. [...] [She is] my nurse, my cook, my chauffer, what else... You name it-, my secretary. She's the lot. Couldn't ask for any better." (P5, Lines 366 & 500)*

### **Attempts to Gain Autonomy**

**Coping well.** Overall, participants reported that they coped well with their GI symptoms. Participants mostly relied on medications to reduce the frequency of their occurrence, which they perceived to be effective. They described employing other simple strategies to gain relief when GI symptoms caused physical discomfort, including engaging in a relaxing activity or eating. One participant described using humour to diffuse the impact of GI symptoms when around others. Participants reported adjusting well to changes in their



bowel function and GI symptoms, with one describing their multiple bowel movements each day as the new “normal”. Participants sought advantages to GI symptoms, such as a decrease in appetite and not needing to use the toilet frequently. Some described feeling drained or lacking in energy after experiencing GI symptoms of nausea and diahorrea, however, GI problems were not perceived to have a significant impact on participants’ psychological or social wellbeing.

*“...that still happens to a certain extent now, that if I’m going to have a bowel motion and I get cleaned out I’ll go three times in about an hour. [...] And so, that’s become me, that’s become normal, so...” (P9, Line 450 & 452)*

**Pragmatism.** Participants reported being accepting of their renal diet as part of the management of their condition and were pragmatic about making necessary changes. One participant described consuming food for nutritional benefit only rather than enjoyment. Some participants described compensatory strategies, such as replacing salt with large quantities of pepper or eating when thirsty. This pragmatic coping style was evident also in participants’ responses to GI problems.

*“It’s alright. I just wish I could eat a bigger range of goodies, um, but it’s no real problem. Because I just eat now because I’ve got to. I’ve got to get that goodness into me. So, it’s no big deal. I don’t get excited that it’s lunchtime.” (P2, Line 229)*

**Maintaining normality.** Some participants described ambiguity about dietary requirements and reported consuming foods they suspected to be prohibited in an attempt to maintain normality. Participants described eating desired foods to break the monotony of the

renal diet and not deprive themselves, adopting an ‘it’s all in moderation’ attitude. One participant reported frequently giving in to cravings and proceeding to eat foods they knew they should not.

*“No, because I still like cravings for cheese ((Chuckles)). [...] And cheese is not a good thing either ((Chuckles)). [...] But sometimes you know, I’ll go through a ‘yes cheese, cheese, cheese, cheese’ and then I thought ‘No I don’t want cheese’, so obviously I’m needing something-, to me, if I’m craving it I’m needing it...and so you know, it’s easier just to give it in.” (P9, Line 504, 506, 508 & 510)*

### **Discussion**

The purpose of the current study was to explore the psychosocial consequences of PD, the renal diet, and GI symptoms in patients with ESRD. This research identified that patients experience a Loss of Autonomy in the various psychosocial impacts of dietary changes and GI symptoms and respond to these with Attempts to Gain Autonomy. This central theme of Autonomy is consistent with previous qualitative research that has explored patients’ broader experiences and opinions of PD therapy. Such evidence has demonstrated the numerous psychosocial impacts of PD, yet that many patients perceive it to be a treatment that offers them opportunities to become self-determining, independent, and gain a level of control in the management of their condition.<sup>7</sup> Prior to this study, research had established that GI symptoms were associated with poor psychological wellbeing and quality of life among dialysis patients, but *how* and *why* this was, had yet to be established. To the author’s knowledge, this study is the first to employ qualitative methods to explore the experiences and perceptions of patients receiving PD regarding GI symptoms and their psychosocial impacts. The overall findings extend the chronic kidney disease literature by demonstrating

that patients perceive various losses of autonomy in the psychosocial consequences of GI symptoms, which are perceived to be closely linked to that of the renal diet and the PD regimen. Patients meet many of these perceived losses of autonomy with pragmatic attempts to regain it, including self-directed or professionally recommended strategies, as well as changes in eating behaviours and attitudes that provide a sense of normality. When successful, these efforts and strategies increase autonomy, promote the patient's psychosocial wellbeing and ultimately, help them cope well. However, patients feel frustrated and discouraged when attempts are inhibited by the confines of ESRD and PD therapy, or result in additional symptoms and difficulties. Patients' grappling with losses of autonomy and attempts to regain it was found to be a dynamic and continual process.

Consistent with previous research,<sup>4, 16, 17</sup> participants in the present study reported experiencing a range of GI symptoms, which were identified as an Interference to Daily Life. Frequent and unexpected bowel movements impacted daily routines, the dialysis process, sleep, and the ability to enjoy particular leisure activities. Participants were wary of the perceptions of friends, family, and partners regarding their GI symptoms. It was noted that one participant described the anticipation of needing to unexpectedly defecate as contributing to their decreased interest in sex since commencing dialysis. The consequences of GI symptoms in patients' day-to-day lives identified in this study are novel findings to add to the chronic kidney disease literature and provide new insight into the mechanisms by which GI symptoms contribute to quality of life impairments. Interestingly, similar psychosocial difficulties resulting from GI dysfunction have been described by patients with irritable bowel syndrome and irritable bowel disease, who commonly experience anxiety, social isolation, and exhibit avoidance behaviour due to fear of incontinence.<sup>39, 44, 49</sup> In the present study, despite participants' frustration due to the impacts of GI symptoms on their lives, they identified as Coping Well with them due to the use of adaptive and pragmatic strategies.

Furthermore, despite evidence of the mind-gut axis connection,<sup>34, 37, 40</sup> participants in the current study did not describe experiences indicative of this. Given the emerging field of mind-gut axis research and the extensive literature on the relationship between psychological status and functional gastrointestinal disorder symptoms,<sup>41, 43, 44</sup> it was anticipated that participants may describe incidences of stress, anxiety, low mood, or catastrophising as preceding or exacerbating GI symptoms. Although an explicit relationship between psychological status and GI symptoms was not described, the findings of this research demonstrate that patients perceive GI symptoms to play a role in the broader psychosocial impacts of PD.

Participants described a sense of Restriction in dietary choice and loss of autonomy in freedom to consume foods and amounts of liquid they desired. Some described particular difficulty adhering to diet and fluid restrictions when outside the home, having implications for one participant's social life. These challenges have been described by patients with varying stages of chronic kidney disease in previous research. The current findings therefore re-iterate that the renal diet can lead to interpersonal difficulties and negatively impact quality of life.<sup>29, 30, 31</sup> In alignment with Salamon et al.'s<sup>33</sup> study, some participants described self-directed eating behaviours to alleviate GI symptoms. Participants also identified Pragmatism and Maintaining Normality in dietary management strategies and attitudes as central to regaining a level of autonomy in the face of diet and liquid restrictions. These efforts ultimately help patients to accept diet and liquid restrictions as part of their health management and comply with dietary instructions. This view is in alignment with the themes of accepting responsibility and valuing self-management identified in Palmer et al.'s<sup>31</sup> review of qualitative studies about diet and fluid restrictions in chronic kidney disease.

Participants described being dependent on their partner to monitor their nutritional intake and prepare appropriate food in accordance with the renal diet. Many participants

reported that their partners had adopted the same diet and had taken on other roles and responsibilities in their PD therapy. Participants described their Partner as a Carer and as actively involved in their health care, referring to them as their “nurse”, “carer”, and “cook”. Similar findings have been reported in other qualitative studies revealing the implications of dietary changes and PD therapy on partner roles and responsibilities within the relationship.<sup>31</sup>

<sup>50</sup> Given patients commonly rely on their partners for various forms of support, further qualitative research is needed to explore the experiences, perceptions, and opinions of these individuals. Not only may this information lead to the enhancement of patient treatment adherence and thus outcomes, the findings of the present study suggest that partners may too experience losses of autonomy, having potential implications for their own psychosocial wellbeing.

Participants also identified Food Aversion as a loss of autonomy over food preferences and eating experiences. Aversions to particular foods were experienced as powerful and bewildering, and for some participants, resulted in disappointment and a loss of pleasure. This change in the emotional and mental experience of eating has been identified in other studies with dialysis and non-dialysis patients, who report “feeling deprived” of pleasurable experiences due to dietary limitations and changes in taste.<sup>31</sup> Food Aversion was described as a physical and psychological experience, whereby the participant’s body would reject food through nausea and gagging, as well as strong sense of disgust. To the author’s knowledge, this theme had yet to be identified in the qualitative literature. These findings complement the existing evidence regarding patients’ experiences of diet and liquid restrictions, by demonstrating that GI symptoms and changes in appetite and taste also contribute to its impacts on their lives.

Participants described a loss of autonomy in navigating the competing demands and consequences of ESRD and PD, including dietary changes, GI symptoms, changes in body

shape, weight gain, fluid retention, identified as Powerlessness and Frustration. Participants attempted to master solutions to these problems, but became frustrated when they were inhibited by dietary and liquid restrictions, or an inability to exercise due to the time consuming PD regimen or treatment complications. This continual process was “physically and mentally draining” and often resulted in patients feeling powerless, subservient to the PD therapy, and for some, dissatisfied with their body image. These concerns and attempts to master PD and adjust to dietary changes have been reported consistently in the literature.<sup>7,31</sup> The present study highlights that patients perceive GI symptoms to be closely related to these issues and feel responsible to manage them successfully due to the strong emphasis placed on bowel and gastrointestinal health by treating healthcare professionals.

The central theme of Autonomy identified in the present study is consistent with previous research with patients with ESRD.<sup>7</sup> Autonomy, control, and self-management have been established as important factors for successful psychological adjustment to the challenges posed by living with chronic disease.<sup>51</sup> Opportunities to enhance patient autonomy in PD therapy may foster treatment compliance, a function that patients have described enables them to maintain a state of relatively normal health and being.<sup>52</sup> ESRD and PD pose inevitable limitations on patients’ lives, which have far reaching psychosocial consequences. The current findings indicate that within these confines, patients attempt to reformulate their attitudes, behaviours, and environments to regain some level of autonomy and control that has been lost with varying degrees of success, a view that has also been reported elsewhere.<sup>53</sup> Regaining a level of autonomy helps the patient to feel self-efficacious and maintain a sense of normality whilst living with a life-limiting illness. The concept map identified in the present study, which highlights the dynamic processes between losses of autonomy and attempts to regain autonomy, may potentially be applied to understand the patient’s experiences of other problems resulting from ESRD and renal replacement therapies, for

example, pain, frailty, and identity changes. This conceptualisation may enable the identification of opportunities for strategies and interventions that promote patient autonomy and thus, improve patient psychological wellbeing and quality of life.

The results of the present study are of applied interest to patients, nephrologists, renal nurses, and renal dieticians. The findings indicate that to promote patient psychosocial wellbeing and adaptive coping behaviours, opportunities that foster patient autonomy in dietary and GI symptom management should be considered. Furthermore, as has been suggested elsewhere,<sup>31, 54</sup> patients' partners may be included during the provision of dietary education and advice to improve recall of nutritional information and adherence to dietary instructions. However, the psychosocial difficulties faced by patients and their partners that were identified in the present study highlight that the burden of PD should not be underestimated. Despite the participants of the present study demonstrating positive psychological adjustment overall, for some patients and arguably their partners, psychological support may be beneficial. The psychosocial burden associated with PD, GI symptoms, and dietary changes provides further support for the notion that greater interdisciplinary management and holistic care is needed in renal units to improve patient quality of life.<sup>32</sup>

To enhance the credibility of conclusions made in qualitative research, the collection of data from multiple sources regarding the same phenomenon is preferable (i.e. triangulation).<sup>55</sup> Thus, future research should explore the perceptions and experiences of patients' partners and family members who support them in adhering to the PD regimen and dietary requirements. The findings of the present study suggest that this may provide an understanding of the difficulties faced by patients' partners due to changes in lifestyle and roles within the relationship. Qualitative research involving renal dieticians should also be conducted to explore their perceptions of patients' GI health and experiences of providing

dietetic advice. This may reveal discrepancies between professional opinions and patient perceptions of GI health and symptom management, and thus identify opportunities for improved care.

Finally, despite the large body of evidence indicating a high prevalence of psychological disorders in dialysis populations, as well as their co-occurrence with gastrointestinal dysfunction, no participants in the present study described significant psychological difficulties resulting from dialysis or associated symptoms. Whilst participants described negative emotions of frustration, anger, and disappointment, overall, they reported coping well with PD and its impacts. There are multiple possible explanations for these findings. First, there were challenges in recruiting patients who identified as being significantly burdened by poor health. Second, those in the study sample described being compliant with the PD therapy and had experienced relief from GI symptoms through various strategies, namely medications. Assessing patients of particularly poor health or those considered 'non-compliant' can be challenging<sup>52</sup> and may therefore limit the transferability of the findings of this study to such groups. Furthermore, it is plausible to suggest that whilst GI symptoms are prevalent, patients consider other impacts of ESRD and renal replacement therapies to have graver consequences for their psychosocial wellbeing. Nevertheless, qualitative research aims to gain rich and in-depth rather than generalisable data. Future research should explore issues of GI health, diet, eating behaviour, and psychosocial wellbeing in other ESRD groups, for example, those receiving CAPD or HD. As these therapies involve different routines and procedures to APD, such patients may have unique psychosocial concerns to those of the participants in the present study. Given the evidence discussed, such research may be warranted particularly among patients with comorbidities such as diabetes, irritable bowel syndrome, depression, and anxiety.



Through qualitative methods, the present study had revealed themes describing the experiences and perceptions of patients undergoing APD regarding the psychosocial consequences of GI symptoms, the renal diet, and the dialysis regimen. The results suggest that patients experience losses of autonomy in multiple life domains as a result of these issues, and in response, attempt various medical, psychological, and behavioural solutions to regain autonomy and reformulate their experience. Furthermore, the findings highlight the breadth of psychosocial challenges faced by patients receiving dialysis that contribute to decrements in quality of life. They also emphasise the view that health care professionals should consider opportunities to promote patient autonomy and self-management, however, improved interdisciplinary care including psychosocial support may be required by some patients and their families. This is an important area of research to be pursued in future qualitative studies, with a view to explore the lived experiences of patients and thus inform interventions to improve quality of life.

### **Acknowledgements**

*Support:* None.

*Financial Disclosure:* Emily Duncanson declares that she has no relevant financial interests.

*Acknowledgements:* Research idea, study design, data interpretation, supervision, and mentorship: Professor Anna Chur-Hansen. Assistance in ethics approval process and project support: Dr Shilpa Jesudason, Dr Richard Le Leu, and Professor Randall Faull.

Participant recruitment: Monique Borlace and Phillippa Southwell. Pilot interview: Anthony Meade. I would also like to acknowledge the assistance of the nurses and administrative staff of the Dialysis Centre and Nephrology Unit at the relevant hospital in arranging interviews.

## References

1. Abbasi M, Chertow GM, Hall YN. End-stage renal disease. *Am Fam Physician*. 2010;82(12):1512-1514. Available from: PubMed Central.
2. Australia and New Zealand Dialysis and Transplant Registry (AZDATA Registry). [Internet]. 2017 [cited 2017 August 17]. Available from [http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c02\\_prevalence\\_v2.1\\_20170418.pdf](http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c02_prevalence_v2.1_20170418.pdf)
3. Almutary H, Bonner A, Douglas C. Which patients with chronic kidney disease have the greatest symptom burden? A comparative study of advanced CKD stage and dialysis modality. *J Ren Care*. 2016; 42(2):73-82. DOI: 10.1111/jorc.12152
4. Cano AE, Neil AK, Kang JY, et al. Gastrointestinal symptoms in patients with end-stage renal disease undergoing treatment by hemodialysis or peritoneal dialysis. *Am J Gastro*. 2007;102(9):1990-1997. DOI: 10.1111/j.1572-0241.2007.01321.x
5. Lew SQ, Piraino B. Quality of life and psychological issues in peritoneal dialysis patients. *Semin Dial*. 2005;18(2):119-123. DOI: 10.1111/j.1525-139X.2005.18215.x
6. Murtagh FEM, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: A systematic review. *Adv Chronic Kidney Dis*. 2007;14(1):82-99. Available from: ScienceDirect.
7. Tong A, Lesmana B, Johnson DW, Wong G, Campbell D, Craig JC. The perspectives of adults living with peritoneal dialysis: Thematic synthesis of qualitative studies. *Am J Kidney Dis*. 2013; 61(6): 873-888. DOI: 10/1053/j.ajkd.2012.08.045
8. Finkelstein FO, Wuerth D, Finkelstein SH. Health related quality of life and the CKD patient: Challenges for the nephrology community. *Kidney Int*. 2009; 76(9):946-952. DOI: 10.1038/ki.2009.307

9. Guney I, Solak Y, Atalay H, et al. Comparison of effects of automated peritoneal dialysis and continuous automated peritoneal dialysis on health-related quality of life, sleep quality, and depression. *Hemodial Int.* 2010;14(4):515-522. DOI: 1111/j.1543-4758.2010.00465.x
10. Wuerth D, Finkelstein SH, Finkelstein FO. Psychosocial assessment of the patient on chronic peritoneal dialysis: An overview. *Adv Chronic Kidney Dis.* 2007;14(4):353-357. Available from: PubMed.
11. Maglakelidze N, Pantsilaia T, Tchokhanelidze I, Managadze L, Chkhotua A. Assessment of health-related quality of life in renal transplant recipients and dialysis patients. *Transplant Proc.* 2011;43(1):376-379. DOI: 10.1016/j.transproceed.2010.12.015
12. Australia and New Zealand Dialysis and Transplant Registry (AZDATA Registry). [Internet]. 2017 [cited 2017 August 17]. Available from [http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c05\\_peritoneal\\_v2.0\\_20170418.pdf](http://www.anzdata.org.au/anzdata/AnzdataReport/39thReport/c05_peritoneal_v2.0_20170418.pdf)
13. Ellam T, Wilkie M. Peritoneal dialysis. *Med.* 2015;43(8):484-488. DOI: 10.1016/j.mpmed.2015.05.001
14. Baillie J, Lankshear A. Patient and family perspectives on peritoneal dialysis at home: findings from an ethnographic study. *J Clin Nursing.* 2014;24(1-2):222-234. DOI: 10.1111/jocn.12663
15. Yilmaz M. Opinions of unmarried patients receiving peritoneal dialysis treatment about sexuality. *Sex Disabil.* 2010;28(4):213-221. DOI: 10.1007/s11195-010-9174-4
16. Dong R, Guo ZY, Ding JR, Zhuo YY, Wu H. Gastrointestinal symptoms: A comparison between patients undergoing peritoneal dialysis and hemodialysis. *World J Gastroenterol.* 2014;20(32):11370-11375. DOI: 10.3748/wjg.v20.i32.11370

17. Figueiredo AE, Goodlad C, Clemenger M, et al. Evaluation of physical symptoms in patients on peritoneal dialysis. *Int J Nephrol*. 2012;20(32):1-4. DOI: 10.1155/2012/305424
18. Affrin NFM, Naing L, Pisharam J, et al. Appetite and gastrointestinal symptoms in end stage renal disease patients. *J Clin Exp Nephrol*. 2016;1(2):1-6. DOI: 10.21767/2472-5056.100006
19. Shirazian S, Radhakrishnan J. Gastrointestinal disorders and renal failure: exploring the connection. *Nat Rev Nephrol*. 2010;6(8):480-492. DOI: 10.1038/nrneph.2010.84
20. Dong R, Guo ZY. Gastrointestinal symptoms in patients undergoing peritoneal dialysis: Multivariate analysis of correlated factors. *World J Gastroenterol*. 2010;16(22):2812-2817. Available from: PubMed.
21. Yasuda G, Shibata K, Takizawa T, et al. Prevalence of constipation in continuous ambulatory peritoneal dialysis patients and comparison with hemodialysis patients. *Am J Kidney Dis*. 2002;39(6):292-1299. DOI: 10.1053/ajkd.2002.33407
22. Strid H, Simrén M, Johansson A-C, Svedlund J, Samuelsson O, Björnsson ES. The prevalence of gastrointestinal symptoms in patients with chronic renal failure is increased and associated with impaired psychological general well-being. *Nephrol Dial Transplant*. 2002;17(8):1434-1439. Available from: PubMed.
23. Zhang J, Huang C, Li Y, et al. Health-related quality of life in dialysis patients with constipation: A cross-sectional study. *Patient Pref Adherence*. 2013;7:589-594. DOI: 10.2147/PPA.S45471
24. Almutary H, Bonner A, Douglas C. Symptom burden in chronic kidney disease: A review of recent literature. *J Ren Care*. 2013;39(3):140-150. DOI: 10.1111/j.1755-6686.2013.12022.x

25. Davis SJ, Phillips L, Naish PF, Russell GI. Quantifying comorbidity in peritoneal dialysis patients and its relationship to other predictors of survival. *Nephrol Dial Transplant*. 2002;17(6):1085-1092. Available from: PubMed.
26. Davison S, Jhangri G. Impact of pain and symptom burden on the health-related quality of life of hemodialysis patients. *J Pain Symptom Manage*. 2010;39(3):477-485. DOI: 10.1016/j.jpainsymman.2009.09.008
27. Jing L, Wu-Jun X, Feng T. Palliative care for patients with malignancy and end-stage renal failure on peritoneal dialysis. *Indian J Palliat Care*. 2014;20(2):137-141. DOI: 10.4103/0973-1075.132636
28. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Intl Suppl*. 2012;3:1-150.
29. Hollingdale R, Sutton D, Hart K. Facilitating dietary changes in renal disease: Investigating patients' perspectives. *J Ren Care*. 2008;34(3):136-142. DOI: 10.1111/j.1755-6686.2008.00034.x
30. Morris A, Love H, van Aar Z, Liles C, Roskell C. The problematic world of following a renal diet outside the home. *J Ren Care*. 2015;41(4):253-259. DOI: 10.1111/jorc.12134
31. Palmer SC, Hanson CS, Craig JC, et al. Dietary and fluid restrictions in CKD: A thematic synthesis of patient views from qualitative studies. *Am J Kidney Dis*. 2015;65(4):559-573. DOI: 10.1053/j.ajkd.2014.09.012
32. Tong A, Sainsbury P, Chadban S, et al. Patients' experiences and perspectives of living with CKD. *Am J Kidney Dis*. 2009;53(4):689-700. DOI: 10.1053/j.ajkd.2008.10.050
33. Salamon K, Woods J, Paul E, Huggins C. Peritoneal dialysis patients have higher prevalence of gastrointestinal symptoms than hemodialysis patients. *J Ren Nutr*. 2013;23(2):114-118. DOI: 10.1053/j.jrn.2012.02.007

34. Carabotti M, Scirocco A, Maselli MA, Severi C. The gut-brain axis: Interactions between enteric microbiota, central and enteric nervous systems. *Ann Gastroenterol.* 2015;28(2):203-209. Available from PubMed.
35. Foster JA, Neufeld KAM. Gut-brain axis: How the microbiome influences anxiety and depression. *Trends Neurosci.* 2013;36(5):305-312. DOI: 10/1016/j.tins.2013.01.005
36. Mayer EA, Padua D, Tillisch K. Altered brain-gut axis in autism: Comorbidity or causative mechanisms? *Bioessays.* 2014;36(10):933-939. DOI: 10.1002/bies.201400075
37. Wing MR, Patel SS, Ramezani A, Raj DS. Gut microbiome in chronic kidney disease. *Exp Physiol.* 2016;101(4):471-477. DOI: 10.1113/EP085283
38. DuPont HL. Review article: Evidence for the role of gut microbiota in irritable bowel syndrome and its potential influence on therapeutic targets. *Aliment Pharmacol Ther.* 2014;39(10):1033-1042. DOI: 10.1111/apt.12728
39. Whitehead WE, Palsson O, Jones, KR. Systematic review of the comorbidity of irritable bowel syndrome with other disorders: What are the causes and implications?. *Gastroenterology.* 2002;122(4):1140-1156. DOI: 10.1053/gast.2002.32392
40. Vaziri ND, Wong J, Pahl M, et al. Chronic kidney disease alters intestinal microbial flora. *Kidney Int.* 2013;83(2):308-315. DOI: 10.1038/ki.2012.345
41. Wouters MM, Boeckxstaens, GE. Is there a causal link between psychological disorders and functional gastrointestinal disorders?. *Expert Rev Gastroenterol Hepatol.* 2016;10(1):5-8. DOI: 10.1586/17474124.2016.1109446
42. Levy RL, Olden KW, Naliboff BD, et al. Psychosocial aspects of the functional gastrointestinal disorders. *Gastroenterology.* 2006;130(5):1447-1458. DOI: 10.1053/j.gastro.2005.11.057

43. Jerndal P, Ringström G, Agerforz P, et al. Gastrointestinal-specific anxiety: An important factor of GI symptoms and quality of life in IBS. *Neurogastroenterol Motil.* 2010;22(6):646-e179. DOI: 10.1111/j.1365-2982.2010.01492.x
44. Betram S, Kurland, M, Lydick E, Locke GRI, Yawn BP. The patient's perspective of irritable bowel syndrome. *Journal Fam Pract.* 2001;50(6):521-525. Available from: PubMed.
45. Christensen A, Ehlers SL. Psychological factors in end-stage renal disease: An emerging context for behavioral medicine research. *J Consult Clin Psychol.* 2002;70(3):712-724. DOI: 10.1037//0022-006X.70.3.712
46. Farrokhi F, Abedi N, Beyene J, Kurdyak P, Jassal SV. Association between depression and mortality in patients receiving long-term dialysis: A systematic review and meta-analysis. *Am J Kidney Dis.* 2014;63(4):623-635. DOI: 10.1053/j.ajkd.2013.08.024.
47. Morse JM. The significance of saturation. *Qual Health Res.* 1995;5(2):147-149. DOI: 10.1177/104973239500500201
48. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ.* 2000;320(7227):114-116. DOI: 10.1136/bmj.320.7227.114
49. Kemp K, Griffiths J, Lovell K. Understanding the health and social care needs of people living with IBD: A meta-synthesis of the evidence. *World J Gastroenterol.* 2012;18(43):6240-6249. DOI: 10.3748/wjg.v18.i43.6240
50. Ekelund M-L, Andersson SI. "I need to lead my own life in any case" – A study of patients in dialysis with or without a partner. *Patient Edu Couns.* 2010;81(1):30-36. DOI: 10.1016/j.pec.2009.10.025
51. De Ridder D, Geenen R, Kuijper R, von Middendorp H. Psychological adjustment to chronic disease. *Lancet.* 2008;372(9634):246-255. Available from: ScienceDirect.



52. McCarthy A, Shaban R, Boys J, Winch S. Compliance, Normality, and the Patient on Peritoneal Dialysis. *Nephrol Nurs J*. 2010;37(3):243-251. Available from: PubMed.
53. Martin-McDonald K. Being dialysis-dependent: A qualitative perspective. *Collegian*. 2003;10(2):29-33. DOI: 10.1016/S1322-7696(08)60052-9
54. Pelto GH, Santos I, Gonçalves H, Victora C, Martines J, Habicht J-P. Nutrition counseling training changes physician behavior and improves caregiver knowledge acquisition. *J Nutr*. 2004;134(2):357-362. Available from: PubMed.
55. Tracy SJ. Qualitative quality: Eight 'big-tent' criteria for excellent qualitative research. *Qual Inq*. 2010;16(10):837-851. Available from: SAGE Journals.
56. Tong A, Winkelmayer WC, Craig JC. Qualitative research: An overview of Methods and Applications. *Am J Kidney Dis*. 2014;64(3):338-346. DOI: 10.1053/j.ajkd.2014.02.026

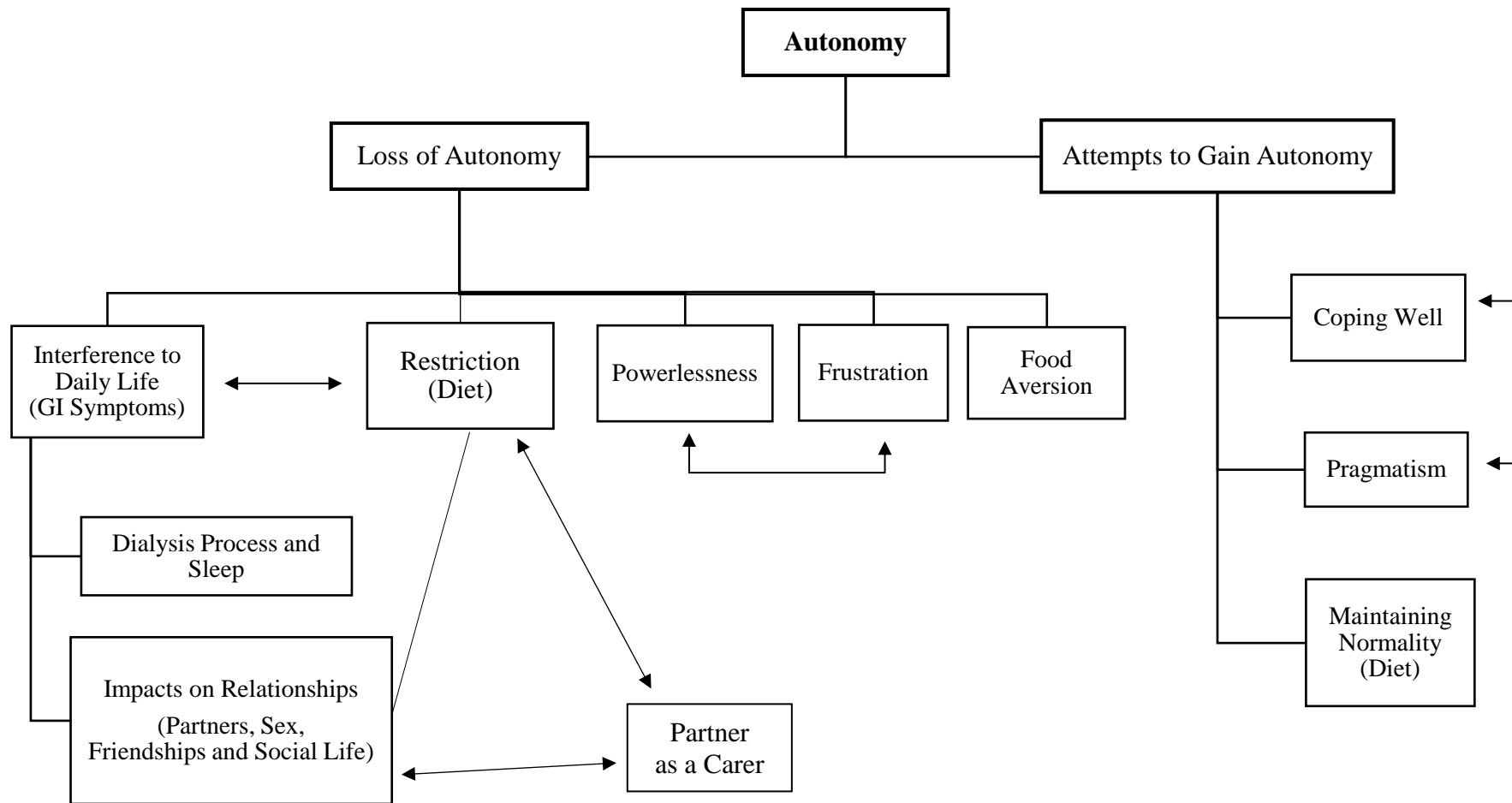


Figure 1. Concept map illustrating the main themes and sub-themes identified from the qualitative data.

## Appendix A

Article Published on the Kidney, Transplant and Diabetes Research Australia (KTDR)

Website

**Exploring the Psychological Impact of Dialysis****August 22, 2017**

Sadly when people living with end stage kidney disease begin to lose the complete function of their kidneys, there are only three avenues of treatment ahead of them. Some will be lucky enough to be able to have a successful kidney transplant, but others will need to maintain dialysis treatment for the rest of their life or choose a palliative pathway.

Clinicians are acutely aware of the effect this dialysis process can have on the mental health of patients, who are not only coming to terms with their condition but also are dealing with the symptoms associated with it and the impact these have on their quality of life.

In her second year of a Masters of Health Psychology at the University of Adelaide, Emily Duncanson with the support of the University's Head of School of Psychology Professor Anna Chur-Hansen is working with patients to better understand the impacts of peritoneal dialysis on their quality of life.

This research is a new collaboration between the Central Northern Adelaide Renal and Transplantation Service (CNARTS) and the School of Psychology at the University of Adelaide.

“When someone is living with chronic kidney disease, their kidneys aren't able to filter their blood and they need a dialysis machine to get rid of any waste, toxins and water for them,” Emily said.

“My project is focused on the effect of a particular form of dialysis called peritoneal dialysis on patients living with end stage kidney disease.”

There are two forms of peritoneal dialysis a patient can opt for, continuous ambulatory PD where they have four cycles of dialysis throughout their day or automated peritoneal dialysis where they are hooked up to the machine every night when they go to bed.

Emily's research is concerned with the gut (stomach and bowel) side effects of this dialysis treatment, which includes vomiting, indigestion and diarrhoea, and the impact this has on a patient's mental health.

“There is fairly new evidence that suggests that gut health is linked to mental health. Patients who have kidney failure and are undergoing dialysis live with a range of symptoms and also have to change their diet and fluid intake.”

“There is also evidence to suggest gastrointestinal problems are really prevalent in people on peritoneal dialysis, but there is little research exploring the patients’ experiences of living with those symptoms.”

“I’ve conducted interviews with 10 patients to ask them what their experiences are in terms of treatment and how that impacts their psychological wellbeing and quality of life. I’m interested in the link between their gut health, their symptoms and their mental health to see if patients perceive there to be a connection there.”

By understanding the link between gut health and a patient’s psychological state, Emily and Anna are hopeful the findings will inform future research aimed at improving outcomes for people living with end stage kidney disease.

“We know that living with a chronic illness has all kinds of psychological impacts. The more we can understand the lived experience of these patients who are on a really intrusive treatment, the more we can work out interventions that can improve their quality of life, care and add to their life length,” Prof Chur-Hansen said.

“We want to help people live the best life for as long as they can,” she added.

## Appendix B

Presentation Slides of Final Results and Concept Map Presented at CNARTS Clinical  
Research Group Meeting

## THE ROLE OF PERITONEAL DIALYSIS IN PSYCHOLOGICAL WELLBEING AND QUALITY OF LIFE OF PATIENTS WITH END-STAGE KIDNEY DISEASE

PROJECT UPDATE

CNARTS & University of Adelaide, School of Psychology

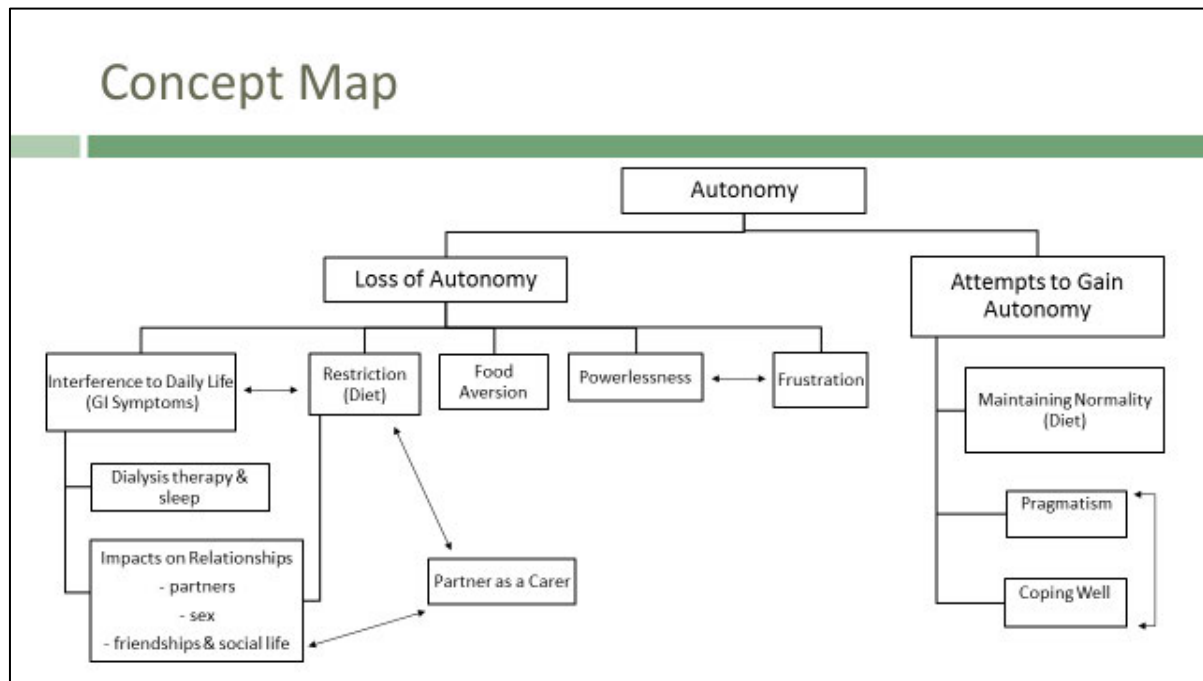
### Research Question

**Original Research Question: What is the role of PD and GI symptoms in psychological wellbeing and quality of life of patients with end-stage kidney disease?**

- 1) Role of PD in QoL
- 2) Role of PD in Psychological Wellbeing
- 3) Role of GI Symptoms in QoL
- 4) Role of GI Symptoms in Psychological Wellbeing

*What are the psychosocial consequences of PD, the renal diet and GI symptoms in patients with end-stage kidney disease?*

## Concept Map



## Loss of Autonomy

### Sub-theme: Interference to Daily Life

*"But there's other issues too I think, I'm not quite sure, you know, you've got to make sure that your bowels are completely empty before you go on the machine otherwise it doesn't work properly. So, you've got to think of these things so you make sure that everything is right, the conditions are right for dialysis to work." (P1)*

*"I mean, my whole body image... it's this horrible thing in my stomach and ummm, you know, am I going to need to go the toilet in the middle of sex - oh that's really nice isn't it?! No. Not good." (P3)*

## Loss of Autonomy

### Sub-theme: Partner as a Carer

*“No you can’t eat the food that you, the food that I like. I can’t eat oysters, you can’t eat prawns, you can’t eat tomatoes, you can’t eat stone fruit. You name it, you can’t eat it. You know, that’s... it’s very much... As I said, if it wasn’t for [wife] (Chuckles), for the food, I’d be as fat as a pig and probably dead by now. (Line 369, P5)”*

## Loss of Autonomy

### Sub-theme: Restriction

*“Yeah, sometimes when my friends call me to go out I just don’t, I can’t be bothered sometimes...I feel that because they basically can have a drink of wine or stuff like that, and I basically can’t. Or they might go out certain places where they can eat certain foods and I can’t, it’s like, well sometimes I think like, ‘Why am I bothering?’, like ‘Why should I go out for?’ (P6)*

## Loss of Autonomy

### Sub-themes: Powerlessness & Frustration

*"So yeah, bit mindful I guess of trying to eat, still eat well 'cause of the weight issue as well... That's probably the one thing that's ummm, a frustration more than anything else, 'cause I can't really... I don't feel like I've got control over it, it's like I'm a bystander to whatever happens with dialysis, just results in X, Y, Z." (P4)*

*"Just...I don't know what's up with them...but it's really annoying...I mean, I've been to the toilet twice today already, I know I'll go again this afternoon and again this evening. I just get sick of it...Yep. Sick, sick, sick of it." (P3)*

## Loss of Autonomy

### Sub-theme: Food Aversion

*"So, I used to love nothing more than a really nice rump steak with a red wine... umm... Annoyed is not the word... Disappointed. Something I liked so much which I can't even stand the...(leans away and grimaces). But lots of foods are doing that to me at the moment. Umm, I couldn't hardly eat last night either, for feeling like that and it's usually only in the mornings I feel like that but-, but last night I just noticed that I couldn't, I wasn't coping with the meal that was in front of me and there was nothing wrong with it." (P8)*



## Attempts to Gain Autonomy

### Sub-theme: Maintaining Normality

*"No, because I still like cravings for cheese... (Chuckles)...And cheese is not a good thing either... (Chuckles)...But sometimes you know, I'll go through a yes cheese, cheese, cheese, cheese and then I thought 'No I don't want cheese', so obviously I'm needing something, to me, if I'm craving it I'm needing it... and so you know, it's easier just to give it in."  
(P9)*

## Attempts to Gain Autonomy

### Sub-themes: Pragmatism & Coping Well

*"It's alright. I just wish I could eat a bigger range of goodies, ummm, but it's no real problem. Because I just eat now because I've got to. I've got to get that goodness into me. So, it's no big deal. I don't get excited that it's lunchtime."  
(P2)*

Appendix C

Journal Article from American Journal of Kidney Diseases

The following article<sup>56</sup> has been included as an exemplar of the reference and formatting style of the American Journal of Kidney Diseases.

## Qualitative Research in CKD: An Overview of Methods and Applications

Allison Tong, PhD,<sup>1,2</sup> Wolfgang C. Winkelmayr, MD, ScD,<sup>3</sup> and Jonathan C. Craig, PhD<sup>1,2</sup>

There recently has been a paradigm shift in health care policies and research toward greater patient centeredness. A core tenet of patient-centered care is that patients' needs, values, and preferences are respected in clinical decision making. Qualitative research methods are designed to generate insights about patients' priorities, values, and beliefs. However, in the past 5 years (2008-2013), only 23 (0.4%) of the 6,043 original articles published in the top 5 nephrology journals (assessed by impact factor) were qualitative studies. Given this observation, it seems important to promote awareness and better understanding within the nephrology community about qualitative research and how the findings can contribute to improving the quality and outcomes of care for patients with chronic kidney disease. This article outlines examples of how qualitative research can generate insight into the values and preferences of patients with chronic kidney disease, provides an overview of qualitative health research methods, and discusses practical applications for research, practice, and policy.

*Am J Kidney Dis.* 64(3):338-346. © 2014 by the National Kidney Foundation, Inc.

**INDEX WORDS:** Chronic kidney disease; qualitative research; patient-centered care.

There recently has been a paradigm shift in health care policies and research toward greater patient centeredness.<sup>1-3</sup> Patient-centered care respects and considers patients' values and preferences in clinical decision making.<sup>4</sup> In chronic kidney disease (CKD), shared decision making is particularly important because the treatment options have different and profound effects on the medical, psychosocial, and quality-of-life outcomes for patients and their families. However, there is an apparent mismatch between professional and patient priorities. Patients on dialysis therapy have indicated that they are willing to sacrifice survival for freedom to travel and that they prioritize caregiver respite<sup>5,6</sup>; these are factors that often are not assessed in research. In kidney transplantation, systematic reviews of immunosuppressive therapy rarely report outcomes that patients prioritize.<sup>7,8</sup>

Qualitative research enables access into in-depth insights about patients' priorities, values, and beliefs<sup>9-11</sup> and is becoming more common in clinical and health services research, especially in the areas of palliative care, oncology, primary care, and mental health.<sup>12-16</sup> Despite their ability to inform patient-centered care, qualitative studies appear sparse in nephrology. In the 5 years prior to May 2013, only 23 (0.4%) of the 6,043 original research articles published in the 5 nephrology journals with the highest impact factors (*Journal of the American Society of Nephrology*, *Kidney International*, *American Journal of Kidney Diseases*, *Clinical Journal of the American Society of Nephrology*, and *Nephrology, Dialysis, Transplantation*) were qualitative studies (Table S1). However, there appears to be increased focus on incorporating patients' contexts and perspectives in clinical care and policy in nephrology. In 2012, the American Society of Nephrology developed recommendations for the "Choosing Wisely" campaign to promote "shared responsibility for understanding individual patients' goals and preferences and for making decisions about treatments."<sup>17(p1.664)</sup> Also, in recent years, attention to and interest in shared decision making in guideline development has increased.<sup>18</sup>

Thus, it seems important to promote awareness and better understanding within the nephrology community about qualitative research and how the findings can contribute to improving the quality and outcomes of care in the context of nephrology. This article provides an overview of qualitative health research methods and discusses practical applications for research, practice, and policy.

From the <sup>1</sup>Sydney School of Public Health, The University of Sydney, Sydney; <sup>2</sup>Centre for Kidney Research, The Children's Hospital at Westmead, Westmead, NSW, Australia; and <sup>3</sup>Division of Nephrology, School of Medicine, Stanford University, Palo Alto, CA.

Received October 29, 2013. Accepted in revised form February 25, 2014. Originally published online April 22, 2014.

Because an author of this manuscript is an editor for AJKD, the peer-review and decision-making processes were handled entirely by an Associate Editor (Raymond Vanholder, MD, PhD) who served as Acting Editor-in-Chief. Details of the journal's procedures for potential editor conflicts are given in the Editorial Policies section of the AJKD website.

Address correspondence to Allison Tong, PhD, Centre for Kidney Research, The Children's Hospital at Westmead, NSW 2145, Australia. E-mail: allison.tong@sydney.edu.au

© 2014 by the National Kidney Foundation, Inc.

0272-6386/\$36.00

<http://dx.doi.org/10.1053/j.ajkd.2014.02.026>

## OVERVIEW OF QUALITATIVE METHODS AND METHODOLOGIES

### Overview

Quantitative research addresses questions about the effectiveness of interventions, prognosis, and strength of associations among risk factors and outcomes. Qualitative research focuses on different but complementary objectives: understanding people's beliefs, attitudes, perspectives, motivations, and values.<sup>19</sup> Qualitative approaches are used to generate hypotheses and theories to explain social and experiential phenomena in health.<sup>9</sup> Therefore, inherent differences exist between quantitative and qualitative approaches,<sup>20</sup> as outlined in Table 1. Many different methodologies and methods are available for use in conducting a qualitative study. Common methodologies used in qualitative health research include grounded theory, ethnography, and phenomenology; these are defined in the glossary in Box 1.

In addition to having a conceptual understanding of the approaches to qualitative research, researchers who conduct interviews and focus groups must demonstrate sincerity, interest, and sensitivity toward participants and be able to reflect on how their own personal characteristics, experiences, and values may influence the research process.<sup>11,19</sup> Also, it is recommended that researchers conduct pilot interviews or focus groups and evaluate their own technique by critiquing audio recordings and transcripts and seeking feedback from others.<sup>19,21</sup>

### Methodologies

Methodology refers to an underlying theory or framework that guides the choice of methods and research process. Common methodologies include grounded theory, ethnography, and phenomenology, which are defined in Box 1.<sup>20</sup>

### Participant Selection Strategies

In quantitative research, random sampling is used to minimize bias and achieve statistically significant and generalizable results. However, in qualitative research, information-rich participants usually are selected because they can offer insight and contribute to emergent concepts and themes pertinent to the research question.<sup>22</sup> Purposive sampling commonly is used, which involves selecting participants who are relevant to the research question with the intention of gaining a diversity of relevant perspectives or more comprehensive understanding of the phenomena of interest.<sup>23</sup> Recruitment may cease when saturation is achieved, that is, when little or no new relevant data are identified in successive data collection.<sup>22</sup> These strategies facilitate comprehensive analysis that can maximize the potential

transferability of the findings to other contexts. Snowballing requires participants to identify potential respondents and usually is used to access hard-to-reach populations or individuals with very specific expertise or divergent opinions who may be unknown to the researcher (Box 1).

The sample size is guided by the research question, qualitative approach, participant population, and available resources. For example, an ethnographic study may include 20-30 participants.<sup>24</sup> Most interview studies do not include more than 50-60 participants, and focus group studies can involve from 6 to more than 50 groups,<sup>19</sup> with 6-12 participants per group to manage group dynamics.<sup>25</sup> Recruiting participants who share a similar experience or demographic in the same focus group can encourage rapport and open discussion.<sup>26</sup> Usually, a smaller number of participants is selected so the researcher can conduct in-depth inquiry and obtain detailed information about the phenomena being investigated.<sup>9,24</sup>

### Data Collection

Data may be produced through interviews and focus groups, documents, or field research, including ethnography. Semistructured interviews and focus groups are used most commonly in qualitative health research, being effective in eliciting people's beliefs, attitudes, preferences, and values to inform and affect practice and policy. Interviews in qualitative research are unstructured, meaning that questions may be reworded, reordered, added, or deleted in order to gain a depth and breadth of understanding about the individual's perspective. Probing questions are used to elicit more details or seek clarification. Focus groups harness the group dynamics, facilitated by encouraging active participation and interaction among participants.<sup>21,26</sup> Within group processes, participants can explore and clarify their views by expressing shared experiences, and the facilitator may encourage participants to challenge and question each other. Robust data collection usually involves audio-taping and transcription so the researcher can focus on collecting data (rather than taking notes) and all data are captured for analysis (rather than just what the researcher remembers or notes down).

### Data Analysis

Unlike quantitative data analysis, in which results are generated using a statistical formula, a "formula" cannot be applied to qualitative data. Qualitative data analysis involves a systematic interpretive and iterative process in which data are conceptualized and coded into concepts (ie, units of meaning) and categorized into themes. Software programs are available to facilitate coding and searching of data. The analytical process aims to define concepts, search for

Table 1. Key Differences Between the Features of Quantitative and Qualitative Research

Feature	Quantitative	Qualitative
Overall purpose	To quantify the relationships among variables	To describe, understand, explore a central phenomenon
Research question and objectives	To explore and/or test hypotheses based on predicted associations among variables To quantify relationships among variables, ie, measure the strength of associations and the probability that the association exists in the larger population	To explore phenomena and generate hypotheses To describe and explain associations (eg, contextual or social reasons)
Assumption about reality	Single, objective reality: concise, narrow	Multiple realities: complex, broad
Researcher's position	Distant from research measurement, which should remain objective and unaffected by the presence of an investigator	Part of the research process (interacting with participants, interpreting the data)
Type of data	Numbers Value-free	Typically text, images Value-laden
Methodological features and approach	Larger sample size (to reduce sampling error, provide adequate power, and achieve statistical representativeness) Deductive (confirming theory) Fixed and controlled (experimental setting: focused on outcomes) Linear process	Smaller sample size (select information-rich participants to gain in-depth insight) Inductive (identify concepts in the data, generating theory) Flexible (natural setting: focused on the process) Iterative, concurrent (eg, rewording interview questions)
Data analysis	Objective Descriptive statistical analysis, variance of responses, determine general trends Inferential analysis and refined analysis using the appropriate statistical tests Software used to conduct statistical analysis	Subjective (interpretive) Reading of the data, making memos, conceptualizing the data, grouping concepts into themes, identifying patterns and relationships among themes Coding and identifying concepts, grouping into themes Software used to store, label, retrieve data (facilitates but does not do analysis)
Presentation of findings	Quantified estimates of effect or associations, statistics Frequency	Narrative and rich description Breadth and depth
Applicability	Emphasis on generalizability (involves statistical analysis to determine the extent to which the findings can be extrapolated to another population)	Emphasis on transferability of concepts and theories (the reader determines whether the findings "fit" or resonate in their own context or experience)

relationships and patterns in the data, see explanations, develop new theory, and provide a complete and compelling picture of the phenomena.

Inevitably, the researcher's background, knowledge, and values influence how the data are analyzed and interpreted; it is acknowledged that there is the potential for a participant's views to be misrepresented. Strategies to preserve the authenticity of the findings include self-reflexivity—the researcher examines how his or her own biases may have affected the research process<sup>27</sup>; researcher triangulation—the researcher involves other investigators who independently reviewed the data to contribute to the analysis<sup>27</sup>; and member checking—the researcher

seeks feedback from participants on the preliminary findings.

#### Appraisal and Reporting

Despite the ongoing debate about appraising qualitative research, guiding principles have been proposed.<sup>9-11,22,27-30</sup> A commonly used appraisal tool is the Critical Appraisal Skills Program (CASP),<sup>28</sup> which provides questions and prompts that address the "appropriateness" of the methodology, study design, recruitment strategy, and data collection. The Enhancing the Quality of Transparency of Health Research (EQUATOR) network recommends the Consolidated Criteria for Reporting Qualitative Health

**Box 1. Glossary of Key Methodological and Methods Terms Commonly Used in Qualitative Health Research****Methodology**

- Grounded theory: An approach to identify and build theory of social phenomena that is grounded in the data and conceptually dense; it involves theoretical sampling (selecting participants to test emergent theory) and "constant comparison" to explore similarities and differences
- Phenomenology: To examine and describe participants' understandings and interpretations of their "lived experience" from their own perspective and expressing these as reasons for their actions and behaviors
- Ethnography: Also termed as a "field study" to describe and interpret phenomena within a specific sociocultural group, with participant observation as a key part of the process
- Symbolic interactionism: To study how people understand, interpret, or make sense of their experiences and situations

**Participant Selection**

- Purposive: To intentionally recruit a participant sample that can provide diverse, comprehensive, and relevant information
- Theoretical sampling: Usually used in grounded theory when participants are selected to test theory emerging in concurrent analysis or to provide further information on specific concepts
- Snowball: To identify subsequent respondents by asking participants to identify individuals who can give important and relevant insights on the research topic
- Convenience: To select participants who are easily accessible and willing to participate

**Data Collection**

- Semistructured or in-depth interviews: To engage a participant in a conversation using predominantly open-ended questions and prompts to stimulate in-depth discussion and gain insight into the participant's beliefs, values, attitudes, motivations, and perspectives
- Focus groups: A facilitated discussion with a group of ~8 participants that harnesses group dynamics and interaction (eg, brainstorming, clarify opinions, debate) and can involve activities to supplement or enhance discussions (eg, ranking or prioritization exercises)
- Observations: *Data*: field notes; observations, video, photos
- Documents: *Data*: journals, website content (eg, blogs), photos, letters, reports of primary qualitative studies for reviews

**Data Analysis**

- Thematic analysis: To derive and identify concepts and themes inductively from the data
- Content analysis: A deductive method involving the identification of codes prior to searching for them in the data, which typically involves testing agreement between multiple researchers who code the data; this is generally used only when there is a meaningful denominator to report proportions.

*Note:* Additional terms and definitions are available in Schwandt<sup>23</sup> and Liamputtong.<sup>56</sup>

Research (COREQ)<sup>30</sup> as a key reporting guideline. COREQ was developed to promote more explicit reporting on aspects of the research team, study methods, context of the study, findings, analysis, and

interpretations so that readers can assess the credibility, dependability, transferability, and confirmability of a qualitative study.<sup>29</sup>

**APPLICATIONS IN RESEARCH, PRACTICE, AND POLICY**

Selected qualitative studies in CKD are summarized in Table 2. Figure 1 provides a framework to illustrate how qualitative research can be applied in the context of research, practice, and policy.

**Research**

Qualitative studies can be conducted as a stand-alone project or within a mixed-methods study that combines both qualitative and quantitative approaches to generate more comprehensive understanding and corroboration.<sup>24,31</sup> Both can make valuable contributions to patient-centered outcomes research. This is particularly pertinent in view of the recent formation of the Patient-Centered Outcomes Research Institute (PCORI) in 2010 by the US Patient Protection and Affordable Care Act to support and promote research that provides information that is relevant to patients' priorities.<sup>3</sup>

A key contribution of qualitative research is in the development and evaluation of trials.<sup>32</sup> Qualitative research can provide pertinent information for the initial design and process and outcomes evaluations in trials (Fig 1). Understanding patients' views is important, particularly when interventions require their active participation.<sup>33</sup> A randomized controlled trial of a self-management intervention for hemodialysis is underway, and qualitative research will be used to ascertain aspects of the program that participants believe are useful and also to identify barriers to change.<sup>34</sup>

Qualitative research can help identify items relevant to patients to include in surveys or other types of patient-reported outcome measures. The Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) health experience questionnaire was developed to measure health-related quality of life in a way that would be sensitive to differences in dialysis modality.<sup>35</sup> Focus groups and semistructured interviews were conducted with patients receiving dialysis to identify specific health-related quality of life domains and their treatment preferences. The findings then were integrated into the CHOICE questionnaire.<sup>35</sup> Morton et al<sup>36</sup> conducted focus groups to identify what characteristics of dialysis were important to patients and family caregivers and the reasons underpinning their preferences. The results were used to develop a discrete-choice experiment to measure and quantify the strength of their preferences for different treatment attributes.<sup>5</sup> Also,

Table 2. Selected Qualitative Studies in CKD

Study	Journal	Topic	Methodology	Data Collection and Analysis	Main Findings	Potential Application in Practice or Policy
Bass et al <sup>51</sup> (1999)	<i>MDM</i>	Patients' concerns about dialysis	NR	Focus groups, content analysis	Patients were concerned about freedom/control, social relationships, anxiety, role function, energy, body image, sex, mental attitude, sleep, and cognitive function.	Provide comprehensive information about treatment choices and discuss potential impact on QoL domains that are relevant to patients.
Cafazzo et al <sup>52</sup> (2009)	<i>CJASN</i>	Barriers to nocturnal home hemodialysis	Ethnography (health belief model)	Survey (n = 209) and interviews (n = 20), thematic analysis	Barriers included lack of self-efficacy and confidence, burden on family, and fear of serious complications.	Screen patients for interest in nocturnal home hemodialysis. Implement strategies to mitigate patients' concerns.
Krespi et al <sup>53</sup> (2004)	<i>PEC</i>	Hemodialysis patients' beliefs about kidney failure and treatment	NR	Interviews (n = 16), identify concepts for survey	ESRD was believed to be due to lack of self-care; patients believed hemodialysis compensates for dietary nonadherence.	Ensure access to education and counseling to address patients' beliefs that might influence adjustment, treatment adherence, and therapeutic relationships.
Howell et al <sup>7</sup> (2012)	<i>AJKD</i>	Patient preferences for outcomes after kidney transplantation	NR	Combined nominal group and focus group (n = 57), thematic analysis	Reasons for priorities included concern for fatal and serious events, relevance to life circumstances, acceptance, trivialization and tolerance, and future outlook.	Facilitate shared decision making that is individualized and involves discussion of outcomes that are important to patients.
Schell et al <sup>38</sup> (2012)	<i>AJKD</i>	Discussion of the kidney disease trajectory by elderly patients	NR	Focus groups and interviews, thematic analysis	Patients were shocked by their diagnosis, uncertain how their disease will progress, and lacked preparation for living with dialysis; nephrologists struggle to explain illness complexity, manage a disease over which they have little control, and tend to avoid discussions of the future.	Develop and implement communication interventions that help patients prepare for the kidney disease trajectory.
Tong et al <sup>54</sup> (2013)	<i>AJKD</i>	Experiences and perspectives of adolescents and young adults with advanced CKD	Adapted grounded theory	Semistructured interviews and journals (n = 27), thematic analysis	Young patients have an impaired sense of self-worth, perceive a precarious future, and believe they have limited potential compared with their well peers.	Promote shared decision making, autonomy, self-efficacy in treatment management. Provide multidisciplinary care that involves strategies to promote opportunity and confidence to participate in educational, social, and work activities.
Xi et al <sup>55</sup> (2011)	<i>NDT</i>	Vascular access decision making	NR	Semistructured interviews (n = 13)	Patients consider impact on daily life, body image, influence on QoL, experience of other patients, maintaining the status quo, and future outlook.	Build rapport; emphasis should be given to potential impact on QoL and patient concerns (not just infection rates).

Note: Articles were selected to represent a range of topics across the spectrum of CKD and different patient populations. Abbreviations: *AJKD*, *American Journal of Kidney Diseases*; *CJASN*, *Clinical Journal of the American Society of Nephrology*; CKD, chronic kidney disease; ESRD, end-stage renal disease; QoL, quality of life; *MDM*, *Medical Decision Making*; *NDT*, *Nephrology Dialysis Transplantation*; NR, not reported; *PEC*, *Patient Education and Counseling*.

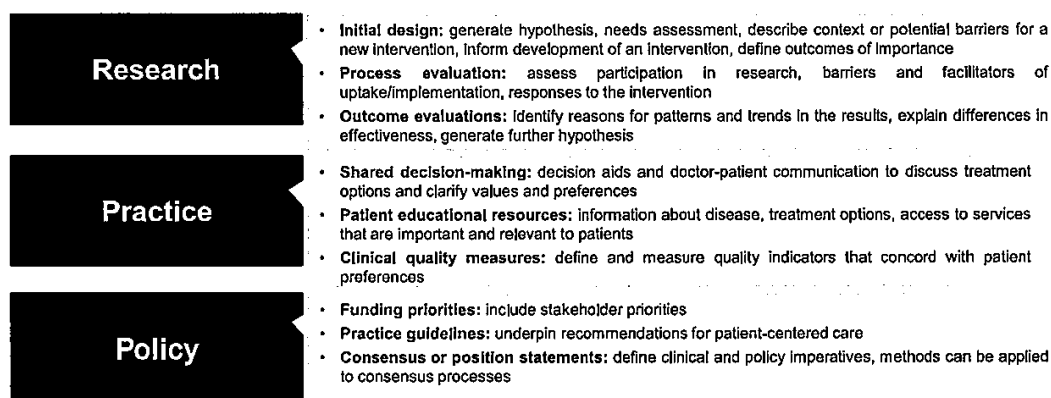


Figure 1. Applications of qualitative research in chronic kidney disease.

qualitative research may be used to ask participants about their reasons for their survey responses or to speculate about results of the group.

#### Practice

Clinical decision making involves integrating the best available evidence and the patient's circumstances and wishes.<sup>37</sup> Findings gained from qualitative research can inform ways to improve various aspects of clinical care, including clinician-patient communication, shared decision making about screening and health management, patient informational resources, and defining and measuring clinical quality measures that concur with patient preferences.

Patients value trust and rapport with their clinicians; this is facilitated by effective patient-information communication, which involves validating and addressing matters and concerns that patients consider important. Schell et al<sup>38</sup> (2012) interviewed elderly patients to ascertain the meaning of prognosis and progression of kidney disease from their perspectives. Patients felt overwhelmed and confused by their diagnosis of CKD, uncertain about their laboratory values and prognosis, and fearful of dialysis. This emphasizes the need to address patients' understanding of the trajectory of CKD and interpretation of pathology results and discuss treatment strategies and goals.

Shared decision making between clinicians and the informed patient is recognized as a fundamental principle in evidence-based medicine and key to the delivery of quality health care.<sup>39,40</sup> Qualitative research on the importance of outcomes is needed to trade off benefits and harms in clinical decision making and guideline development. Patient information and decision aids must address or encompass aspects of treatment that patients deem relevant, which qualitative research can elicit. The following 3

examples are provided to highlight different aspects of the treatment decision-making process across the spectrum of CKD.

Morton et al<sup>6</sup> systematically reviewed and synthesized qualitative studies on decision making and choice for renal replacement therapy and palliative care. Central to patients' treatment choices were the experiences of other patients, timing of information, lifestyle impact, family influences, and maintaining the status quo. Subsequently, the authors conducted a focus group study and found that the characteristics of dialysis important to patients and family caregivers included survival, convenience, dialysis-free days, respite, and ability to travel. These preferences were based around privacy, social support, perceived quality-of-life benefits, and concern about side effects and infections.<sup>36</sup>

Boulware et al<sup>11</sup> facilitated focus groups involving both African American and non-African American patients with CKD to identify barriers to discussing preemptive living-donor kidney transplantation. Patients expressed concerns about their ability to initiate conversations about living donation, discussions being misinterpreted as requests, and potentially imposing burden, guilt, and coercion on family members. The barriers identified by family members included patients' denial of their illness, feeling overwhelmed by the patients' disease, stress, and uncertainty about health risks.

To understand hope in the context of advance care planning in patients with end-stage kidney disease, Davison and Simpson<sup>42</sup> conducted in-depth interviews with 19 patients. The findings highlighted the importance of hope in enabling patients to choose future goals of care. Being provided timely and comprehensive information that focused on how the treatment options would affect their daily lives and being empowered to initiate advance care planning



discussions enhanced and sustained patients' sense of hope. As such, patients could envisage an improved future outlook that was consistent with their preferences, values, and hopes.

Qualitative research can be used to develop patient education. For example, information for potential donors about living kidney donation predominantly focuses on the workup process and medical risks. Based on a systematic review of qualitative studies of the motivations and experiences of living kidney donors,<sup>43</sup> Garg<sup>44</sup> developed a resource for potential living kidney donors. The resource was evaluated in transplantation programs in Canada, then revised for clarity and augmented with evidence-based information, then used to help prepare donors for what they may experience emotionally.

In the United States, the Centers for Medicare and Medicaid Services clinical quality measures assess "processes, experiences and/or outcomes of patient care, observations or treatment that related to one or more of the Institute of Medicine (IOM) domains of health care quality (e.g. effective, safe, efficient, patient-centered, equitable and timely)."<sup>45(p1)</sup> Patient perceptions of care can be used to inform such measures.

### Policy

Findings also can be applied at the policy level to inform funding priorities, as well as guidelines and policy statements. For example, qualitative research was conducted with patients to identify topics and outcomes for the development of clinical practice guidelines on early-stage CKD.<sup>46</sup> An additional guideline subtopic was titled "Symptoms, natural history, and outcomes of chronic kidney disease" to address the issues that patients identified as important: the spectrum and progression of CKD and the symptoms patients might experience in the earlier stages of CKD. The guidelines also were augmented with patient-focused issues, such as the impact of clinical appointments on their daily lives.

### CONCLUSION

Patient centeredness is now widely espoused in health care. Qualitative research can identify patients' values and attitudes, which essentially shape their perceptions of illness, health, and health care and thus influence their behavior. More recently, systematic review and synthesis of multiple primary qualitative studies have emerged to provide evidence about the experiences and perspectives of participants across different populations, cultures, health care contexts, and settings, as well as identify knowledge gaps and thus inform subsequent primary studies.<sup>47-49</sup> Our article highlights the unique and important insights that qualitative research can add to patient-centered

research, care, and policy. Hence, it is surprising that remarkably few qualitative studies have been published in leading nephrology journals. As mentioned in our recent editorial, we speculate that this may be due partly to the variability in transparency of reporting of qualitative studies, but at the same time, we note that efforts are being made to increase the profile of qualitative research in peer-reviewed biomedical journals.<sup>50</sup> We believe that the contribution of qualitative research to patient-centered research must be fostered and strongly encouraged in order to advance patient centeredness in nephrology practice and policy and ultimately improve outcomes that matter to patients.

### ACKNOWLEDGEMENTS

*Support:* None

*Financial Disclosure:* The authors declare that they have no relevant financial interests.

### SUPPLEMENTARY MATERIAL

Table S1: Original Research Articles Published in the 5 Nephrology Journals With the Highest Impact Factor

Note: The supplementary material accompanying this article (<http://dx.doi.org/10.1053/j.ajkd.2014.02.026>) is available at [www.ajkd.org](http://www.ajkd.org)

### REFERENCES

1. Stewart M, Ryan BL, Bodea C. Is patient-centred care associated with lower diagnostic costs? *Health Policy*. 2011;6(4):27-31.
2. Rozunblum R, Bates DW. Patient-centred healthcare, social media and the internet: the perfect storm? *BMJ Qual Saf*. 2012;22(3):183-186.
3. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA*. 2012;307(15):1583-1584.
4. National Research Council. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
5. Morton RL, Snelling P, Webster AC, et al. Dialysis modality preference of patients with CKD and family caregivers: a discrete-choice study. *Am J Kidney Dis*. 2012;60(1):102-111.
6. Morton RL, Tong A, Howard K, Snelling P, Webster K. The views of patients and carers in treatment decision making for chronic kidney disease: a systematic review and thematic synthesis of qualitative studies. *BMJ*. 2010;340.
7. Howell M, Tong A, Wong G, Craig JC, Howard K. Important outcomes for kidney transplant recipients: a nominal group and qualitative study. *Am J Kidney Dis*. 2012;60(2):186-196.
8. Howell M, Tong A, Wong G, Howard K, Webster AC, Craig JC. Do Cochrane systematic reviews report patient-important outcomes? In: *19th Cochrane Colloquium*. Madrid, Spain: Cochrane Collaboration; 2011:C304.
9. Giacomini MK, Cook DJ. Users' guides to the medical literature XXIII. Qualitative research in health care A. Are the results of the study valid? *JAMA*. 2000;284(3):357-362.
10. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII Qualitative research in health care B. What are the results and how do they help me care for my patients. *JAMA*. 2000;284(3):357-362.

11. Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *BMJ*. 2008;337:a688.
12. McKibbin KA, Gadd CS. A quantitative analysis of qualitative studies in clinical journals for the 2000 publishing year. *BMC Med Inform Decis Making*. 2004;4:11.
13. Mays N, Pope C. Rigour and qualitative research. *BMJ*. 1995;311(6997):109-112.
14. Borroni C, Miccinesi G, Brunelli C, Lina M. An increasing number of qualitative research papers in oncology and palliative care: does it mean a thorough development of the methodology of research? *Health Qual Life Outcomes*. 2004;2:7.
15. Thomas T, Fahy T, Somerset M. The content and methodology of research papers published in three United Kingdom primary care journals. *Br J Gen Pract*. 1998;48(430):1229-1232.
16. Boulton M, Fitzpatrick R, Swinburn C. Qualitative research in health care: II. A structured review and evaluation of studies. *J Eval Clin Pract*. 1996;2(3):171-179.
17. Williams AW, Dwyer AC, Eddy AA, et al. Critical and honest conversations: the evidence behind the "Choosing Wisely" campaign recommendations by the American Society of Nephrology. *Clin J Am Soc Nephrol*. 2012;7(10):1664-1672.
18. Van Biesen W, van der Veer SN, Jager KJ, Fouque D, Wanner C, Vanholder R. What guidelines should or should not be: implications for guideline production. *Nephrol Dial Transplant*. 2013;28(8):1980-1984.
19. Pope C, Mays N. *Qualitative Research in Health Care*. 3rd ed. Malden, MA: Blackwell Publishing/BMJ Books; 2006.
20. Padgett D. *Qualitative and Mixed Methods in Public Health*. Los Angeles, CA: Sage Publications; 2012.
21. Barbour RS, Kitzinger J. *Developing Focus Group Research. Politics, Theory and Practice*. London, UK: Sage Publications; 1999.
22. Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ*. 2008;337:a1035.
23. Schwandt TA. *The Sage Dictionary of Qualitative Inquiry*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2007.
24. Creswell JW, Clark VLP. *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage Publications Inc; 2011.
25. Morgan DL. *Focus Groups as Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1996.
26. Kitzinger J. Introducing focus groups. *BMJ*. 1995;311:299-302.
27. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet*. 2001;358(9280):483-488.
28. CASP. Critical appraisal skills programme. Making sense of evidence about clinical effectiveness. 10 questions to help you make sense of qualitative research. 2011. [http://www.caspinternational.org/mod\\_product/uploads/CASP%20Qualitative%20Research%20Checklist%2031.05.13.pdf](http://www.caspinternational.org/mod_product/uploads/CASP%20Qualitative%20Research%20Checklist%2031.05.13.pdf). Accessed October 14, 2013.
29. Tong A, Chapman JR, Idrani A, Gordon EJ, Craig JC. Qualitative research in organ transplantation: recent contributions to clinical care and policy. *Am J Transplant*. 2013;13(6):1390-1399.
30. Tong A, Sainsbury P, Craig JC. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health*. 2007;19(6):349-357.
31. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *J Mixed Methods Res*. 2007;1(2):112-133.
32. Lewin S, Glenton C, Oxman AD. Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *BMJ*. 2009;339:b3496.
33. Candy B, King M, Jones L, Oliver S. Using qualitative evidence on patients' views to help understand variation in effectiveness of complex interventions: a qualitative comparative analysis. *Trials*. 2013;14:179.
34. Griva K, Mooppil N, Siet P, Krishnan DSP, James H, Newman SP. The NKF-NUS hemodialysis trial protocol—a randomized controlled trial to determine the effectiveness of a self management intervention for hemodialysis patients. *BMC Nephrol*. 2011;12:4.
35. Wu AW, Fink NE, Cagney KA, et al. Developing a health-related quality-of-life measure for end-stage renal disease: the CHOICE health experience questionnaire. *Am J Kidney Dis*. 2001;37(1):11-21.
36. Morton RL, Tong A, Webster AC, Snelling P, Howard K. Characteristics of dialysis important to patients and family caregivers: a mixed methods approach. *Nephrol Dial Transplant*. 2011;26(12):4039-4046.
37. Haynes B, Haines A. Barriers and bridges to evidence based clinical practice. *BMJ*. 1998;317(7153):273-276.
38. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulskey JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis*. 2012;59(4):495-503.
39. Montori VM, Guyatt GH. Progress in evidence-based medicine. *JAMA*. 2008;300(15):1811-1816.
40. Committee on Quality of Health Care in America Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington DC: National Academic Press; 2001.
41. Boulware EL, Hill-Briggs F, Kraus ES, et al. Identifying and addressing barriers to African American and non-African American families' discussions about preemptive living related kidney transplantation. *Prog Transplant*. 2011;21(2):97-104.
42. Davison SN, Simpson C. Hope and advanced care planning in patients with end stage renal disease: qualitative interview study. *BMJ*. 2006;333(7574):886.
43. Tong A, Chapman JR, Wong G, Kanellis J, McCarthy G, Craig JC. The motivations and experiences of living kidney donors: a thematic synthesis. *Am J Kidney Dis*. 2012;60(1):15-26.
44. Garg AX. Preparing potential living kidney donors for what they will experience emotionally. *Am J Kidney Dis*. 2012;60(1):1-2.
45. AMA. Overview of clinical quality measures reporting in the Centers for Medicare & Medicaid Services (CMS) Final Rule on Meaningful Use. 2013. <https://download.ama-assn.org/resources/doc/washington/x-pub/medicare-incentives-meaningful-use.pdf>. Accessed June 20, 2013.
46. Tong A, Lopez-Vargas P, Howell M, et al. Consumer involvement in topic and outcome selection in the development of clinical practice guidelines. *Health Expect*. 2012;15(4):410-423.
47. Tong A, Fleming K, McInnes E, Oliver S, Craig JC. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol*. 2012;12:181.
48. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8:45.
49. Ring N, Ritchie K, Mandava L, Jepson R. A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews. 2011.

[http://www.healthcareimprovementscotland.org/programmes/clinical\\_cost\\_effectiveness/sltg/synth\\_qualitative\\_research.aspx](http://www.healthcareimprovementscotland.org/programmes/clinical_cost_effectiveness/sltg/synth_qualitative_research.aspx). Accessed August 1, 2013.

50. Tong A, Craig JC. Horses for courses: promoting transparent reporting of qualitative research in AJKD. *Am J Kidney Dis*. 2014;63(1):1-3.

51. Bass EB, Jenckes MW, Fink NE, et al. Use of focus groups to identify concerns about dialysis. *Med Decis Making*. 1999;19:287-295.

52. Cafazzo JA, Leonard K, Easty AC, Rossos PG, Chan CT. Patient-perceived barriers to the adoption of nocturnal home hemodialysis. *Clin J Am Soci Nephrol*. 2009;4:784-789.

53. Krespi R, Bone M, Admad R, Worthington B, Salmon P. Haemodialysis patients' beliefs about renal failure and its treatment. *Patient Educ Counsel*. 2004;53:189-196.

54. Tong A, Henning P, Wong G, et al. Experiences and perspectives of adolescents and young adults with advanced CKD. *Am J Kidney Dis*. 2013;61(3):375-384.

55. Xi W, Harwood L, Diamant MJ, et al. Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrol Dial Transplant*. 2011;26(10):3302-3308.

56. Liamputtong P. *Qualitative Research Methods*. 3rd ed. Melbourne, Australia: Oxford University Press; 2009.

## **Information for Authors and Journal Policies**

### **American Journal of Kidney Diseases**

#### **Editorial Office Contact Information**

Office E-mail: [AJKD@med.upenn.edu](mailto:AJKD@med.upenn.edu)

Direct Line to Managing Editor Nijsje Dorman: +1 215-746-4467

AJKD Editorial Office

Centre for Clinical Epidemiology and Biostatistics

Perelman School of Medicine at the University of Pennsylvania

812 Blockley Hall

423 Guardian Drive

Philadelphia, PA 19104-6021

The American Journal of Kidney Diseases, published monthly by Elsevier on behalf of the National Kidney Foundation, serves clinicians and scientists who treat and investigate kidney disease and associated conditions. AJKD is dedicated to providing high-quality, clinically relevant information in the form of original research articles, case reports, and a rich variety of educational features.

## **ARTICLE TYPES**

### **Original Investigations**

Original Investigations evaluate pathogenesis, consequences, and treatment of kidney disease and hypertension, acid-base and electrolyte disorders, dialysis therapies, and kidney transplantation. Manuscripts must focus on clinical research; laboratory studies are suitable only if they are directly linked to measurements or outcomes in humans.

An Original Investigation includes a structured abstract of up to 300 words and is limited to 3,500 words (excluding abstract, references, acknowledgements, tables, and figure legends); most Original Investigations will have no more than 50 references and 8 figures/tables/boxes in total. The body of the manuscript is organized into Introduction, Methods, Results, and Discussion sections; the Introduction and Discussion should not include any subheadings.

Criteria for review include validity, clinical importance, and interest. Reporting requirements vary by study design, which are listed in alphabetical order in this section. In all cases, use AJKD's structured abstract headings, even if the reporting guideline recommends a different

format. If reporting company-sponsored research, consult the Good Publication Practice recommendations (GPP3).

### **Case Series**

A retrospective description of the clinical course of 11 or more individuals or patients with a condition of interest. A case series typically focuses on the description of variations in clinical presentation and, unlike an observational study, does not pursue evaluation of research hypotheses.

### **Clinical Trial**

An experimental study that assesses the effect of an intervention or compares the effects of 2 or more interventions. AJKD requires registration in a public trials registry (see clinical trial registration policy).

For randomized controlled trials, include a CONSORT flowchart to report participant flow through enrollment, allocation, follow-up, and analysis. Follow the CONSORT checklist matching the study design:

- Trial With Parallel Group Design (more info)
- Cluster-Randomized Trial
- Noninferiority and Equivalence Trial
- Pragmatic Trial
- Trial of Herbal Medicine Intervention (more info)
- Trial of Nonpharmacologic Treatment (more info)
- Trial With Patient-Reported Outcomes
- N-of-1 Trials (more info)

Consider following the TIDieR checklist to describe the intervention. If appropriate, follow CONSORT's checklist for reporting of harms.

For nonrandomized trials evaluating behavioral and public health interventions, follow the TREND checklist.

### **Decision Analysis or Cost-Effectiveness Analysis**

An analysis that weighs choices in clinical care by modeling the projected consequences of different strategies to identify the optimal choice and/or to inform clinical decision making or public policy. Follow the recommendations of the Second Panel on Cost Effectiveness in Health and Medicine (Sanders et al. JAMA. 2016;316[10]: 1093-1103) to report economic evaluations of health interventions.

### **Diagnostic Test Study**

A study that compares the performance of 2 or more diagnostic tests or strategies. Follow the STARD checklist.

AJKD endorses the recommendations of the Consortium of Laboratory Medicine Journal Editors regarding methodological information to be included in studies using laboratory testing of biomarkers.

### **Observational Study**

A study that observes and describes individuals or patients based on their exposure to a potential risk factor or an intervention with the purpose of assessing the validity of research hypotheses. In contrast to a trial, investigators do not deliver an intervention or manipulate its use; ie, they do not assign patients to treatment or control groups. Follow the STROBE checklist (more info) pertaining to the study design:

- Cohort Study
- Case-Control Study
- Cross-sectional Study

For genetic association studies, follow the STREGA checklist.

Although no dedicated guidelines are available for reports from registries, AJKD also considers observational studies of this type.

### **Prediction Study**

A study that describes the development or use of a model designed to estimate risk of reaching a specific clinical end point within a defined period of time. Prediction models may also be referred to as prognostic (or predictive) indices, rules, tools, or instruments. Follow the TRIPOD checklist (more info); for risk prediction models involving genetic risk factors, consult the GRIPS checklist (more info).

### **Qualitative Study**

A study used to gain an understanding about people's behaviors, attitudes, and values. Qualitative approaches include focus groups, in-depth or semi-structured interviews, observations, or document analysis. For qualitative research based on interviews and focus groups, follow the COREQ checklist.

### **Quality Improvement Report**

A description of an activity that was conducted as an initiative to improve quality of care and that does not follow the design of a prospective research study such as a clinical trial or an observational study. Follow the SQUIRE checklist (more info).

### **Systematic Review or Meta-analysis**

A systematic review follows an explicit protocol to systematically identify, appraise, and synthesize the findings of studies that address a similar question; a meta-analysis, which contains a quantitative synthesis of the results of the systematic review, is preferred, whenever possible.

Include a PRISMA flow diagram to report study yield and selection (if relevant, adapt the format according to the specific reporting guidelines being followed).

For systematic review/meta-analysis of health care interventions, follow the PRISMA checklist (more info); for observational studies, follow the MOOSE checklist (Stroup et al, JAMA. 2000;283[15]:2008- 2012).

For meta-analyses of gene-disease association studies, consult the Human Genome Epidemiology Network Review Handbook, Evangelou & Ioannidis (Meta-analysis methods for genome-wide association studies and beyond. Nat Rev Genet. 2013;14: 379-389), and Sagoo et al (Systematic reviews of genetic association studies. PLoS Med. 2009) for recommendations.

For synthesis of primary qualitative studies (including by thematic synthesis, meta-ethnography, and critical interpretive synthesis) report the approach for conducting the literature search and selection, appraisal, and synthesis of findings in accordance with the ENTREQ checklist.

For systematic reviews and meta-analyses of individual participant data, follow the PRISMA-IPD checklist.

For network meta-analyses, follow the PRISMA network meta-analysis extension.

Authors of systematic reviews are encouraged to prospectively register study protocols at the PROSPERO international registry, reporting the registration number in the Methods.

### **Research Letters**

Research Letters report research findings relevant to clinical practice in a concise format comprising up to 800 words, 10 references, and a total of 2 figures or tables. Criteria for review include validity, clinical importance, and interest. Research Letters include an introduction, brief methods, key results, and a discussion, but no subheadings are used. Authors should use online supplementary material (combined into a single “Item S1”) for detailed methods or supporting data. Since reports of cases do not include methods, they are not suitable as Research Letters.

### **Case Reports**

Case Reports provide a succinct presentation and discussion of a notable case or cases (up to 10), and should have a single, well-defined message. Criteria for review include clinical importance, originality, and the clarity of the case presentation. These articles are limited to 1,500 words and an unstructured abstract (up to 200 words) is required; most Case Reports will have no more than 20 references and 2 figures/tables/boxes in total. The format consists of an Introduction, Case Report, and Discussion. Authors should consult the CARE checklist for clinical case reporting, but since not all reports of cases fit naturally with these guidelines, discretion should be used in applying each item.

### **Features**

AJKD features are designed to strengthen knowledge in the field of nephrology and help physicians provide their patients with the highest standard of care. Feature types for which ad hoc submissions are considered are described in this section.

### **In a Few Words**

A nonfiction narrative essay which gives voice to the personal experiences and stories that define kidney disease. Submissions from physicians, allied health professionals, patients, or

family members are welcome, and may concern the personal, ethical, or policy implications of any aspect of kidney disease in adults and children. Details may be omitted to preserve patient confidentiality, but information should not be changed; the patient's written permission will be needed if details are sufficient to recognize him/herself. References or footnotes are discouraged. Essays are limited to 1,500 words and up to 1 image.

### **Narrative Review**

A review that covers a clinical, translational, or basic science topic of interest to practitioners. Narrative Reviews should describe the treatment, diagnosis or pathogenesis of a disease process or its complications, emphasizing recent advances in the field. Articles pertaining to basic science topics should give particular attention to cellular and molecular mechanisms of disease and their relation to diagnostic approaches or therapeutic applications. Criteria for review include clinical relevance, comprehensiveness, and balance. These articles are limited to 4,000 words; an unstructured abstract (up to 200 words) is required, and most Narrative Reviews will have no more than 100 references. The editors encourage the use of figures and tables (up to 8 total) to help convey the central concepts.

### **Perspective**

An in-depth commentary on an issue of significance to the nephrology community. Criteria for review include originality, rigor of argument, and clinical relevance. Perspectives are limited to 3,000 words and 4 figures or tables; an unstructured abstract (up to 200 words) is required, and most Perspectives will have no more than 70 references.

### **Policy Forum**

This feature will highlight current and emerging issues in nephrology that impact the clinical medicine in the United States and worldwide. The Policy Forum will discuss issues of payment policy, social policy, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients. Policy Forum articles are limited to 3,000 words and 4 figures or tables; an unstructured abstract (up to 200 words) is required, and most articles of this type will have no more than 50 references.

### **Quiz**

An educational feature that recurs monthly and tests readers' acumen in resolving a diagnostic or therapeutic dilemma. The first section includes a concise clinical history (200 words or fewer), a maximum of 4 figures/tables, and 1 to 4 brief questions pertaining to the case. An answer to each question, further information regarding the clinical entity, and a brief statement of the final diagnosis are provided in a separate answer section, which may include an additional 2 to 4 figures and in most cases has no more than 400 words and 5 references. For initial submission, Quizzes should include a standard title page.

### **Special Report**

An article summarizing the activities, perspectives, or findings of a group or initiative relevant to clinical practice or research in nephrology. Examples include position statements, reports of scientific workshops, and descriptions of the rationale or progress of initiatives or consortia. Criteria for review include the importance and clinical relevance of the issue addressed, timeliness of the topic, the appropriateness of the authors' expertise and backgrounds for the scope of the article, and the novelty and anticipated impact of the conclusions. Articles of this type are limited to 4,000 words, and an unstructured abstract (up



to 200 words) is required; most Special Reports will have no more than 80 references and 8 figures/tables/boxes in total.

If a report of a conference, the article should make clear the motivation, participants, sponsors, and scope of the meeting, and should specify if the conclusions are endorsed as an official position of the sponsor. For such submissions, the review process will focus on making constructive suggestions for placing the report in context, rather than requesting changes to the recommendations/outcomes of the conference.

### **Teaching Case**

A feature designed to educate readers regarding the diagnosis and/or treatment of a clinical problem. These articles focus on interpretation of pathology findings, laboratory tests, or imaging studies. Criteria for review include the clarity of case presentation, clinical applicability and interest, and educational value. Teaching Cases typically include an Introduction, a Case Presentation (with 4 suggested subsections: Clinical History and Initial Laboratory Data, Additional Investigations, Diagnosis, and Clinical Follow-up), and a Discussion. In general, each Teaching Case includes a table of laboratory data, relevant images, a box of key teaching points, and a summary of the authors' approach to the clinical problem. These articles are limited to 2,000 words and require an unstructured abstract (up to 200 words). Most Teaching Cases will have no more than 30 references and 4 figures/tables/boxes in total. Although Teaching Cases are often invited, they may be submitted without invitation.

## **OTHER CONTENT**

### **Letters to the Editor**

Letters must be in response to an article in AJKD and should not exceed 250 words (up to 5 references and 1 figure or table may also be included) and 3 authors. Priority will be given to letters submitted within 4 weeks of the article's date of online or print publication, whichever occurs first.

### **Custom Features**

Certain content in AJKD is published by special arrangement only. The editors regularly invite editorials commenting on an article published in AJKD, or (for the In the Literature feature) that evaluate recent articles—typically in non-nephrology journals—that affect the nephrology community. Other custom features include clinical practice guidelines, commentaries on such guidelines, and reports of kidney disease surveillance data from private or public health agencies.

## **SUBMISSION POLICIES**

Submission of a manuscript is understood to signify that the authors have complied with all policies in this document. Individuals who violate these policies are subject to editorial action including, but not limited to disclosure of violations to relevant entities (employers, funding agencies, etc) and/or the wider public via publication of an erratum, editorial, editorial expression of concern, or retraction.

### **Originality**

Manuscripts are considered for publication if the article or its key features (1) are not under consideration elsewhere, (2) have not been published, and (3) will not appear in print or

online prior to publication in AJKD. This restriction does not apply to abstracts published in connection with scientific meetings; in addition, press reports arising from a conference will not be considered prior publication, provided that authors who discuss their work with reporters do not offer more detail than was contained in their oral or poster presentation. If copies of posters, slide sets, or audio/video recordings of presentations are produced in conjunction with a scientific conference, this is permissible as long as the materials are intended for meeting participants only.

Any text, figure, table, or data from other sources must be clearly attributed. If copyright permission is required for any component of the submission, appropriate documentation must be on file before publication. To monitor compliance with the journal's requirements regarding attribution, accepted manuscripts are screened using plagiarism detection software. Consistent with the position of the US Office of Research Integrity, AJKD does not consider "limited use of identical or nearly-identical phrases which describe a commonly used methodology or previous research" to meet the definition of plagiarism.

### **Authorship**

In accordance with International Committee of Medical Journal Editors (ICMJE) recommendations, each author must meet all 4 of the following conditions; moreover, each person fulfilling these conditions must be listed as an author.

- (1) the individual made a substantial contribution to conception and design of the study, to data acquisition, or to data analysis and interpretation; and
- (2) the individual drafted the article and/or revised it for important intellectual content; and
- (3) the individual approved the final version of the submitted manuscript; and
- (4) the individual accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

If revision is requested, item 3 applies to any revised versions submitted to AJKD. Item 4 is intended to make clear that the responsibilities of authorship are not limited to direct accountability for the parts of the work that the author performed, but also cover knowing which co-authors are responsible for which other parts of the work, and having confidence in the accuracy and integrity of these co-authors. If questions arise about an aspect of a study or article, the authors have a collective responsibility to ensure the issue is resolved.

Any individual who does not qualify as an author but who contributed to the work described in the manuscript must be named in the Acknowledgements. In particular, if medical writer(s)/editor(s) have been involved, their role must be explicitly acknowledged, and their affiliation/source of funding must be listed.

For Original Investigations and Research Letters, a brief description of the contribution of each individual listed as an author must be provided in the Acknowledgements. (At their discretion, the editors may request this information for other article types.)

**Potential Conflicts of Interest for Authors**

AJKD's conflict of interest policies generally follow those of the ICMJE Recommendations.

A conflict of interest exists for an author when s/he has financial or personal relationships with other persons or organizations that may inappropriately influence or bias his or her actions. There is a potential for a conflict of interest whether or not an individual believes that a relationship affects his or her scientific judgment. Conflicts can occur as the result of financial relationships, personal and family relationships, or academic competitive pressures. As described in the Support and Financial Disclosure Declaration section, authors must disclose all relationships that could be viewed as a potential conflict of interest. Editors may use information disclosed in conflict of interest statements as the basis for editorial decisions.

**Patient/Participant Protections**

All manuscripts reporting research studies involving human participants or data must include a statement that the research was approved by the appropriate research ethics committee (eg, an institutional review board), quoting the approval number. If the relevant ethics committee exempted the study from the need for approval, the name of the committee and a brief explanation must be provided. In all cases, the research must have been conducted according to principles having their origin in the Declaration of Helsinki. Studies related to transplantation must comply with the Declaration of Istanbul.

Manuscripts reporting research studies must either state that written, informed consent was obtained from all participants or that the responsible ethics committee ruled that informed consent did not apply (eg, for a case series). If investigators have potential conflicts of interest, these must be disclosed to study participants, and a statement should be included in the manuscript to indicate that such disclosure was made.

Manuscripts reporting quality improvement activities must include a statement that the plan for the quality improvement activity was approved by the clinical leadership of the organization whose experience is reported.

Whenever possible, any information identifying individual patients or study participants should be avoided. If identifying information is necessary, the individual must be shown the manuscript and provide written informed consent before publication.

**Clinical Trial Registration**

To help limit publication bias and to aid in the identification of clinical trials for meta-analyses, AJKD requires authors of manuscripts pertaining to clinical trials to register their study in a public trials registry. AJKD defines a clinical trial as any research project that prospectively assigns participants to an intervention (with or without a comparison group) to study the cause-and-effect relationship between a health-related intervention and a health outcome. Interventions include but are not restricted to drugs, biological products, surgical/radiologic procedures, devices, behavioral treatments, process-of-care changes, and preventive care. This definition includes phase 1 to 4 studies.

For trials that were completed before 2006, authors may, in lieu of registration, cite a published peer-reviewed article describing the study. Authors should provide a digital version of this article as a "Relevant Reprint" at the time of submission. If there is no previous publication, then the trial must be registered retroactively.

A list of other acceptable registries is maintained on the WHO Primary Registries page. Authors must include the minimum required information at the time of registration, and are encouraged to update the record with the full journal citation when the results are published.

### **Research and Publication Integrity**

AJKD endorses the Singapore Statement on Research Integrity, which lists the responsibilities of researchers in upholding research integrity. AJKD considers irresponsible and unethical research practices to include fabrication (invention of data), falsification (tampering with data, including images), misrepresentation (plagiarism, duplicate publication, misattribution), or any other behavior that lessens the reliability or integrity of the research record. AJKD takes seriously its responsibility to respond to suspicions or allegations of misconduct according to its misconduct handling policy.

For all research articles (Original Investigations and Research Letters), authors have a responsibility to report methodology accurately, clearly, and with sufficient detail such that the findings can be independently confirmed. Collectively, the authors are responsible that the article is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

For all article types, the editors may at their discretion request to inspect raw data or unprocessed images. AJKD's expectations regarding image processing are detailed in the Tables and Figures section.

## **MANUSCRIPT PREPARATION GUIDANCE**

### **Title Page**

The title should be concise and descriptive. Reports of studies should not summarize the results in the title. For Original Investigations, a subtitle stating the study design is recommended. Other elements that should be included on the title page are: each author's first and last names and highest degree(s); institution of each author; corresponding author's contact information; word counts for the abstract (if present) and the body of the manuscript; and a short title (45 characters or fewer, including spaces) to be used as a running head (not necessary for Quizzes or correspondence).

Note: The author list must comply with AJKD's definition of authorship.

### **Abstract**

Abstracts for Case Report, In Practice, Narrative Review, Perspective, Special Report, and Teaching Case manuscripts are unstructured and are limited to 200 words. Authors should provide a list of index words under the abstract.

Original Investigations must include a brief (300 words or fewer) structured abstract followed by a list of index words. Formats for abstracts differ according to type of study, as shown in Table 1.

The abstract headings listed in Table 1 may differ from published reporting guidelines; AJKD authors should follow the journal's preferred headings.

Table 1. Subheadings for structured abstracts of Original Investigations.

<p style="text-align: center;"><b>Case Series</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Predictor <i>or</i> • Factor (if applicable)</li> <li>• Outcomes</li> <li>• Measurements (if applicable)</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Clinical Trial</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Intervention</li> <li>• Outcomes</li> <li>• Measurements</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Decision Analysis/ Cost-Effectiveness Analysis</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Population</li> <li>• Model, Perspective, &amp; Timeline</li> <li>• Intervention</li> <li>• Outcomes</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>
<p style="text-align: center;"><b>Diagnostic Test Study</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Index Test</li> <li>• Reference Test <i>or</i> • Outcome</li> <li>• Other Measurements (if applicable)</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Observational Study</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Predictor <i>or</i> • Factor</li> <li>• Outcomes</li> <li>• Measurements (if applicable)</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Prediction Model</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Candidate Predictors</li> <li>• Outcomes</li> <li>• Analytical Approach</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>
<p style="text-align: center;"><b>Qualitative Study</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Methodology</li> <li>• Analytical Approach</li> </ul> <ul style="list-style-type: none"> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Quality Improvement Report</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Participants</li> <li>• Quality Improvement Plan</li> <li>• Outcomes</li> </ul> <ul style="list-style-type: none"> <li>• Measurements</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>	<p style="text-align: center;"><b>Systematic Review or Meta-analysis</b></p> <ul style="list-style-type: none"> <li>• Background</li> <li>• Study Design</li> <li>• Setting &amp; Population</li> <li>• Selection Criteria for Studies*</li> <li>• Intervention, Predictor, Factor, or Index Tests (select 1)**</li> <li>• Outcomes <i>or</i> • Reference Tests**</li> <li>• Results</li> <li>• Limitations</li> <li>• Conclusions</li> </ul>

\*Use the heading "Search Strategy & Sources" if a systematic review of qualitative studies.

\*\*Replace with the single heading "Analytical Approach" if a systematic review of qualitative studies.

## Manuscript Body

Manuscripts must be double-spaced with numbered pages; use of 12-point Times New Roman and an unjustified right-hand margin is preferred.

Word limits are provided in the Article Types section of this document. If following the recommended formats for reporting original research causes the manuscript to exceed the stated length limitation, the authors need not reduce the manuscript length before submission: if revision is requested, the editors will provide guidance on appropriate reductions or the use of supplementary online material.

## Acknowledgements

Authors wishing to express thanks or note assistance should do so in the first paragraph of the Acknowledgements, which should be located after the manuscript text and before the reference list. In addition, any individuals who contributed to the work described in the manuscript but who do not qualify as authors must be named in this section. Authors are responsible for informing all those listed that they are being mentioned in the manuscript and for obtaining their approval prior to publication.

## Support

This section must report any support for the work described in the submission, whether

directed to an author or that individual's institution. Types of support include, but are not limited to:

- grants, active or pending (including industry grants)
- consulting fees or honoraria related to the study
- funding of travel related to the study
- fees related to data monitoring boards, statistical analysis, end point committees, etc
- funds for writing or reviewing the manuscript
- nonmonetary support (eg, writing or administrative assistance), or provision of medicines or equipment
- employment

Authors should specify whether or not the funders had any role in study design; collection, analysis, and interpretation of data; writing the report; and the decision to submit the report for publication.

### ***Financial Disclosure***

This section lists financial relationships with entities that did not support the study, but that might reasonably be considered to be relevant stakeholders. For manuscripts that discuss tests or treatments, relationships with entities offering alternatives to those tests or treatments are considered pertinent. The beneficiary may be an author or that individual's institution, and the types of relationships include, but are not limited to:

- patents (planned, pending, or issued) or royalties
- employment or consultancy
- board membership
- payment or reimbursement of travel/accommodation expenses for expert testimony or lectures (including service on speakers' bureaus)
- stock/stock options

The disclosure must cover the 36 months prior to submission of the manuscript, unless there are prior relationships that a reader could reasonably criticize an author for omitting (eg, long-term financial relationships that have now ended). A financial disclosure statement must be provided for each author; if no financial conflict of interest is identified, a statement such as "Drs X, Y, and Z declare that they have no relevant financial interests" must be included. In general, however, authors should disclose information even when there is a question as to whether a relationship constitutes a conflict.

### ***Other Disclosures***

If there are relevant nonfinancial associations (personal, professional, political, institutional,

religious, or other) that a reasonable reader would want to know about in relation to the submitted work, authors should include this information in the “Enter Comments” text box provided during the submission process. Authors should disclose information even when there is a question as to whether it constitutes a conflict.

### ***Contributions***

For Original Investigations and Research Letters, the Acknowledgements must contain a description of each author’s contributions and a statement of collective responsibility, eg:

Contributions: research idea and study design: AB, CD, EFG; data acquisition: HIJ; data analysis/inter-pretation: AB, EFG; statistical analysis: KL; supervision or mentorship: EFG, MN. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

### **Tables and Figures**

Tables and figures should be cited in numerical order in the text using Arabic numbering.

Each table should be on a separate page of the manuscript file, ordered immediately after the references. The table number and title should be included above the table. Any additional information, including conversion factors for international units, should be included in notes below each table.

Each figure should have a legend (figure title and other explanatory text); legends should be placed at the end of the manuscript file, after the references or tables (if present). Titles and legends should not appear in the figure files themselves.

Figures should not be embedded within the manuscript file; instead they should be uploaded in the Editorial Manager system as separate files. For initial evaluation, figures must be of sufficient quality to be interpretable. If revision is requested, production-quality figures will be required, for which advice will be given. In general, authors should minimize conversions between file types. Resolution should not be reduced except in cases where file size would otherwise be impractically large; in most cases, pixel-based images should have a resolution of at least 1,200 dpi for graphs and flowcharts or 500 dpi for micrographs and other images. Color figures should use CMYK color mode.

For all borrowed material, authors are responsible for applying for permission from the relevant publisher(s) for both print and electronic rights and are responsible for paying any permissions fees. In addition to providing proof of permission to the editorial office, authors must include appropriate wording in the figure legend or table note to indicate the source of the material.

Photographs of identifiable persons must be accompanied by a signed release that indicates informed consent.

AJKD’s expectations for image processing are that (1) adjusting contrast/levels or rescaling is acceptable if the adjustment was performed across the entire image; and (2) if certain parts of an image have been altered (other than obscuring confidential patient information), the

authors must explain what has been done in a text box provided during the submission process and must be prepared to provide the original image for the editors' inspection.

### **Supplementary Material**

When important supporting information for an article is too extensive for print publication (eg, a lengthy study questionnaire), it should be submitted as online-only supplementary material. Supplementary material should also be provided in lieu of stating "data not shown."

Supplementary material file(s) should be provided at the time of manuscript submission, and should be called out in the text (eg, Table S2, Fig S1, Item S4). A brief title for each piece of supplementary material should be provided in a section between the Acknowledgements and the References. Unlike standard figures, for supplementary figures, titles/ legends should be included in the file containing the supplementary figure.

Online supplementary material is governed by the same copyright transfer policies as the article; if supplementary material has been reproduced from another source, the authors must provide documentation granting permission for its reuse in AJKD.

### **Journal Style**

Provided the manuscript is clear and complete, editors will not penalize submissions that do not follow journal style. However, for publication, manuscripts must conform to journal style, and thus style changes may be requested at revision.

### ***Units of Measurement***

Values should be expressed in US conventional units; international equivalents or conversions are not necessary in running text. However, conversion factors should be provided in figure legends and table notes, as appropriate, eg, "Conversion factors for units: serum creatinine in mg/dL to  $\mu\text{mol/L}$ ,  $\times 88.4$ ; urea nitrogen in mg/dL to mmol/L,  $\times 0.357$ ."

A list of values requiring unit conversions, as well as conversion factors, is available for download.

### ***Reporting P Values***

Numerical values should always be reported for P, even if they are nonsignificant. If the P value is greater than or equal to 0.9, it should be reported as 0.9, eg, 0.97 become 0.9. P values from 0.001 through 0.9 (inclusive) should be rounded to one nonzero digit, eg, 0.0105 rounds to 0.01 and 0.0452 rounds to 0.05. P values less than 0.001 should be reported as  $<0.001$ , eg, 0.0009 and  $1.92 \times 10^{-6}$  become  $<0.001$ .

### ***Reference Style***

References should be compiled at the end of the manuscript according to the order of citation in the text, in the format shown in the following examples.

*Journal article (6 or fewer authors):*

Al-Absi A, Gosmanova EO, Wall BM. A clinical approach to the treatment of chronic hypernatremia. *Am J Kidney Dis.* 2012;56(6):1032-1038.

*Journal article (more than 6 authors):*



Matsui S, Imai E, Horio M, et al. Revised equations for estimated GFR from serum creatinine in Japan. *Am J Kidney Dis.* 2009;53(6):982-992.

*Journal article published online but not yet in print:*

Li Y, Kottgen A. Genetic investigations of kidney disease [published online ahead of print March 4, 2013]. *Am J Kidney Dis.* doi:10.1053/j.ajkd.2012.11.052.

*Supplement:*

National Kidney Foundation. KDOQI clinical practice guidelines and clinical practice recommendations for anemia in chronic kidney disease. *Am J Kidney Dis.* 2006;47(5)(suppl 3):S1-S145.

*Item presented at a meeting but not yet published:*

Weiner D, Tighiouart H. Nutritional supplement use and mortality in dialysis. Poster presented at: Kidney Week 2012; October 30–November 4, 2012; San Diego, CA.

*Published meeting abstract:*

Pudur S, Savin VJ, McCarthy ET, Sharma M. Albumin permeability in FSGS is associated with rapid progression to ESRD [NKF abstract 127]. *Am J Kidney Dis.* 2006;47(4):B50.

*Website:*

National Kidney Foundation. What is a kidney biopsy? <https://www.kidney.org/atoz/content/kidney-biopsy>. Accessed February 5, 2015.

*Complete book:*

Ahmad S. *Manual of Clinical Dialysis*. London, England: Science Press Ltd; 1999.

*Book chapter:*

Curhan G. Nephrolithiasis. In: National Kidney Foundation's Primer on Kidney Diseases. 6th ed. Philadelphia, PA: Saunders; 2013:405-411.

Information attributed to a “personal communication” should be cited in-text. Prior to publication, the author must provide documentation showing that the individual cited has given permission to be named in the article as the source of this information.

Where appropriate, authors are encouraged to cite underlying or relevant datasets. Data references should include the author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. So that Elsevier can tag the reference properly, authors should add the text “[dataset]” immediately before the reference (this identifier will not appear in the published article).

## MANUSCRIPT CONSIDERATION PROCESS

All manuscripts are submitted and processed using the online manuscript handling system Editorial Manager ([www.editorialmanager.com/ajkd](http://www.editorialmanager.com/ajkd)).

Unless the manuscript is out of scope or clearly inappropriate, two editors will review all submissions. If the editors deem that the manuscript is unlikely to be published in AJKD, it may be rejected at this stage. Otherwise, except for In a Few Words, Quizzes, Letters to the Editor and their Replies, and content published by special arrangement (KDOQI commentaries, etc), manuscripts will then undergo external review. Except in cases in which expedited handling is needed, Original Investigations, Research Letters, Case Reports, Narrative Reviews, Perspectives, Special Reports, and Quizzes are discussed at an editorial meeting before being invited for revision. Essentially all research articles will undergo statistics/methods review before being invited for revision; In addition, manuscripts with pathology or radiology content will generally be screened by individuals with appropriate expertise.

Authors may provide editors with the names of persons they feel should not review their manuscript because of a potential conflict. However, when possible, authors should explain the reason(s) for their concerns. Editors will try to avoid selecting reviewers who have potential conflicts of interest, and will ask those who are invited to review to declare any relevant competing interests. Further information is available in the Potential Reviewer Conflicts and Review Policy sections.

Manuscripts which have an author who is associated with the editorial team are handled by a separate workflow; information on the journal's procedures for the treatment of such submissions is available in the Potential Editor Conflicts section.

## AFTER ACCEPTANCE

### Prepublication Embargo

AJKD will not publish content that has already been published or disseminated. If the confidentiality of an AJKD article or its key elements is not maintained up to the point it is published by AJKD, the article's acceptance for publication may be forfeited. The confidentiality restriction does not apply to information presented at scientific or clinical meetings, or publication of a conference abstract, provided that authors do not present or distribute the manuscript or its full findings. If copies of posters, slide sets, or audio/video recordings of presentations are produced in conjunction with a scientific conference, this is permissible as long as the materials are intended for meeting participants only. Press reports arising from a conference will not be considered prior publication, provided that authors who speak to reporters do not offer more detail about their work than was contained in the oral or poster presentation.

If an author's institution is interested in preparing a press release regarding the upcoming AJKD publication, the editorial office should be contacted for information regarding embargo dates. Authors may not discuss their accepted manuscript with reporters without the prior approval of the journal.

In rare instances, such as an urgent public health need or testimony before a government body, authors may be permitted to discuss their unpublished AJKD article, even though it is

under embargo. Authors anticipating such a situation should contact the editorial office for approval before releasing any information contained in the article.

### **Copyright**

AJKD offers authors the choice of subscription or open access publication. For subscription articles, Elsevier will contact the corresponding author by e-mail to request completion of a “Journal Publishing Agreement,” and the copyright will be assigned exclusively to the National Kidney Foundation, Inc., including the right to reproduce the article in all forms and media. Authors of open access articles retain copyright, and Elsevier will contact the corresponding author to request completion of an “Exclusive License Agreement.”

### **Article Access**

In the subscription publishing option, articles are made available to subscribers as well as developing countries and patient groups through Elsevier’s access programs.

In the open access publishing option, articles are freely available to both subscribers and the wider public, and may be reused according to the terms of the license; an open access publication fee is payable by authors or their funders.

### **Open Access User Licenses**

All articles published open access will be immediately and permanently free for everyone to read and download. Permitted reuse is defined by the corresponding author’s choice of Creative Commons user license.

The default license is the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) License, which, for noncommercial purposes, lets the article be distributed, copied, and included in collective works, as long as it is not altered and the authors are credited.

In accordance with Elsevier’s agreements with funding bodies, corresponding authors may apply for the CC BY license if it is necessary to comply with their funding body’s policy; further information will be available from Elsevier once the open access publishing option has been selected.

### **Open Access Publication Fee**

For each article published open access in AJKD, the authors or their research funders will be charged a publication fee. The fee excludes taxes and other potential author fees such as color and page charges. Information on agreements with funding bodies on the Elsevier website specifies the funding bodies that will prepay or reimburse publication fees. The standard publication fee is \$3,000; however, if at least one of the article’s authors is a National Kidney Foundation member, a preferred rate of \$2,400 applies.

An author’s publication choice will have no effect on the peer-review process or acceptance of submitted articles.

### **Compliance With NIH Public Access Policy**

If the corresponding author reports receipt of NIH funding when completing Elsevier’s Journal Publishing Agreement, Elsevier will send PubMed Central (PMC) the final peer-reviewed manuscript as accepted for publication and will authorize that the article be posted for public access 12 months after final publication; authors will receive further

communications from the NIH regarding the manuscript. In accordance with AJKD's author agreement, authors should not post manuscripts directly to PMC.

### **Proofreading**

Corresponding authors are provided with proofs via e-mail to check for typesetting and/or copy- editing errors. Important corrections to data presentation are allowed, but authors will be charged for excessive alterations to proofs. Corrections should be returned within 48 hours.

### **Page Charges**

For articles in excess of 2 journal pages, authors are responsible for paying a fee per page or partial page. If the first and last authors are both NKF members, the per-page charge is \$50; otherwise, the per-page charge is \$75. One journal page is approximately equivalent to 3.5 double-spaced manuscript pages, 40 references, or 2 tables/figures. The editorial office will e-mail the corresponding author with an estimate of the page charges before typesetting; the invoice itself will be sent by the National Kidney Foundation after the article is published in print. If no response to the invoice or subsequent reminders is received, the editorial office will place a publication hold on all further papers from the corresponding author and all listed co-authors until the outstanding invoice is paid in full. Page charges and color reproduction costs are billed separately.

Page charges are waived when the corresponding author for the manuscript is based in a Reasearch4Life Group A country; a 50% discount is available when the corresponding author for the manuscript is based in a Reasearch4Life Group B country (see [www.research4life.org/eligibility/](http://www.research4life.org/eligibility/)).

### **Color Reproduction Charges**

With the exception of authors of Quizzes, authors desiring to have any or all figures printed in color are responsible for a \$600 per-article color charge. After receiving a manuscript with at least 1 color figure, Elsevier will contact the corresponding author to ask whether color will be purchased. Provided that interpretability is not affected, the corresponding author may opt to have the color figure(s) appear in color online and in black and white in the print version of AJKD. Authors who choose color printing will be billed by Elsevier. Color reproduction costs and page charges are billed separately.

### **Share Link and Reprints**

For articles not published open access, the corresponding author will, at no cost, receive a customized Share Link providing 50 days' free access to the final published version of the article on ScienceDirect. This link can be used for sharing the article via any communication channel, including e-mail and social media.

For an extra charge, the corresponding author may order paper offprints via the offprint order form, which is sent by Elsevier once the article is transmitted for copyediting and typesetting. In addition, any author may order offprints at any time via Elsevier's Webshop.

### **Retained Author Rights**

Authors (or their employers or institutions) retain certain rights. For subscription articles, authors may use their articles for a wide range of scholarly, noncommercial purposes, provided there is no systematic or organized distribution of the published article. Permitted reuse of open access articles is determined by the author's choice of user license.

## **OTHER EDITORIAL POLICIES**

AJKD policies generally follow those provided in the ICMJE Recommendations and the Committee on Publication Ethics (COPE) Code of Conduct for Journal Editors.

### **Review Policy**

AJKD conducts single-blind review: authors' identities are not masked to the reviewers, but reviewers' identities are masked to the authors. With the exception of In a Few Words essays, the Acknowledgements of each published article will contain a statement summarizing the review process.

If a manuscript is rejected, a copy is retained in the journal's manuscript handling system for internal recordkeeping; the confidentiality of the files and associated records will be maintained unless requested otherwise by the authors or in exceptional circumstances involving suspected misconduct.

AJKD endorses the COPE guidelines for ethical peer review. The manuscript must be kept confidential and the reviewer must request permission from the Editor beforehand if a colleague is to be consulted. Reviewers must not appropriate any information contained in the manuscript for their own work, nor should they contact the authors directly. Reviews should be kept confidential, even if the manuscript is later published. Comments should be constructive and professional. Reviewers should rate the manuscript, but should not state in the comments to the author whether the manuscript should be published. If a review does not meet these objectives, the editor may edit the reviewer's comments or may in extreme cases omit the comments from the material sent to the author.

### **Author Appeal Policy**

Authors who believe that their manuscript was rejected due to a misunderstanding or mistake may e-mail the editorial office to explain why they believe the decision to be in error. Appeals must include substantive new information with direct bearing on the decision (eg, a well-reasoned argument providing compelling evidence that a key critique raised in the rejection letter relied on incorrect or outdated information). A difference of opinion as to the interest, novelty, or suitability of the manuscript for the journal is not sufficient reason for an appeal.

The appeal will be considered by the EIC and other relevant editors. The journal's response to the appeal will be final. Even if the journal agrees to reconsider the manuscript, acceptance is not guaranteed, and the reconsideration process may involve previous or new reviewers or editors and substantive revision.

### **Conflict of Interest Policy**

AJKD's conflict of interest policies generally follow those of the ICMJE Recommendations.

A conflict of interest exists when an author, reviewer, or editor has financial or personal relationships with other persons or organizations that may inappropriately influence or bias his or her actions. There is a potential for a conflict of interest whether or not an individual believes that a relationship affects his or her scientific judgment. Conflicts can occur as the result of financial relationships, personal and family relationships, or academic competitive pressures. All participants in the peer review and publication process must disclose all

relationships that could be viewed as a potential conflict of interest. Editors may use information disclosed in conflict of interest statements as the basis for editorial decisions.

### **Potential Author Conflicts**

The Support and Financial Disclosure Declaration section explains how authors must disclose the potential conflicts of interest.

### **Potential Reviewer Conflicts**

Individuals who have potential conflicts of interest should not serve as peer reviewers. This includes individuals who work in the same institution as any of the authors (or will be joining that institution or are applying for a job there); who are or have been within the past 3 years mentors, mentees, close collaborators (in clinical care or research), or joint grant holders; and/or who have a close personal relationship with any of the authors. However, if the manuscript pertains to a large consortium to which a potential reviewer has contributed data but has not otherwise been involved, AJKD does not consider this to be a disqualifying condition. In addition, prior review of the manuscript for another journal does not necessarily disqualify an individual, provided that the reviewer considers the submission in its current form and according to AJKD's article type criteria.

Editors will try to avoid selecting reviewers who have potential conflicts of interest. Editors will also attempt to honor authors' requests to exclude potential reviewers with conflicts of interest, provided that rigorous and comprehensive review is possible if these individuals are excluded.

At the time they are invited to review, individuals must disclose any conflicts that could bias their opinions, and they must disqualify themselves from reviewing when appropriate. If a conflict of interest becomes apparent during the review process, the reviewer must contact the journal office and, when appropriate, ask to be recused.

### **Potential Editor Conflicts**

Editors and editorial staff must not use information gained in the course of their duties for private gain.

In addition, to manage potential editor conflicts, AJKD has customized handling procedures for Original Investigation, Research Letter, Case Report, Narrative Review, Perspective, Special Report, Core Curriculum, In Practice, Policy Forum, and Teaching Case manuscripts.

In particular, if any editor who participates in editorial meeting discussions (Editor-in-Chief [EIC], Deputy Editor, Education Editor, Associate Editor, International Editor, Health Equity Editor) is an author of a manuscript, editorial staff select an Editorial Board Member to serve as Acting EIC. The Acting EIC must confirm that s/he has no conflicts of interest before beginning work on the manuscript. The Acting EIC may involve any unconflicted Feature Editor or Statistics/Methods Editor. The identity of the Acting EIC, reviewers, or any other individuals who were consulted will be kept confidential from all conflicted editors; however, if the manuscript is published, the name of the Acting EIC will be published with the article.

If an editor who does not participate in editorial meeting discussions (Feature Editors, Statistics/Methods Editors) is an author on a submission, and it is not an article type the editor would ordinarily handle, it can be handled by the usual process.

All AJKD editors (including Editorial Board Members asked to serve as Acting EICs) must recuse themselves from editorial responsibilities (and, if applicable, from the editorial meeting discussion of a manuscript) if they have a personal, intellectual, or financial involvement that potentially interferes with their ability to remain impartial. Potential conflicts of interest include:

- close collaboration in clinical care or research with any author of a manuscript;
- having a financial interest related to the subject matter of a manuscript;
- or being a member of (or closely affiliated with) the same institution as one of the authors.

If the EIC is recused, editorial staff will select an Associate Editor, International Editor, or Health Equity Editor without conflicts of interest to serve as Acting EIC. The identity of the Acting EIC and all others who are involved in the consideration process will be kept confidential; however, if the manuscript is accepted, the Acting EIC's name will be published with the article. If no Associate Editor, International Editor, or Health Equity Editor is unconflicted, editorial office staff will select an Editorial Board Member to serve as the Acting EIC.

### **Misconduct Handling Policy**

The AJKD editors recognize their role in making all reasonable efforts to maintain the integrity of the scholarly record, and will generally follow COPE recommendations when they suspect or receive credible allegations of a breach of journal policies. Any reports of potential misconduct submitted to the journal should include as much detailed information as possible to assist the editors in their investigation. Because of the time and resources required to thoroughly investigate allegations, AJKD must prioritize these activities on the basis of the most compelling evidence.

In exceptional circumstances, the EIC may reach the conclusion that, in order to investigate possible misconduct, manuscript or review records must be shared confidentially with, for example, another journal office or with an author's institution. In general, however, AJKD will first contact the author(s) to request an explanation concerning an allegation or suspicion of misconduct.

When authors are unable to provide an explanation that the journal deems satisfactory, the authors are subject to editorial action including but not limited to contact with relevant institutions and/or regulatory bodies to disclose violations and/or request an investigation and/or publication of an editorial, editorial expression of concern, and/or retraction.

The efforts of the editors in preventing, detecting, and responding to misconduct do not remove the responsibility of the authors for the validity of their work and publications.

### **Complaint Policy**

As a member of COPE, AJKD seeks to follow the COPE Code of Conduct for Journal Editors. Authors, readers, reviewers, or members of the public who have a well-founded concern that the journal's conduct deviates from the Code of Conduct should e-mail the EIC via the editorial office. Complainants who believe that the matter has not been satisfactorily

resolved may contact COPE by the process laid out in COPE's complaints and concerns page.

### **Advertising Policy**

Editorial independence is crucial to scholarly publishing, and the editorial team has full authority to decide on the content of the journal. The criteria for editorial decision making regarding journal content do not include any perceived effect on advertising revenue. The EIC has the right to review all new advertising that is proposed to be associated with the journal and may reject any advertising that he deems is not in keeping with the journal's mission.

### **Supplement Policy**

AJKD will consider publication of sponsored supplements that are of interest to its readers and demonstrate scientific validity. The content must be of sufficient informational value and quality to warrant a separate journal issue and must relate to a unifying theme. Submission of a supplement from a symposium or conference must occur in a timely fashion; in general, supplements will not be published if the publication date is more than 12 months after the date of the symposium or conference. No more than 2 supplements per month will be published. Publication costs must be borne entirely by the sponsor(s). Further information on sponsorship opportunities may be obtained from the publisher.

Following initial contact with the publisher, a written proposal for a supplement to AJKD must be submitted to the EIC via the editorial office for consideration. The proposal must contain:

- The Guest Editor's or Coordinator's name, affiliation, and contact information.
- Topic(s) to be covered by the supplement, with a preliminary table of contents.
- If the supplement is to be based on a conference or symposium, information on dates, venue, and financial supporter(s).
- An estimate of the total number of double-spaced manuscript pages.
- Sponsor(s) of the supplement.

A Guest Editor is a subject expert who is responsible for the content of the supplement, ensuring the quality of each component manuscript and its contribution to a cohesive, coherent whole. The Guest Editor is responsible for ensuring that all manuscripts are in final form before submitting. The Guest Editor may elect to write an introduction or summary, but each article must include sufficient introduction and description of methods to stand on its own. In the absence of a Guest Editor, the authors are fully responsible for ensuring that the articles are consistent with one another and that their manuscripts are in final form before submitting. In such cases, a Coordinator is responsible for handling all submissions and facilitating communications between the authors and the editorial office.

AJKD can provide the Guest Editor or Coordinator with information on the journal's production schedule, and can recommend deadlines for receipt of materials that are intended to allow enough time for review, revision, and reconsideration of the supplement manuscripts. It should be noted that any estimated publication date is simply a projection



based on the information available at the outset; whether it can be met will depend on receipt of the completed manuscripts at the AJKD editorial office in a timely fashion, the nature of the review required, and the extent of mandatory revisions. Ideally, a supplement based on a conference or symposium should be planned so that authors submit manuscripts to the Guest Editor or Coordinator at the time of the meeting.

The manuscripts must be prepared and submitted according to standards governing regular journal content. Manuscripts that do not follow journal format will be returned for editing before review; furthermore, the editorial office will not begin processing the supplement articles until all of the manuscripts for the supplement are received.

All supplements will undergo appropriate review of their contents. The review process depends on the number and length of articles and the nature of their content. Articles will almost invariably require revision; in addition, the EIC reserves the right to reject portions of the supplement, or the entire supplement. The editorial office will contact the Guest Editor or Coordinator regarding the decision to accept, reject, or require additional revisions. Once a supplement has been accepted it is formally scheduled for publication; changes to the publication date at this stage cannot be accommodated.

The supplement must contain a statement indicating the source(s) of funding. It is the responsibility of the Guest Editor or Coordinator to disclose to the editorial office at the time of submission any restrictions or expectations communicated to the Guest Editor or Coordinator by the sponsor(s) regarding the contents of the supplement. Furthermore, the Guest Editor or Coordinator must state what, if any, financial relationship they may have with the sponsor of the supplement. Likewise, all authors should disclose what, if any, financial relationship they have with the sponsor of the supplement, or the manufacturer of any products, or competing products, that are discussed in their manuscripts. Each manuscript must indicate any support that was obtained for the manuscript or its contents. If medical writer(s)/editor(s) have been involved, their role must be explicitly acknowledged, and their affiliation/source of funding must be listed. Additionally, if the sponsor has a financial interest in a product either directly or indirectly discussed in the manuscript, this relationship should be identified, along with the name of the product. Information about sponsorship and related products will be published with each article in the supplement.

Publication of a supplement does not constitute product or sponsor endorsement by the National Kidney Foundation or AJKD, and a disclaimer indicating this will be printed in each supplement.

Articles published in a supplement of AJKD are subject to the same copyright restrictions that apply to articles published in regular journal issues.