ILLNESS PERCEPTIONS IN TURKISH CYPRIOT PATIENTS RECEIVING DIALYSIS

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PhD RELATED PUBLICATIONS

Keskindag, B., Farrington, K., Oygar, D. D., Mertan, B., Hucker, A., & Sharma, S. (2021). Illness perceptions of Turkish Cypriot patients receiving haemodialysis: A qualitative study. *Journal of Renal Care*, *47*(2), 113-122. https://doi.org/10.1111/jorc.12351

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Conference Presentations

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Abstract

Chronic kidney disease (CKD) is a public health concern across the globe. As it progresses, individuals who are diagnosed with advanced kidney failure require kidney replacement therapy (KRT), either through dialysis (haemodialysis [HD] or peritoneal dialysis [PD]) or kidney transplantation. Although dialysis is a common treatment modality for survival, it is a burdensome treatment hence patients often experience challenges that interfere with quality of life and other problematic psychological and clinical outcomes. As such, much effort has focused on understanding adjustment in this context, with the illness perceptions framework having been applied consistently to explore how patients understand, interpret and respond to their circumstances. Understanding the patient experience is critical to providing efficient interventions in kidney healthcare for psychosocial support though the majority of evidence in the field is drawn from white majority patient groups from more advanced healthcare systems.

This programme of research aimed to understand illness perceptions of Turkish Cypriot patients receiving dialysis. This was to address under-representation in research and to provide a bank of evidence to progress kidney care in the local context. A series of studies were designed to examine illness perceptions of this patient group within the specific socio-cultural context. The research programme included: 1) qualitative enquiry of illness experiences of Turkish Cypriot patients receiving HD; 2) a systematic review of qualitative studies examining illness perceptions of patients receiving dialysis more generally; 3) a prospective longitudinal questionnaire study considering correlates of illness perceptions among patients receiving dialysis; and 4) qualitative interviews to understand perspectives of healthcare professionals on psychosocial care needs of patients receiving dialysis in Northern Cyprus.

In study 1, qualitative interviews were conducted with the patients receiving HD. The interview topic guide was designed by using the illness perceptions framework. As this patient group has not been studied earlier, a qualitative method was utilised to gain in-depth understanding of how Turkish Cypriot patients receiving HD experience and make sense of their condition. In total, fourteen patients who receive in centre- HD were interviewed. Interviews were conducted in Turkish and were transcribed verbatim. The analysis was inductively completed by using reflexive thematic analysis in Turkish, and then it was translated into English. Three themes represented the patient experience: (1) 'Illness Appraisal' related to making sense of kidney disease and expectations of prognosis; (2) 'Life changing effects' highlighted the negative impact of treatment modality on emotional and physical well-being; (3) 'Active coping strategies' elucidated cultural beliefs that facilitate cognitive re-framing. Findings indicated cultural influences on adjustment to HD, which have been poorly understood in the local CKD context. The findings suggest the stability of illness perceptions cross-culturally as a framework from which to explore illness experiences, and importantly demonstrate culture bound mechanisms that shape responses to life on HD.

A systematic review synthesised illness perceptions guided qualitative data on patients receiving dialysis. The review aimed to understand the extent to which the findings from study 1 are reflective of broader qualitative data on the illness experiences of patients receiving dialysis. Four studies were identified as eligible for inclusion. By using reflexive thematic analysis, available data were analysed inductively to begin and then applied deductively to the illness perception framework in NVivo software. Six themes were identified within the first stage of the synthesis. They related to the meaning, experience and impact of having diagnosis of kidney failure. These themes were mapped onto the overarching five domains of the illness perceptions framework (i.e., timeline, causality,

control/cure, identity, and consequences). The findings highlighted that patients had difficulty in labelling and making sense of kidney disease. They were faced with uncertainty and frequently reported physical and psychological consequences of life on HD. Struggles to regain normality and changes in functionality influenced perception of self. Sources of support were culturally influenced and contributed to cognitive reframing to cope. The synthesis indicated that patients may experience similar challenges however, culture seems to influence sense-making of the condition and behavioural responses to treatment burden.

A prospective longitudinal questionnaire study further examined the relationship between illness perceptions and related variables (e.g., clinical measures, depression and dialysis symptoms) in both patients in the pre-dialysis and dialysis phase. Patients in the pre-dialysis phase who were expected to start dialysis treatment were observed to examine potential differences when commencing dialysis treatment. Little research has longitudinally studied correlates of illness perceptions. Patients were recruited from four dialysis centres in Northern Cyprus. Data were collected from 181 patients (124 patients receiving dialysis [91.1% HD] and 57 patients in the pre-dialysis phase) at baseline (Time 1). Both patient groups were followed at six months (Time 2) and at 12 months (Time 3 = one year). Self-reported measures used included Brief Illness Perceptions Questionnaire (B-IPQ), Patient Health Questionnaire-9 (PHQ-9), Chalder Fatigue Scale (CFS) and Dialysis Symptom Index (DSI). Patients receiving dialysis were found to report higher perception of consequences, emotional response and lower perception of personal control compared to patients in the pre-dialysis phase. Trajectories of illness perceptions were examined and showed that overall patients' perceptions of consequences and emotional response were expected to decrease over a one year period. Additionally, depressive symptoms were found to be relatively stable over a one-year period. However, those patients who reported higher levels of illness perceptions of consequences and emotional response at baseline were more likely to report greater

depression symptoms. There was no significant difference in terms of dialysis related symptoms between patients receiving HD and those receiving PD. Dialysis symptoms were found to be stable over time among patients receiving HD or PD, nevertheless, those patients receiving dialysis who reported greater emotional response and lower levels of personal control at baseline were more likely to report dialysis symptoms. The findings overall seem to be consistent with existing evidence examining illness perceptions in this patient group in the literature. Regular psychological assessment has been suggested to be included in the local nephrology department to screen negative illness perceptions and emotional distress.

The final study within the programme included qualitative interviews to understand the perspectives of healthcare professionals' involved in kidney care in relation to psychosocial support needs of patients receiving dialysis in Northern Cyprus. Semi-structured interviews were conducted with sixteen healthcare professionals (2 nephrologists and 14 nurses) in Turkish. Transcripts were inductively analysed using reflexive thematic analysis, with the findings then translated into English. Three themes were developed: (1) 'Adjustment to dialysis' emphasised the way that healthcare professionals intrinsically linked patient well-being to adjustment to life on dialysis and finding a new sense of balance with the associated routine; (2) 'Multi-faceted nature of well-being' emphasised the range of individual, family, economic, hospital and system level factors that impact patients' overall mental health; (3) 'Compassionate care' brought into stark focus the need for empathy with patient situations but recognising the limits within which staff needed to operate due to knowledge, skills and system resources. Feeling stuck particularly in response to demanding patient experience was evident. Healthcare professionals in Northern Cyprus recognise self-management as an important driver of psychological adjustment and identify with a stuckness in their capacity to extend further care.

The findings of the thesis have implications for the development of care pathways that take a more integrated approach to patient physical and mental well-being. This thesis provides comprehensive information on Turkish Cypriot patients who receive dialysis which is an under-represented cultural group in kidney research Self-management strategies for patients should be developed within the local nephrology units. To support this, culturally tailored interventions targeting illness perceptions have been suggested which may improve health outcomes. Finally, psychosocial practice policy is required to provide structured support for patients receiving dialysis in Northern Cyprus.

Chapter 1: Introduction to Chronic Kidney Disease

1.1 Introduction

This introductory chapter aims to provide information about the kidneys and their function. Moreover, failure of the kidneys and progression to and treatment for chronic kidney disease (CKD) are explained. This is to provide a contextual overview that will inform the programme of research reported within this thesis. In order to do so, it is important to first build an understanding of CKD and how it impacts a patient's life at its different stages.

1.1.1 The Kidneys and Their Function

Kidneys are important organs in the body that excrete metabolic waste and other potentially toxic substances from the body. Additionally, kidneys balance electrolyte levels, play an important role in maintaining blood pressure, healthy bones, and in the production of red blood cells (Eckardt et al., 2013).

There are two kidneys and they are located retroperitoneally in the lumbar region. Each weighs nearly 150g. In appearance, the kidneys are bean shaped. Each kidney includes up to 1 million nephrons that have many functions. A nephron consists of modified blood vessels called glomerulus linked to a tubule. When blood flows to the glomerulus, it is filtered and the filtered fluid then enters the tubule. In the tubule, chemicals and water are regulated according to the body's needs. This involves selective absorption or secretion process carried out by the tubule. At the end of this process the final product is urine (National Kidney Foundation, 2022). The kidneys thus regulate the body's internal environment which is crucial to maintain health (MedicineNet, 2018). For instance, when the body is dehydrated, the kidneys retain water in the body, less is excreted and the urine becomes concentrated. On the other hand, when there are sufficient amounts of water in the body, more water is

excreted and the urine is dilute. The kidneys filter and return around 150 litres of fluid to bloodstream every 24 hours. Approximately 1.5 litres of fluid are discharged from the body as urine. The kidneys also play part in regulating salt, potassium, and acid content in the body (National Kidney Foundation, 2022). The regulation of fluid and electrolytes is important the control of blood pressure. `

The kidneys also produce many hormones which can act locally within the kidney and also interact with the functions of other organs. For instance, *renin* produced by the kidney is important in the regulation of blood pressure. *Erythropoietin* is a hormone produced in the kidney that helps to make red blood cells. Related cells in the kidney sense the oxygen level in the blood. When this level decreases, *erythropoietin* levels increase and the bone marrow starts producing more red blood cells. Another hormone, *calcitriol* helps to control calcium metabolism. In summary the kidneys have critical functions including removing waste products from the body, balancing fluids and electrolytes, producing hormones that regulate blood pressure, activate vitamin D that helps to keep bones healthy, and controlling red blood cell production (MedicineNet, 2018).

1.1.2   Kidney Function – Glomerular Filtration

Glomerulus is a complex component in the nephron that is responsible for filtration of plasma (fluid). The glomerular capillaries act as barrier for selective filtration. For instance, water, urea, sodium pass easily through the glomerular membrane which prevents the passage of large proteins (e.g., albumin) (Ebefors et al., 2021). The glomerular filtration rate (GFR) is the rate of net filtration. It results from the pressure gradient across the glomerular membrane (P_{net}) and the surface area (A) of the membrane. Provided membrane function is normal;

$$GFR = P_{net} \quad x \quad A$$

Normally, GFR is approximately 20% of fluid flow rate. Under normal physiological

conditions, differences in GFR can be caused by modified glomerular capillary pressure or

altered surface area of glomerular capillaries. These can affect the fluid flow, filtration

pressure and GFR. GFR is typically equal to total fluid ultrafiltration rate. Normally, this

value is approximately 120 mL/min per 1.73 m^2 body surface area (BSA) for adult women

and 130 mL/min per 1.73 m^2 BSA for adult men. During childhood, GFR increases

consistently with growth. However, it starts to decrease by about 1 mL/min per year from

when people reach age 40. GFR can be measured using a substance such as inulin which is

filtered by glomerulus. Inulin is neither secreted nor reabsorbed by tubules hence, the amount

excreted reflects filtration. This allows measurement of GFR. In clinical practice creatinine

is commonly used to calculate GFR.

Decreased GFR can be a consequence of a decrease in the number of functioning nephrons or

a decrease in the average single-nephron GFR (SNGFR) due to physiological or

hemodynamic changes. It is not possible to directly measure the GFR in humans therefore,

"accurate" GFR cannot be determined exactly. GFR can be calculated by clearance

measurements (measured [mGFR]) or estimated from serum levels of endogenous substances

– usually creatinine or cystatin C – using empirical algorithms (estimated GFR [eGFR])

(Gilbert & Weiner, 2018). Typically, "measured" GFR is specified from the urinary clearance

of an "ideal" filtration indicator (inulin) or in clinical practice, creatinine. Urinary clearance

of the marker (in ml/min) is measured as the urinary excretion rate of the marker (in

mmol/minute) divided by mean serum concentration of the marker (in mmol/ml) during the

urine collection period. Urine collection for a period of time is necessary to calculate urine

volume for the urinary clearance. Incomplete urinary collection will prevent the accurate

calculation of the clearance. This is one of the reasons that measured GFR may differ from

accurate GFR. However, GFR is normally estimated with serum level endogenous filtration indicators to overcome the difficulties of measuring GFR (Gilbert & Weiner, 2018).

1.2   Kidney Disease

The level of GFR is important to determine the stage of CKD. The assessment of GFR is required for evaluation and management of CKD. Although eGFR based on serum creatinine is sufficient for making treatment decisions in most cases, sometimes confirmation using measured clearance is useful. Examples of this include instances when potentially nephrotoxic drugs might be necessary for the management of comorbid conditions, decisions on initiation of dialysis treatment, or suitability for kidney donation (Mula-Abed et al., 2012). Clearance measurements usually involve timed urine collections as well as blood tests.

Kidney disease can be acute or chronic. The important difference between acute kidney injury (AKI) and chronic kidney disease (CKD) is the potential reversibility of the former, contrasted with the irreversibility of the latter. AKI usually occurs when an insult produces a relatively sudden loss of kidney function producing a decrease in urine volume and an increase in serum creatinine. There is usually a delay following the insult before the creatinine rises and during this period, both the serum levels of creatinine and eGFR do not reflect the true GFR (Gilbert & Weiner, 2018).

CKD is considered as abnormalities of kidney function that present for more than 3 months. Kidney damage can result in a wide range of abnormalities resulting from loss of excretory, endocrine and metabolic functions (Levin et al., 2013). According the "Definition and classification of Kidney Disease: Improving Global Outcomes (KDIGO) criteria", CKD is defined as GFR < 60 ml/min/1.73 m^2 or markers of kidney damage for more than 3 months

(Levey et al., 2020). Generally people with CKD do not have major symptoms before significant amounts of kidney function have been lost. It is known that most kidney functions reduce in parallel with GFR in CKD (Levin et al., 2013). A major task of health professionals is to slow down the progression of the disease with interventions. AKI may be observed in patients with CKD and contribute to progression to kidney failure (Hsu et al., 2008). CKD progression refers to worsening GFR or albuminuria (Levey et al., 2020).

The term, *kidney failure* has been recommended to describe chronic conditions which described by KDIGO guideline as GFR < 15 ml/min/1.73 m^2 or the need for dialysis treatment (Levey et al., 2020). According to KDIGO 2019 consensus conference report, nomenclature used to define kidney disease have been revised to increase clarity, consistency and effective communication in kidney health community. Some terms have been suggested to avoid for instance, the term *end stage renal disease* (ESRD), may be demoralising and stigmatising for the patients. Regarding treatment for kidney failure, *kidney replacement therapy* (KRT) has been suggested to use with further specification such as with dialysis or transplantation. Similarly, *kidney failure with replacement therapy* (KFRT) may be used instead of ESRD. KFRT represent patients with CKD treated by dialysis or those who had kidney transplantation (Levey et al., 2020).

Damage to kidneys can be observed within large blood vessels. The markers of kidney damage often indicate the possible damaged area within the kidney. These may also help to understand the causes of the problem. The followings are some of the markers of kidney damage (Levin et al., 2013).

Proteinuria

This term represents increased level of protein in the urine. This is usually due to abnormal loss of plasma proteins through a damaged glomerular membrane. Clinical studies have found that proteinuria is an important marker of kidney damage, and a predictor of rate of progression of CKD (Remuzzi et al., 2006).

Albuminuria

Albuminuria is defined as abnormal loss of albumin in the urine. Albumin is a kind of plasma protein present in the urine in very small quantities in healthy individuals, yet it is at higher level in most patients who are affected by kidney disease. It is a more specific indicator of early kidney damage particularly in patients with diabetic nephropathy than proteinura in general (Zhang & Reisin, 2000).

Urine sediment abnormalities

Elements such as cells, crystals and microorganisms may be observed in the urine sediment in different kidney diseases (Cavanaugh & Perazella, 2019).

Electrolyte and other abnormalities due to tubular disorders

These abnormalities may stem from problems related to tubular function. The causes may be genetic, though there are many other causes including problems caused by nephrotoxic drugs (Ghane Shahrbaf & Assadi, 2015).

Pathologic abnormalities directly observed in kidney

By biopsy, abnormalities that are unrelated to eGFR can be directly observed in kidney. However, kidney biopsies are not conducted in the majority of patients with CKD (Levin et al., 2013).

Structural abnormalities

Structural abnormalities can be detected by imaging such as ultrasound, computed tomography and angiography. As a result, several abnormalities can be identified for instance, polycystic kidneys, dysplastic kidneys, small and hyperechoic kidneys and enlarged kidneys due to infiltrative diseases (Levin et al., 2013).

1.2.1 Known Causes of Chronic Kidney Disease

The causes of CKD conventionally differ according to presence or absence of underlying systemic diseases. In systemic diseases, the kidney is influenced by a specific process such as diabetes mellitus, drugs, systemic autoimmune disease, systemic infections, hypertension, systemic sclerosis, polycystic kidney disease, Alport syndrome and Fabry disease. Some of leading public health issues such as obesity, hypertension and diabetes are considered as main risk factors of developing CKD across globe (Levin et al., 2013).

Causes of CKD may show differences according to geographical location. In high income countries in the west, the most common causes of CKD are hypertension and diabetes, particularly among elderly. Sometimes, it can be difficult to differentiate CKD due to hypertension and diabetes from CKD which might arise from other problems in populations where the prevalence of hypertension and diabetes is high (Levin et al., 2013). This may be related to overlap of diabetes, hypertension, and CKD particularly in elderly (MacKinnon et al., 2015). On the other hand, in other countries, there may be several causes of CKD that can coexist with diabetes and hypertension such as, glomerular disease in East Asia (Levin et al., 2013). According to a study conducted in 2000, the global prevalence of hypertension in adults was found to be approximately 26% (972 million), and most cases were from low income countries (Kearney et al., 2005), yet the prevalence was found to be higher in urban

areas than in rural areas in the high income countries (Ibrahim & Damasceno, 2012). When the factors of age and gender are adjusted, worldwide hypertension prevalence is expected to increase to 1.56 billion by 2025 (Kearney et al., 2005). Similar findings were found for diabetes. The global prevalence of diabetes in adults was estimated to be 6.4% influencing 285 million people and also is predicted to increase to 7.7% by 2030 (439 million) (Shaw et al., 2010). Highest increases in prevalence are estimated in low income areas such as the Middle East, 163%, India. 151%, and China, 104% (Wild et al., 2004).

Glomerulonephritis and unknown causes are more frequently observed in some countries of Asia and sub-Saharan Africa. These differences may be due to several factors such as chronic lifestyle related disorders, low rate of births, longer life expectancy in high income countries (Engelgau et al., 2011). On the other hand, infectious disorders are still prevalent in low income countries where safe water is not sufficiently supplied (Ayodele & Alebiosu, 2010). Moreover, environmental pollution, analgesic abuse, frequently used unregulated food additives are also found to contribute to CKD in low income countries (Jha, 2004). Also, specific genes have been determined to contribute to CKD, for instance, variations in MYH9 and APOL1 have been related to non-diabetic CKD in people who are from African origin (Kao et al., 2008; Kanji et al., 2011). More detailed diagnostic testing including kidney biopsy is applied when confirmatory analysis is required. Overall, it is often not possible to specify the exact cause of the disease. It is frequently inferred or not known (Levin et al., 2013).

1.2.1.1 Aging

Epidemiological findings have suggested that prevalence of low eGFR is high in older people. Age-related findings are controversial since low level of GFR in older individuals

may make it difficult to differentiate pathological conditions from the normal aging process (Abdulkader et al., 2017). Many studies have investigated abnormalities linked with aging process, these include glomerular sclerosis and vascular sclerosis. Although aetiology of this relation is not clear yet, it may represent completely different issues, for instance, vascular disease (Silva, 2005; Weinstein & Anderson, 2010). Since low eGFR can be observed in older individuals, old age can be accepted as a risk factor to have CKD. Although decline in GFR is expected in older individuals, healthy older individuals do not necessarily show low levels of GFR. As older people are more likely to have cardiovascular disease (CVD), this is also one of the risk factors that are associated with CKD (Wesson, 1969).

1.2.1.2 Low level of GFR without markers of kidney damage

Different clinical conditions have been found to be related to low level of GFR for more than 3 months without structural changes in the kidney. Therefore, it has been suggested that some patients affected by specific conditions may be considered as having CKD, for instance, heart failure and cirrhosis of the liver (Levin et al., 2013). It is known that some people with these disorders with low level of GFR tend to have worse prognosis compared to others without decreased GFR (Levin et al., 2013). Protein intake can also affect the level of GFR (King & Levey, 1993). Healthy people who consume decreased protein may show a lower level of GFR. Some studies have indicated that people with anorexia nervosa have a low level of GFR. Therefore, malnutrition may be also one of the issues that should be evaluated (Levin et al., 2013). Moreover, there are several key points that have not been clarified such as prognosis in kidney donors, and further studies are required. It is known that most donors' usual GFR level is approximately 70% of the pre-donation level. This generally ranges between 60 to 90 ml/min/1.73 m^2. However, GFR level of some donors may decrease to lower than 60 ml/min/1.73 m^2, therefore kidney donors require closer after care (Levin et al.,

2013). Nevertheless, living kidney donation does not usually lead to problems as long as individuals engage in monitoring to detect hypertension, albuminuria and a mildly reduced GFR. It has also been recommended to avoid obesity and excessive salt intake for those living with one kidney (Schreuder, 2018).

1.2.1.3 Persistent albuminuria without low level of GFR

Persistent albuminuria in the absence of decreased GFR should be carefully evaluated. For instance, obesity and metabolic syndrome are associated with albuminuria and can decrease during weight loss. People with these conditions are known to be at higher risk for developing diabetes and hypertension and their prevalence is increasing in both low and high income countries (Dinsa et al., 2012). Therefore, KDIGO recommends that these conditions should be studied to clarify the risks associated with persistent albuminuria (Levin et al., 2013).

1.2.2　Stages of CKD

KDIGO recommends that CKD classification should be based on cause, GFR level and albuminuria (Levin et al., 2013). CKD can be classified according to 5 different stages (Table 1.1). Stage 5 represents the most severe stage of the disease. In stage 5, the disease has progressed to kidney failure which requires may benefit from KRT (i.e., dialysis or kidney transplantation) to survive (Levey et al., 2002). Patients who do not prefer to undergo KRT may receive comprehensive conservative care for the treatment of symptoms of kidney failure (Levey et al., 2020).

Table 1.1: Stages of Kidney Failure According to eGFR

Stage	Kidney Function	GFR (ml/min/1.73m2)
G1	Normal or high	≥90
G2	Mildly decreased	60-89
G3a	Mildly to moderately decreased	45-59
G3b	Moderately to severely decreased	30-44
G4	Severely decreased	15-29
G5	Kidney failure	<15

Adapted from Levin et al. (2013).

Complications may occur due reduced kidney function. These include drug toxicity, metabolic and endocrine complications, increased risk for CVD and other issues such as infections and cognitive dysfunction (Hailpern et al., 2007; James et al., 2009; 2010). Complication/s may be observed at any stage and may lead to death without developing kidney failure. They may even result from adverse effects of treatment of the disease and related comorbidity (Levin et al., 2013). Research has demonstrated the relationship of low level of eGFR and risks of cardiovascular mortality, AKI, kidney failure and CKD progression (Gansevoort et al., 2011; Chronic Kidney Disease Prognosis Consortium, 2010; van der Velde et al., 2011). On the other hand, several cardio-metabolic risk factors (e.g., diabetes/prediabetes, hyperuricemia, obesity/overweight, hypertriglyceridemia) have been associated with high prevalence of CKD and its prognosis (Moţa et al., 2015). It is common to observe multiple dysfunctions in CKD. A meta-analysis has indicated chronic liver disease (CLD) is prevalent among patients receiving dialysis treatment for kidney failure (Swift et al., 2021). It is known that CLD and kidney failure share several cardio-metabolic risk factors such as diabetes mellitus (Vernon et al., 2011; Webster et al., 2017).

1.3   Treatment

1.3.1   Pre-dialysis

Patients with stages 1 to 3 of CKD are usually managed within primary care. Patients with more advanced disease are referred to specialists depending on the cause of their disease, age, comorbid condition/s and CKD stage. Pre-dialysis care requires regular visits to a nephrologist to control hypertension protein excretion, monitor disease progression, manage comorbid condition/s, and plan KRT (Qaseem et al., 2013). During this period, patients obtain detailed information about dialysis modality choice in the context of factors such as physical and mental health status and life expectancy (Van De Luijtgaarden et al., 2012). Pre-dialysis preparation usually begins kidney function decreases below 20-30 ml/min/1.73 m^2. Care is multidisciplinary involving dieticians, nurses and nephrologists (Sijpkens et al., 2008).

Patients with comorbid conditions such as diabetes can experience a sharp decrease in GFR and kidney disease can progress quickly hence, screening at nephrology service is very important for these patients. On the other hand, those who are referred to nephrology service late are more likely to experience anaemia, bone disease, and hypertension. They are more likely to be hospitalised and are at greater risk for mortality (Jungers et al., 2006). As a consequence of delayed referral, patients are more limited on the choice of KRT modality, and they tend to have a poorer psychosocial adjustment (Sesso & Yoshihiro, 1997). Early detection of CKD is important as it can help delay or prevent progression. Patients referred early tend to have more flexibility on the choice of KRT modality. They tend to have less need for urgent dialysis and are less likely to experience longer stays in hospital (Chan et al., 2007). Patients receiving pre-dialysis care tend to have better nutritional status. Patients with progressive CKD who are at risk of requiring KRT within 1 year have been suggested to be

referred for specialist KRT planning. This also facilitates early interventions targeting issues such as anaemia (Levin et al., 2013).

Changes in lifestyle can be an important factor in delaying the progression and to address complications that may occur. Therefore, modification of lifestyle in number of areas may be important. The effective changes include regular exercising, decreasing alcohol use, targeting healthy weight, smoking cessation, and sodium restriction (Qaseem et al., 2013; Levin et al., 2013). Self-management and support groups promoting healthy habits and perceptions in relation to understanding the disease and adherence to treatment, may even improve glycaemic and blood pressure control (Cueto-Manzano et al., 2010). Multidisciplinary approaches may be useful to achieve treatment goals (Levin et al., 2013). Another important approach is to encourage patients to engage in preventative behaviours. Individuals with diabetes, hypertension, CVD, autoimmune disease who may have potentially family history of kidney disease are suggested to screen for kidney disease (Levey et al., 2002).

KDIGO clinical practice guidelines suggest regular physical activity for patients with CKD (KDIGO, 2012). There is emerging evidence on importance of physical activity in CKD. A multicentre longitudinal study found higher mortality rate and greater CKD progression among patients with CKD who were not physically active when compared with those who were highly active (Hoshino et al., 2020). Similarly, another study showed that physical activity increased health related quality of life (HRQOL) in patients with non-dialysis CKD (Oh et al., 2022). HRQOL refers to how well an individual functions and how they perceive their well-being in physical, mental, and social aspects (Stenman et al., 2010). Although it is frequently used interchangeably, quality of life (QOL) on the other hand, is a broad term that have been defined by using different approaches. It has been described as an individual's satisfaction with their life, this may include both health related and non-health related aspects

of life (e.g., economic circumstances) (Karimi & Brazier, 2016). It has been suggested that simple, home-based, personalized exercise programme may improve physical functioning among patients receiving dialysis (Mallamaci et al., 2020). Findings of observational and experimental studies have shown physical activity may be associated with several benefits in CKD such as slower decline in kidney function, and increasing levels of physical function, and QOL (Wilund et al., 2021).

Along with physical activity, dietary changes have been indicated as effective strategy to improve well -being in patients with CKD. A randomised control trial (RCT) study examined the effect of caloric restrictions and aerobic exercise on metabolic health in patients with moderate to severe CKD. After 4 months, results of the trial showed dietary change and exercise had significant benefit on body weight and markers of inflammatory response among patients (Ikizler et al., 2018). A meta-analysis of cohort studies found healthy dietary changes were related to both lower incidence of CKD and lower incidence of albuminuria, however, no significant relation was found between healthy dietary patterns and eGFR decline (Bach et al., 2019). More specifically, salt reduction is known to relate to better blood pressure. A meta-analysis of RCTs examined the impact of salt intake among patients with non-dialysis CKD on change in blood pressure, proteinuria and albuminuria. Findings showed moderate salt restriction decreased blood pressure and proteinuria/albuminuria in patients with CKD (Stage 1–4) (Garofalo et al., 2018).

Most effective and cost-free treatment approaches include keeping salt and protein intake at the optimum level. KDIGO guidelines suggest that patients should decrease salt intake (<90 mmol [<2 g] per day of sodium). High sodium intake leads to increased proteinuria and glomerular hyperfiltration. However, reducing sodium intake helps to decrease albuminuria (Levin et al., 2013). A review suggested that higher salt intake was linked with worse

albuminuria and this was associated with higher risk of decreased GFR (Jones-Burton et al., 2006). Decrease in sodium intake reduces blood pressure (Campbell et al., 2014; McMahon et al., 2013) as well as protein excretion (Slagman et al., 2011). Additionally, it decreases the risk of cardiovascular complications that may occur (Heerspink et al., 2012). KDIGO guidelines suggest that patients should lower protein intake (to 0.8g/kg/day) especially those with diabetes or those without diabetes but having GFR <30 ml/min/1.73 m^2 (stages G4 and G5). High protein diet results in increased uremic toxin generation. On the other hand, lack of protein may result as malnutrition especially in older patients. Protein restrictions help to decrease metabolic waste burden that may negatively affect appetite and may contribute to muscle wasting. Progression in CKD has been associated with protein wasting syndrome and this has been found to be closely related to morbidity and mortality. Higher protein intake especially non-dairy animal protein may expedite the reduction of kidney function in patients with early stages of CKD (Levin et al., 2013). A longitudinal study analysed women with eGFR ≥ 80 ml/min/1.73 m^2 (normal kidney function) and those with eGFR 55-80 ml/min/1.73 m^2 at baseline. High protein intake was not found to be related to change in eGFR in women with normal kidney function at baseline, however, protein intake was found to be significantly related to change in eGFR (-1.69 ml/min/1.73 m^2) in those who had lower eGFR level at baseline (Knight et al., 2003).

1.3.2   Dialysis

According to KDIGO, dialysis treatment should commence when patients with an eGFR < 15 ml/min/1.73 m^2 experience one or more symptoms of the following: inability to control blood pressure, impairment in nutritional status that is not easily changeable through diet restrictions, cognitive impairment and kidney failure related abnormalities (Levin et al., 2013). Dialysis treatment is the most commonly used treatment for patients with kidney

failure as transplantation is limited by organ availability. Although dialysis is an advanced

treatment option, kidney disease is associated with high risk of morbidity and mortality

(Foote & Manley, 2008).

Although excessive salt and water can be removed by dialysis, patients should limit their salt

and water intake carefully. Generally, in patients with little urine output, fluid intake is

restricted to 0.5-1 litres per day. This is commonly frustrating for the majority of the patients.

Unsurprisingly fluid non-adherence has been indicated as a common problem (Vijay & Kang,

2021). Exceeding limits of salt and water intake may put the patient at risk of experiencing

complications including congestive heart failure with increased risks of hospitalisation and

death (Bame et al., 1993).

1.3.2.1 Peritoneal dialysis

In peritoneal dialysis, dialysate is instilled into the peritoneal cavity through permanent

peritoneal catheter. Waste products are discharged from the blood across the peritoneal

membrane through diffusion and filtration. Therefore, patients on PD need to instil and drain

manually several litres of fresh dialysate every day. The amount of solute removal is

dependent on the frequency of exchanges that are completed. Peritonitis is a common

complication that can be a result of PD. The advantages of PD include 1) stable blood

pressure due to slower filtration process, 2) greater maintenance of residual kidney function,

3) convenient for elderly patients and very young patients who may not adjust to HD well, 4)

greater sense of freedom (particularly for continuous ambulatory peritoneal dialysis

[CAPD]), 5) less likely to lose blood and iron and this may facilitate anaemia management.

On the other hand, PD also has some disadvantages, for instance, 1) reduced serum protein

due to peritoneal protein loss and decreased appetite as a result of feeling full (abdominal

fullness) - this may lead to malnutrition, 2) catheter related problems including exit site infection, 3) risk of peritonitis, 4) insufficient filtration and solute dialysis in patients with larger body size and those with minimal residual kidney function, 5) frustration due to high number of technical failures, 6) patients may be at higher risk of obesity due to high level of glucose absorption, 7) patients tend to have more back pain complaints. Generally, PD is a less efficient modality of dialysis hence it should be continuously applied to obtain a good level of clearance of waste products. Technical developments in PD, have improved patient outcomes. Morbidity rate has decreased among patients on PD compared to early 1980s. PD is a convenient alternative to HD treatment for patients especially for those patients who wish to preserve their independence. However, infection related difficulties can cause complications and are the main cause for change of modality to HD. Patients with peritonitis usually experience abdominal pain, fever, chills and nausea (Foote & Manley, 2008). As a PD option, automated PD (APD) is home modality and designed particularly for those patients who need more dialysis. The automated cycler does exchanges generally every 1 to 2 hours during the night. APD is widely used among patients with PD (Bethesda, 2007).

1.3.2.2 Haemodialysis

Generally, HD is performed three times in a week, each session ranging from 3 to 5 hours (Centres for Medicare and Medicaid Services, 2007). Although home HD has several advantages, the vast majority of patients dialyse in centre (Bethesda, 2007). During an HD session, they are connected to the HD machine by blood lines via a access point to the patient's circulation - a surgically created AV fistula or central venous catheter. A pump moves the blood from patient's body via the access to a dialyzer, and then back to patient again. The dialyzer can be considered as a replacement kidney (American Association of Kidney Patients [AAKP], 2022). Waste products are discharged from the blood by diffusion

into dialysis fluid within the dialyser. Excess fluid in the body is removed by the same route. The HD machine controls the extracorporeal circulation and dialysis fluid characteristics and delivery. It monitors blood flow, blood pressure, and how much fluid is removed from patient's body during the session. Many patients on HD tend to experience cramps and hypotension during the process. They can also face serious complications such as, infection and thrombosis of vascular access.

Most incident dialysis patients start on HD treatment. There are advantages of HD treatment, and including 1) greater solute clearance, which allows patients to receive the dialysis at specific intervals, 2) dialysis adequacy can be easily determined, 3) technical problems are uncommon. On the other hand, HD has some disadvantages, 1) those patients who receive HD treatment need to visit the centre multiple times each week and this reduces independence 2) adjustment to HD can take longer for patients as symptoms of hypotension and muscle cramp are widely experienced, 3) infections can be experienced such as vascular access related problems, 4) decrease in residual kidney function is quicker compared to PD. Complication/s can occur during the HD process, these include cramps, hypotension, nausea, chest pain, back pain, headache, fever and chills. Hypotension is the most widely experienced complication, and it is known to be related to mainly the great amount of fluid removed during a session and its rate of removal. The type of access is known to be important risk factor for vascular access related infection – central venous catheters being much more prone than native AV fistulas (Foote & Manley, 2008).

1.3.3   Transplantation

Although the prevalence of kidney failure globally has risen, rate of transplantation has not increased among in patients with kidney failure (Foote & Manley, 2008). The transplantation

process involves kidney donation either from a living or deceased donor. The main advantage of kidney transplantation is better quality of life. A study showed that, HRQOL in all aspects (i.e., emotional, social and physical) increased in patients after transplantation regardless of diabetes status and age (Laupacis et al., 1996). However, the number of patients waiting on the list for kidney transplantation is greater than the number of kidney donors. This extends the dialysis treatment period. Those patients who receive a kidney transplant tend to live longer than other patients compared to those receiving dialysis treatment (Port et al., 1993; Schnuelle et al., 1998). However, there are some factors that may influence mortality in kidney recipients, for instance, comorbid conditions, dialysis treatment before the transplantation, (Curtis, 1992; Cosio et al., 1998), age and race of the recipient (Hariharan et al., 2002). Risks associated with transplantation have improved due to the availability of improved techniques and more effective anti-rejection drugs against risk factors such as hypertension (National Institute of Health, 1999).

1.4 Incidence & Prevalence

1.4.1 Incidence

Data related to incidence and prevalence rates of CKD and kidney failure are obtained through different countries from different Registries such as Australia and New Zealand Dialysis and Transplant Registry, European Renal Association - European Dialysis and Transplant Association (ERA- EDTA), Turkish Registry of Nephrology, Dialysis and Transplantation, UK Renal Registry and United States Renal Data System (USRDS). Incidence rates of KFRT may differ although similar prevalence rates of CKD have been found in different communities. This may be related to threshold at which KRT is initiated. Also, progression rates of the disease have an impact on the incidence of KFRT in a

population. Since the disease slowly progresses, large samples should be followed up for a long time to better establish the incidence of CKD in a population (Falodia & Singla, 2012).

European Renal Association - European Dialysis and Transplant Association (ERA- EDTA) is an organisation for clinicians and scientists who work in areas of nephrology, dialysis and kidney transplantation. According to data collected by ERA-EDTA registry in 2015, general unadjusted incidence rate of KFRT was indicated as 119 pmp. The incidence rate ranged between 24 pmp in Ukraine and 232 pmp in Czech Republic and Portugal with 227 pmp. This data also has shown that majority of the patients starting to receive KRT were men and half of the patients were older than 65 years old, also one-fourth had diabetes when they were diagnosed with kidney disease. According to ERA- EDTA 2015 annual report, majority of the patients (85%) commenced KRT with HD in Europe (Kramer et al., 2018). A review study recently examined the global epidemiology of kidney failure and reported that the predominant KRT modality in most countries was HD (Thurlow et al., 2021). United States Renal Data System (USRDS) reported that Taiwan, Mexico, United States and Brunei had the highest incidence rate of KRT (476 pmp, 411 pmp, 378 pmp, 393 pmp, respectively). Diabetes has been indicated as the primary cause for more than half of the patients with KFRT (USRDS, 2017). On the other hand, evidence highlights family history of kidney failure. For instance, approximately 23% of incident dialysis patients have reported to have first or second-degree relative who were diagnosed with KFRT. In the same study, family history of kidney failure was found to be negatively associated with white race (Freedman et al., 2005). Overall, ethnic differences have been observed while investigating the incidence of CKD. A community-based study examined 4119 young African-American and white adults' eGFR levels at 10, 15 and 20 years after the baseline measurement. The results showed that CKD incidence rate was higher in African American individuals than white individuals.

Increased level of albuminuria found in African American individuals has been suggested as an important risk factor for CKD (Muntner et al., 2012).

The incidence of KRT is high and it has been closely associated with diabetic nephropathy in most of the Eastern Mediterranean societies including Turkish Cypriots, Greece and Turkey (84.4 pmp, 53.5 pmp. 61.6 pmp, respectively) (Connor et al., 2013). According to ERA-EDTA registry report, age-adjusted incidence rates at day 90 for Turkey, Greece and Tunisia were recorded as 349 pmp, 160 pmp, and 239 pmp respectively (Stel et al., 2011). The Turkish registry report states that incidence rate of KRT in Turkey was found as 146.5 pmp in 2017. Also, the most common modality of KRT was found to be in centre HD (81.7%), followed by 7.4% PD and 10.9% transplantation. More than half of the incident KRT patients were male and majority of them were older than 45 years old. Furthermore, diabetes was indicated as the major cause of kidney failure in those patients who commenced HD (38%), followed by hypertension (27.5%) and unknown aetiology (14.9%) (Süleymanlar et al., 2018). A study conducted in Northern Cyprus determined that KFRT incidence rate at 90 days was 234 pmp. Majority of the patients (62%) were male and the participants' mean age was 63. Moreover, 91.1% of the Turkish Cypriot patients with kidney failure commenced HD and only 4.4% of them started on PD and 3.5% of them had transplantation. Similar to other Mediterranean countries, diabetes has been indicated as the most common cause of kidney failure (36%), while second major cause was unknown (30%). This patient group partly represent late referral with limited diagnostic assessments. Moreover, 18% of the incident patient group reported to have a family history of KFRT (Connor et al., 2013). CKD development and incidence of kidney failure treated with KRT have been found to be related to multiple genetic loci (Böger et al., 2011; Köttgen et al., 2009).

1.4.2   Prevalence

As the early stages of CKD are less symptomatic compared to KFRT, accurately determining the prevalence rate of the early stages of CKD may be challenging. (Levin et al., 2013). Diagnosing elderly people as having CKD due to increased age related lower level of GFR may also be problematic in determining prevalence rate of CKD (Falodia & Singla, 2012). Overall, different prevalence rates in the CKD may depend on various factors such as representativeness of the sample in the research, ethnicity, participation rate and calculation of both albuminuria and estimated GFR (Mills et al., 2015). For instance, National Health and Nutrition Examination Survey (NHANES) reported that the prevalence of CKD stages including stage 1 to 4 in US was 13.1% in 1999-2004 (Snyder et al., 2009). However, this rate decreased since clinicians have started to use a different algorithm for measurement of GFR (i.e., CKD-EPI) (Levey et al., 2009). Therefore, the differences between prior and recent prevalence rates may be due to the usage of CKD-EPI measurement to determine GFR level. Even creatinine estimation techniques may differ between clinical settings and this may be also one of the important problem contributing to different rates of prevalence of CKD (Falodia & Singla, 2012). On the other hand, it has been recently suggested to use algorithms which exclude race from the CKD-EPI equation to estimate eGFR as it may influence prognosis in predominantly in white European populations (Fu et al., 2022).

Important proportion of the variance in CKD prevalence may be due to different factors apart from diabetes, obesity and hypertension such as, physical activity, smoking, birth weight and socioeconomic level which may differ according to different regions (Bruck et al., 2016). For instance, some countries in Europe which reported to have higher level of diabetes and hypertension differed in terms of CKD prevalence rate (Bruck et al., 2016). There may be risk factors other than diabetes and hypertension that have not been identified yet. To better understand the prevalence at country level, genetic factors, dietary habits and environmental

risk factors should be more studied (De Nicola & Zoccali, 2016; Bruck et al., 2016). Mediterranean diet has been suggested to be beneficial to prevent CVD (Estruch et al., 2013) which has been linked with CKD (Heerspink et al., 2012; Huang et al., 2013; Khatri et al., 2014). Other factors may include environmental and herbal related causes. For instance, low income populations are known to be at higher risk of developing CKD. This expectation may worsen if the rate of diabetes and hypertension persist in the population (Jha et al., 2013). 80% of the patients with KFRT are assumed to represent high income countries which have large elderly populations (White et al., 2008). For instance, Europe, Canada, USA and Australia had more frequent CKD compared with low – middle income regions such as India and sub Saharan Africa. Nevertheless, CKD prevalence is assumed to increase also in low income countries where elderly population is large (Jha et al., 2013; Hill et al., 2016).

There are some studies investigating ethnic differences in CKD prevalence. A study comparing 13,626 Chinese, 9006 American white, 4626 Hispanic and 3447 African American individuals reported that those of Chinese heritage had lower level of adjusted albuminuria and CKD prevalence compared with others. Also, diabetic American ethnicities were at least 1.5 times more likely to have CKD and higher level of albuminuria compared to diabetic Chinese group (Xu et al., 2009). Subpopulations within the countries are estimated to be at higher risk of developing CKD and/or disease progression. These subpopulations may include black and South Asian people in the UK, Native Americans, Hispanics and black heritage people in USA and Australian aboriginal community in Northern Australia (Feehally, 2005; McDonald et al., 2003). African American and Hispanic individuals are more likely to develop kidney failure at younger age compared to white ethnicities in the USA (Feehally, 2005). Moreover, CKD prevalence has differed between native Chinese and various Americans ethnic groups. A study comparing Chinese, white, African American and Hispanic individuals reported that Chinese individuals had the least prevalence rate of

diabetes, hypertension and obesity. These characteristics may explain the low prevalence rate of CKD in Chinese individuals compared to those form other ethnicities (Xu et al., 2009).

The prevalence of CKD ranges from 8 to 16% across the globe (Jha et al., 2013). A recent meta-analysis has demonstrated that the prevalence rate of CKD of all stages is 13.4% (11.7-15.1%) worldwide. More specifically, prevalence rates of stages 1, 2, 3, 4 and 5 were reported as 3.5%, 3.9%, 7.4%, 0.4% and 0.1% respectively (Hill et al., 2016). A community-based study conducted in 13 European countries established variations in CKD prevalence across European countries. For instance, adjusted CKD prevalence rate (stage 1-5) ranged from 3.31% (Norway) to 17.3% (Germany). Stages 3-5 of adjusted CKD prevalence also showed variance ranging between 1% (Italy) and 5.2% (Germany) (Bruck et al., 2016). According to ERA-EDTA 2015 annual report, the prevalence of patients receiving KRT was recorded as 936 pmp. More specifically, Portugal had highest unadjusted prevalence rate of KRT (1824 pmp) followed by Catalonia and Valencia (1355 pmp and 1333 pmp respectively) districts of Spain (Kramer et al., 2018). However, USRDS (2017) observed the highest prevalence of KFRT in Taiwan (3317 pmp), Japan (2529 pmp) and United States (2138 pmp) in 2015. Majority of the countries (82%) used in-centre HD as KRT. Compared to other countries, Taiwan, Turkey, Thailand, Egypt, France, UK, Iran and Spain reported high number of patients with KFRT and this ranged from 50,000 to 98,000 in 2015. On the other hand, Bangladesh, Ukraine, Indonesia, Russia, South Africa, Albania, Philippines and Morocco were among the countries reported low prevalence of KFRT which ranged between 119 to 540 pmp. The report also indicates that large increases in the rate of KFRT prevalence were determined in Thailand, Philippines, and Jalisco district of Mexico and these countries followed by Malaysia, Turkey, Brazil, Russia and Republic of Korea. Although kidney transplantation is not common modality of KRT, global findings comparing 2002/03 to 2014/15 reports indicate that transplantation rate has increased particularly in Iceland,

Turkey, Russia, Thailand, Scotland, Korea, Netherlands, Brazil (from 54% to 1203%) (USRDS, 2017).

The 2017 annual report of the Registry of the Nephrology, Dialysis and Transplantation in Turkey indicates that the prevalence rate of KFRT was 956.7 pmp (Süleymanlar et al., 2018). On the other hand, Connor and colleagues have found that the age adjusted prevalence rate of Turkish Cypriot patients receiving KRT was 1543 pmp in 2011 in Northern Cyprus (Connor et al., 2013). This rate can be considered as high.

Diabetes, unknown aetiology and hypertension have been identified as common causes in CKD (Falodia & Singla, 2012). The ERA-EDTA 2015 annual report stated that the prevalence of diabetic nephropathy was 26 pmp (n = 2.048) (Kramer et al., 2018). Similarly, in Turkey, the prevalent number of diabetic nephropathy was found as (n= 2.366) (Süleymanlar et al., 2018). Consistently, diabetes was indicated as a major cause among Turkish Cypriot patients with KFRT. The second most important cause was indicated as unknown aetiology which is followed by family history of KFRT (Connor et al., 2013). Although they show some similarities in the aspects of diet and lifestyle, Turkish Cypriots and Greek Cypriots are genetically different from people who are from Turkey and Greece mainland (Novembre at al., 2008; Irwin et al., 2008). Therefore, investigating unidentified factors causing CKD in Turkish Cypriot population is critical.

1.5   Comorbidity

Having multiple chronic conditions is known as multimorbidity (Fortin et al., 2005). Multimorbidity is widely observed and it has been found to be related to more negative clinical outcomes and more health care costs in comparison to a single chronic condition

(Barnett et al., 2012; Fortin et al., 2010; Lehnert et al., 2011). Risks can be examined according to different categories such as susceptibility to kidney dysfunction due to sociodemographic and genetic factors as well as exposure to factors that may trigger kidney dysfunction. Symptoms at early stages of the disease are not easily observed and kidney dysfunction may be detected during the evaluation of comorbid chronic disorders (Levin et al., 2013).

Older individuals are more likely to have comorbid conditions than the younger individuals with CKD. These conditions include but are not limited to CVD and abnormalities that hinder management of CKD (Stevens & Levey, 2005). Comorbid conditions in CKD are identified individually. For instance, diabetes is recognised as having history of diabetes, using medication for diabetes and hypertension is identified when a patient has history of hypertension, or they use medication for hypertension. Moreover, haemoglobin is measured to identify anaemia (< 13.5 g/dL for men and < 12 g/dL for women), yet anaemia is reported for individuals only who show eGFR < 60 mL/min/1.73 m^2. Conditions including cancer, stroke, and cholesterol are self-reported comorbid conditions (Levin et al., 2013). There is high prevalence of CKD in older individuals who have other conditions and biochemical abnormalities. Particularly, the elderly population is at higher risk of developing CVD, also, they are at risk of side effects of medications used to treat the conditions they may already have. This may be considered as risk of developing AKI and CKD progression (Stevens et al., 2010). The rate in eGFR decline has been reported to be 1.5 to 3 times higher in patients with CKD with comorbid conditions compared to patients with CKD but without comorbid condition (Imai et al., 2008; Hemmelgarn et al., 2006). A follow-up study found that death was a much more likely outcome (10 times more likely) than progression to KFRT in patients with CKD at stage 2, 3 and 4 (Keith et al., 2004). Gullion and colleagues (2006) established that comorbidities in patients with CKD are highly prevalent when compared with individuals

without CKD after adjusting for age and sex. They also indicated the importance of non-traditional risk factors for coronary artery disease (CAD) in mortality apart from smoking and diabetes. The strong association between lower GFR and risk for death was confirmed even in patients with mild kidney dysfunction and who are younger than 60 years. Their analysis indicated that lower GFR was related to mortality independently even after controlling for other comorbidities. The comorbidities that mostly related with mortality were found to be heart failure (CHF), anaemia, proteinuria and peripheral vascular disease (PVD) (Gullion et al., 2006). However, CVD is known as the most prevalent cause of mortality, yet correlates of traditional risk factors including blood pressure, cholesterol and body mass index to mortality are not clear. Overall, these associations have been suggested to be confounded by disease severity, inflammation, malnutrition and comorbid disorders. Since comorbid conditions are highly prevalent in CKD, multi-directional interventions adopting a multidisciplinary approach have been suggested to improve outcomes in patients with CKD (Levin et al., 2013).

Like chronic conditions including heart diseases and cancer, CKD is one of the common causes of death in the modern world. This is partly due to requirement of dialysis or transplantation. Recent findings have shown that some patients with kidney disease may never progress to kidney failure, yet low level of GFR may be reflected by proteinuria which has been found to be related to risk of death from heart disease (Collins et al., 2003; Levin et al., 2001). Therefore, kidney disease is recently considered as an independent risk factor for CVD by American Heart Association (Sarnak et al., 2003). By using United States Renal Data System (USRDS) data between 2005- 2015, kidney transplantation was found to be related to significant improvement in expected survival. More specifically, survival of living-donor transplants was found to be increased by 57% over patients receiving dialysis (Axelrod et al., 2018). According to ERA- EDTA 2019 annual report, 5 year survival probability for

dialysis was 47.4% when age, sex, primary kidney disease were adjusted. It was also shown that survival probability after kidney transplantation was found as ranging between 96.7% and 98.4% when age, sex, and primary kidney disease were adjusted (ERA-EDTA Registry, 2021).

A recent study investigated mortality rate at 28 days after COVID 19 diagnosis across European KRT population. Results showed those patients with kidney transplant had 28% higher risk compared to matched patients receiving dialysis. Regarding patients receiving dialysis and diagnosed with COVID-19, the 28-day probability of mortality was 25.0% in those receiving PD and 23.8% in those receiving HD treatment (Jager et al., 2020). These findings reveal COVID-19 pandemic has a significant effect on mortality in patients with KRT, due to CKD and multimorbidity. A retrospective cohort study analysing COVID-19 related death found that patients with kidney failure receiving HD were 37.8% more likely to experience in- hospital mortality compared to those without kidney failure (Rastad et al., 2021). A meta-analysis including data from 12 countries demonstated that the overall estimated case fatality rate of COVID-19 in patients with KFRT was 18.06% which was found higher than the global average case fatality rate of COVID-19 in the general population (4.98%) (Nopsopon et al., 2021). Evidence shows that kidney failure compromises health and well-being in many direct and indirect ways.

It is well known that smoking is a modifiable major cause of morbidity and mortality in general population. There is evidence linking cigarette smoking with CVD and cancer. The negative outcomes of smoking have been also recorded in individuals with CKD (Orth & Hallan, 2008; Foley et al., 2003; Shlipak et al., 2005). Staplin and colleagues (2016) conducted a longitudinal study analysing the relation between smoking and adverse outcomes such as cancer, kidney failure and vascular problems in patients with CKD. At baseline, 13%

of the participants were current smokers, 35% were former and 51% reported that they never smoked. After five years of follow-up, 25% had at least one vascular problem, 7% had diagnosis of cancer, and 34% developed kidney failure and 24% died. Yet authors did not find increased risk of kidney failure among participants who were current or former smokers. Another study reported an association between smoking and increased risk of kidney failure (Klag et al., 1996). On the other hand, there are studies observing a relation between smoking with the progression of CKD (Yoshida et al., 2008; Grams et al., 2012), yet not all of these reported smoking as an independent risk factor for loss of kidney function (Tanaka et al., 2013).

1.6   Symptoms of CKD

CKD may cause no symptoms at early stages of the disease. Hence, patients are often unaware of their disease and its symptoms. Patients mostly do not report symptoms until they reach stage 3 of CKD (i.e. when kidneys have lost 30% of their function) (Jha et al., 2013). At stage 3, patients tend to report more symptoms such as, sleeping difficulties, restless legs, breathlessness, weight loss, loss of appetite, itching, nausea, swelling, fatigue, high blood pressure, blood in urine, more frequent urination (especially at night) (National Kidney Foundation, 2022; MedicineNet, 2018; De Goeij et al. 2014; Abdel-Kader et al. 2009). Since patients with CKD are likely to be diagnosed with diabetes and CVD, they may also show diabetes and CVD related symptoms in comparison with patients who do not have comorbid conditions (De Goeij et al., 2014). The non-specificity of these symptoms makes it difficult for patients to often be aware of the need for support. This is particularly true in low income countries where public health literacy may be lower (Das et al., 2017; Heine et al., 2021). The result in low income countries is that patients often 'crash land' therefore in need of urgent intervention, though given the health care infrastructure, mortality rates are high due to

intervention costs. In countries with insurance programmes or care free at the point of access, late diagnosis may have negative impact on wellbeing. Late diagnosis has been shown to be related to increased rate of morbidity and mortality (National Clinical Guideline Centre [UK], (2014). On the other hand, high income countries tend to rely on well-established prevention strategies. These include mainly screening individuals who are at risk to diagnose and treat CKD at early stages (Luyckx et al., 2020). A systematic review has shown that high income countries including US and Canada use cost-effective CKD screening programmes by eGFR and/or albuminuria, particularly for high risk populations (i.e., diabetic and/or hypertensive) (Komenda et al., 2014).

1.6.1   Physical Symptoms

Physical symptoms play a critical role as patients' experiences are likely to influence their lives. Age, ethnicity and dialysis vintage may affect symptom burden (Kimmel et al., 2003; Barrett et al., 1990). However, female patients receiving dialysis have reported greater number of symptoms than the male patients (Weisbord et al., 2005) except sexual dysfunction (Seibel et al., 2002).

Patients with CKD including those with kidney failure were mostly found to be bothered from dry mouth, itchy skin, lack of energy, excessive thirst, fatigue, muscle soreness, sleep related difficulties, lower physical functioning (Holley et al., 1991; Unruh et al., 2003; 2004; Abdel-Kader et al., 2009). More specifically, patients receiving dialysis frequently report symptoms such as, dry skin, lack of energy, itching and joint/bone pain etc (Merkus et al., 1999; Weisbord et al., 2005). Most severe symptoms include bone/joint pain, chest pain, difficulty of sexual arousal and vomiting (Weisbord et al., 2005). A systematic review suggests that pain is approximately experienced by 65% of patients with CKD ranging from

38% to 90% (Almutary et al., 2013). Another study conducted among patients receiving HD showed that half of the patients reported pain (Kimmel et al., 2003). Those patients with pain who receive dialysis may be at higher risk of mortality (Weisbord et al., 2014; 2016).

1.6.2   Psychological Symptoms

Patients with CKD tend to experience higher levels of anxiety and depression compared to the general population as well as patients with other long-term conditions (Ozgur et al., 2003). Depression and anxiety together have been found to be predictor of suicidal ideation (Chen et al., 2010; Wang et al., 2012). Although estimates of the prevalence tend to vary depending on screening tools used, a study found 44% of the patients receiving HD had a psychiatric comorbid condition (Goyal et al., 2018). The observed disorders include depression, anxiety, organic brain, mental and sexual disorders (O'Donnell & Chung, 1997). However, the most common psychiatric disorder in patients receiving HD is depression (Kimmel, 2001). A longitudinal study conducted among patients receiving HD determined that depressive affect at baseline was the most significant predictor of chronic depression in 16 months follow-up (Cukor et al., 2008). Patients receiving dialysis reported that they tend to feel hopeless (Basaran et al., 2016). With dialysis treatment, patients may feel social restrictions as well as dependence towards dialysis machine, health professionals and family. These factors may increase the tendency to develop depression (Yavuz et al., 2012). Prevalence of depression in CKD ranges from 22% to 39% (Shirazian et al., 2017). Specifically, depressive symptoms have been recorded in patients receiving HD ranging from 8.1% to 68.2% (Ibrahim et al., 2013). Accordingly, the patients' QOL is likely to be negatively influenced (Davison & Jhangri, 2005; Kimmel, 2000; Unruh et al., 2005; Chan et al., 2009). Longitudinal studies have indicated that those patients who report depression are at higher risk of death (Kimmel et al., 2000; Peterson et al., 1991). Those who have advanced

CKD but do not require KRT also reported burden of symptoms, depression and low QOL

(Abdel-Kader et al., 2009; Holley et al., 1991).

1.6.3 Association between Physical and Psychological Symptoms

CKD related symptoms and low HRQOL are commonly observed even among patients

receiving pre-dialysis treatment. Symptoms can be observed when kidney function starts to

decrease to half of the normal function (Meyer & Hostetter, 2007). This decrease has been

found to be linked with HRQOL (Perlman et al., 2005; Kusek et al., 2002). Even incident

patients who are in early pre-dialysis phase have reported many symptoms including fatigue,

and loss of energy. The biggest change in symptom prevalence and severity and occurs

during the 6-12 months prior to beginning dialysis. This is reflected in a substantial reduction

in HRQOL during this period. The most commonly experienced symptoms include

breathlessness, weight loss and fatigue at start of dialysis treatment (De Goeij et al., 2014).

HRQOL, particularly physical health can be negatively affected even at early stages of CKD

(Pagels, 2012). Symptom burden and severity have been negatively associated with both

HRQOL and depressive symptoms and patient life satisfaction (Kimmel et al., 2003;

Weisbord et al., 2005). The relation between symptom severity and HRQOL was still strong

even after adjusting the effect of depression. These associations may be potentially related to

mortality and morbidity in patients receiving dialysis (Weisbord et al., 2005; Tsai et al.,

2009). Moreover, anaemia related to kidney failure contributes to fatigue in approximately

80% of the patients receiving HD. This negatively affects HRQOL (Merkus et al., 1999;

Curtin et al., 2002).

Research has shown that depression in patients with kidney failure was associated with worse

outcomes (Chilcot et al., 2010). It has been shown to predict mortality (Silva et al., 2014) and

behavioural non-adherence (Kimmel et al., 1998) and greater number of physical

comorbidities (Chen et al., 2010) in patients receiving HD. Moreover, depression has been

found to predict decreased serum albumin levels (Friend et al., 1997; Wang et al., 2012). This

evidences the complex relationship between psychological and physical wellbeing as defined

by important clinical markers of health in this population. Patients receiving HD with

depressive symptoms have been observed to have decreased residual kidney function even

after adjusting several clinical characteristics such as dialysis vintage (Chilcot et al., 2009).

Although depression and anxiety may co-vary, depression has been shown to be related to

more physical symptoms whereas anxiety has been mostly found to be related to emotional

upset (Vázquez et al., 2005). Anxiety has been found to influence up to 50% of the patients

with kidney failure (Buemi et al., 2018). It has been found to be related to perceptions of

QOL in patients with CKD (Yoong et al., 2017). These perceptions have been related to

clinical outcomes such as treatment and diet adherence and even mortality (Cohen et al.,

2016). On the other hand, comorbidity in patients receiving PD (diabetes was the most

common comorbidity) has been independently linked with decreased physical and cognitive

function, and emotional well-being (Bakewell et al., 2002). Similarly, patients receiving HD

who had diabetes reported worse QOL which has been negatively associated with dialysis

vintage (Anees et al., 2011).

A study using symptom cluster model found that psychological symptoms, stage of CKD and

age were important factors explaining symptom experience in patients with advance stages of

CKD. The symptom clusters including fatigue, restless leg and negative sexual symptoms

determined the biggest impairment in QOL (Almutary et al., 2017). CKD stage and

depression together have been shown to predict physical component of QOL in patients with

CKD (Seidel et al., 2014). On the other hand, a review has shown that vascular dysfunction,

physical dysfunction and cognitive impairment are important risk factors for being dependent

on somebody else, worse HRQOL, mortality and morbidity (Bronas et al., 2017). Cognitive

function (Kurella et al., 2004), physical and emotional health and HRQOL have been

observed to be negatively influenced in both CKD and kidney failure regardless of

management of the disease (Kittiskulnam et al., 2017). Bujang and collegues (2015) have

determined that those patients who had greater depression, stress and anxiety reported worse

QOL (especially, domains of physical and psychological health and social consequences)

than those who reported less psychological symptoms. Similarly, a study comparing mood

and somatic symptoms in the prediction of HRQOL established that mood was a more

powerful predictor of physical and mental domains of HRQOL in patients receiving HD who

had a range of physical symptoms (Perales Montilla et al., 2016). For example, depressive

symptoms have been associated with greater pain and poorer sleep (Weisbord, 2016).

The impact of mind on the body has led to lot of interest in factors that can help understand

and predict illness outcomes (Vitetta et al., 2005). There is emerging evidence on variation

among individuals in terms of how they cope with their condition (Schick-Makaroff et al.,

2018; Kalfoss et al., 2019). Therefore, research has focused on identifying factors that help

explain different responses. Illness perceptions have been one of the key areas in

understanding responses to and management of chronic conditions. According to the illness

perceptions framework, after diagnosis or onset of illness, patients develop a set of beliefs

that shape how they cope with their condition (Leventhal et al., 2003). There is number of

studies investigating how illness perceptions play a role as psychological associates of

important outcomes (Chilcot et al., 2018; Dempster et al., 2015). Hence identification of

illness perceptions may be a critical step in supporting patient adjustment. However, research

generally is biased to countries with more advanced health infrastructure.

1.7   Development of CKD Care and Management in Northern Cyprus

The kidney care infrastructure in Northern Cyprus is still developing. The first kidney biopsy was conducted in 2004. There was only one nephrologist working in Northern Cyprus (Turkish Republic of Northern Cyprus) while the southern part of Cyprus which is governed by the Republic of Cyprus had 9 to 10 nephrologists in 2011. There was little information about people with CKD especially those who were at the earlier stages. To gain detailed data about people who were at early stages of CKD, a community-based study needed to be conducted. Regulations/ laws regarding cells, tissues and organs in Northern Cyprus have been studied to adapt to EU laws in 2008 with a hope to provide kidney transplantation in the following years. The Nephrology Department in the State Hospital in Northern Cyprus used to refer living donors to transplantation centres in Turkey since there was no laboratory to check suitability of kidney donors in Northern Cyprus in 2011 (Haftanin potresi, 2011, January 31).

In 2014, there were only two centres where HD treatment have been provided in Nicosia (capital city) and Famagusta in Northern Cyprus. There were 25 HD machines in Nicosia and it provided 15,000 HD sessions annually. On the other hand, 7 HD machines in Famagusta provided 6,000 HD sessions annually. As patients from far villages and towns had difficulties to travel to these cities, authorities attempted to provide more HD centres in different cities (i.e., Kyrenia) (Uc bolgeye hemodiyaliz hizmeti saglanacak, 2014, March 12). However, difficulties in CKD management continued due to an insufficient number of specialist nephrologists. In 2015, there were 150 HD patients receiving HD in hospitals, 80-100 transplant patients and 30 patients who had dialysis treatment at home (KKTC'de nefrolog sorunu, 2015, July 3). Later in the same year, another HD centre has started to provide HD treatment in Kyrenia, a city in Northern Cyprus.

In 2016, with a collaboration of University College London (UCL) in UK, Dr Oygar, a local nephrologist conducted a clinical study to investigate the clinical characteristics of patients receiving HD since there were a high number of genetics related kidney complaints. As a result of the study (Gale et al., 2016), they defined new genetics related kidney disease in Northern Cyprus (Uzmanlar Kibris'ta yeni bir bobrek hastaligi tanimladi, 2016, November 29). They indicated a novel COL4A1 frameshift mutation in familial kidney disease by highlighting importance of the C-terminal NC1 domain of type IV collagen. This is important part of protein that is critical for normal functioning (Gale et al., 2016).

In 2017, another nephrologist joined the Nephrology Department of Dr Burhan Nalbantoglu Nicosia State Hospital. The local nephrologists have frequently conducted interviews in local media to increase awareness regarding CKD and its risk factors. During one of the interviews with local newspaper, they said that obesity, lack of exercise, and overuse of salt may be important factors for developing kidney disease in Northern Cyprus. They stated that 60-65 patients with KFRT receive HD per day only in Nicosia and 100-120 of these patients are on the waiting list for kidney transplantation. The importance of kidney transplantation particularly from non-living body was highlighted. The kidney transplantation may be more advantageous compared to dialysis treatment for both patients as well as healthcare services in terms of cost and QOL. The first kidney transplantation was carried out from father to son in November 2015 in Northern Cyprus. In total, 14 kidneys were transplanted, 8 kidneys were from non-living body and 6 of these were from live donors in 2017. Kidney transplantation processes can be completed legally in the State Hospital only. If a person would like to be a donor but is not relative of the patient, their application is strictly reviewed by an ethics committee of the Ministry of Health in Northern Cyprus. With a new regulation, people are now able to register themselves as organ donor so that their organs can be donated in case of death (Yuz yirmi diyaliz hastasi bobrek nakli bekliyor, 2017, May 31).

When patients are referred to the Nephrology Department, they receive short training about CKD. The department provides handbooks and brochures explaining kidney function, kidney disease, treatment options, and useful tips to manage their disease. These materials have been prepared by a Pre-dialysis Education Program study group with contribution of Eczacibasi (Eczacibasi Holding is a group of Turkish companies providing pharmaceutical products) and Baxter (international health care company providing products to treat many acute and chronic medical conditions including kidney disease) in Turkey.

Lack of established structure in healthcare has resulted in less focus on psychological care needs of patients in Northern Cyprus. The main focus of the research programme will be to contribute novel insights into how patients here experience life with CKD; how the patients structure their representation of illness; quantifying the need for psychological support through establishing prevalence of depression and other symptoms; gleaning staff perspectives on psychological care needs. The following chapter will now provide a background as to why illness perceptions in particular might be a useful focal area for this thesis which aims overall to raise awareness of and provide insights into the need for psychological care in the Turkish Cypriot CKD and KFRT population.

Chapter 2: A Review of the Common Sense Model of Illness Perceptions

2.1   Introduction

Kidney care is one of the healthcare areas that is under-developed in Northern Cyprus. Along with providing medical treatment for chronic kidney disease (CKD), local nephrology departments provide short patient training about CKD mainly focusing on kidney disease, treatment options, and required dietary changes. Lack of resources and structure in local healthcare has resulted in failure to meet the psychological support needs of patients. Particularly it has not yet known how patients respond to living with illness. CKD, and its care is burdensome, patients require support to adjust to illness. Nevertheless, it is known that culture plays an important role in how patients perceive and respond to health problems. The psychological approach to health aims to explore factors that are related to maintaining health and improving wellbeing. To achieve this, various methods are used to understand and predict health behaviours (Kaptein & Weinman, 2004). Exploration of illness perceptions has accelerated especially, after Leventhal's proposition of Common Sense Model (CSM) of self-regulation (Leventhal et al., 2003). CSM has been frequently studied to understand health behaviours, also in diverse patient populations from different cultural background. However, it is unclear how this model applies for Turkish Cypriot patients. This chapter will seek to discuss culture and health within the illness perceptions framework of CSM.

CKD has been shown as a global public health concern and its prevalence has been estimated at up to 15% (Hill et al., 2016). People diagnosed with CKD face difficulties including psychological and physical burdens. Recent research has focused on identifying illness perceptions in CKD as this may assist in developing strategies to enhance patients' well-

being. Literature highlight the utility of using both quantitative and qualitative methods while studying illness perceptions. The mixed methods approach is recommended particularly when studying different cultural groups as it can facilitate an understanding of how culture may influence illness beliefs and behavioural responses (Curry et al., 2009). This chapter presents an overview of:

1. Theoretical background of CSM of self-regulation

2. Illness perceptions

3. Cultural aspects of health and illness

4. Cultural influence on illness perceptions

5. Methodological rationale of the research programme

2.2   Theoretical Background of CSM of Self-Regulation

The development of CSM of self-regulation began with earlier model suggested by Leventhal and colleagues (Leventhal et al 1997). In other words, the CSM is an extended version of the originally proposed model. This model, known as *parallel response model* had two characteristics: 1) cognitive representation of health danger is processed independently from fear, 2) representation of health threat is different from the procedures (strategies) to engage in actions. Parallel response model was developed to explain the findings of fear induced communications in the context of health related responses. The model suggested that health threats produce emotional changes, both fear and distress. This leads to the need to develop corresponding procedures that will manage emotions (fear control) and cognitive representations of health threat (danger control). These are parallel actions that are evaluated later for their efficacy in reducing health threat (Cameron & Leventhal, 2003). According to the model, the most important positive effect was the intention to engage in a protective response. Yet intentions alone were not adequate to observe the action, therefore requirement

of an action plan was highlighted as necessary for a protective response to occur (as cited in Leventhal et al., 1997). It has been suggested that action helped to maintain protective responses for a long time in the presence of fear messages otherwise, action plans were considered insufficient to elicit behaviour even in the short term. The action plan developed strategies which transformed belief regarding health threats into action, yet it did not necessarily motivate the behaviour. It was indicated that it was not fear as its effect did not last long (as cited in Leventhal et al., 1997). However, fear was considered as person's concrete, perceptual experience and interpretation of this experience. Several research studies were conducted to assess the impact of perception of somatic changes on fear level and efficient self-management behaviours. Easterling and Leventhal (1989) studied cognitive labelling among women in relation to breast cancer. They found those who received treatment for breast cancer reported greater levels of cancer specific worry compared to those without history of cancer, although women did not differ in terms of daily anxiety symptoms. The authors concluded that experience of somatic symptoms may lead to cognitive label which may interfere with interpretation of bodily sensations. This finding was found to be parallel with Schachter and Singer's (1962) theory suggesting emotions are outputs of cognitive representation and physiological changes. Nevertheless, earlier studies of Leventhal and colleagues demonstrated that health threats were represented semantically (abstract) and perceptually (concrete experience) (Cameron & Leventhal, 2003). Accordingly, it has been suggested that the interaction of abstract and concrete levels of processing generates fear (Leventhal et al., 1997).

As early studies have not clearly defined the process, Leventhal and colleagues have labelled it as *cognitive representation of the disease*. This helped them to better explain and clarify the content assumed by the proposed construct (Leventhal et al., 1997). During this process, Leventhal and colleagues conducted a series of experimental studies to investigate the change

in emotional reaction and behavioural responses of individuals where a response was directed towards problem-solving in the context of preparation for a health threatening situation. Problem solving as a term is widely used where individuals engaged in behaviour that is informed, therefore the action is purposeful to determine aims, current states and adopting strategies to reach the desired outcome while overcoming any obstacles that may exit in the process (Cameron & Leventhal, 2003). Brownlee and colleagues (2000) defined problem solving as *the management of physical self and subjective feelings of the self*. Leventhal and colleagues concluded that mental representation of bodily health threats has perceptual dimensions that link individuals to situational factors. The information provided as part of preparation for health threatening situations aimed to reshape the perceptions from threatening to adaptive to increase efficient behavioural procedures. They also focused on self-reports that patients perceived somatic changes as representing their main condition (Leventhal et al., 1997). For instance, several studies were conducted to understand attributes of illness perceptions related to hypertension and results indicated both perceptual and conceptual attributes. Perceptual attributes have been demonstrated as playing a critical role in emotional responses (Leventhal et al., 1997). This showed that representations for both cognitive and affective attributions are bi-directional. For instance, an early study found an increase in negative emotion increased reporting of symptoms in patients with disease and also increased symptom severity (Salovey & Birnbaum, 1989).

 Throughout the studies, open-ended interviews that generated qualitative data along with quantitative approaches such as multidimensional scaling helped to clarify attributes of illness perceptions, such as, identity (labels), 2) timeline (duration), 3) consequences, 4) controllability, and 5) causes (as cited in Leventhal et al., 1997, Cameron & Leventhal, 2003). Bishop (1991) used a combination of qualitative data obtaining descriptions of symptoms and quantitative data to cluster the descriptions. When participants were asked

what else they experienced, 90% of the participants' responses could be clustered into one of

the five dimensions (i.e., identity, cause, control, consequences, timeline). Each dimension is

represented with both semantic (abstract) and perceptual or experiential (concrete)

information. Stimuli interpreted are assumed to convert into representations. These

representations are repeatedly shaped by output of procedures (strategies). The way

information is interpreted and made sense of represents what an individual uses as questions

to evaluate the process. Each component of self-regulation will be reshaped at different stages

(particular instances) and over time by the social environment. The CSM of self-regulation

therefore highlights the significance of cultural and social factors. Particularly, engagement in

social contexts becomes obvious when a person receives a diagnosis and make sense of their

symptoms (Cameron & Leventhal, 2003). For instance, a person engages in healthcare

seeking behaviour from primary care services for a diagnosis and treatment when bodily

changes are novel and/or lasts longer than expected (Mora et al., 2002). Similarly, individuals

might tend to consult their family members and close friends first and then seek medical

advice (Cameron et al., 1993; Suls et al., 1997).

Although the CSM of self-regulation offers a model to make sense of illness perceptions and

coping procedures, it is acknowledged that illness perceptions can overlap with perception of

self as a function of factors such as family history of disease. This can increase the perception

of personal vulnerability as genetics may be perceived as a fundamental factor in causal

perception of the disease. Similarly, research has shown age may influence the self-regulation

process as older individuals were found to delay healthcare seeking behaviour and to show

avoidant behaviours (Leventhal et al., 1997). Understanding the self and acknowledging its

relation to self-regulation process is critical. Self has been described as a broad concept that

includes sets of self-representations and identities that relate to procedures for obtaining the

goals specified. The integrity of self is challenged by the problem (i.e., disease), at the same

time, the regulation of some aspects of self (i.e., emotional and physical) becomes essential in case of diagnosis. Social cognition theorists have been attempting to clarify the associations between self-constructs (e.g., self-efficacy) and self-regulation (as cited in Cameron & Leventhal., 2003).

Personal characteristics and/tendencies have been also studied along with illness perceptions. Longitudinal assessments have been carried out to investigate associations between optimistic versus pessimistic attitudes and self-assessments of health (as cited in Leventhal et al., 1997). Those individuals with more optimistic attitudes rated their health more positively compared to individuals with pessimistic attitudes. Self-assessment of health even predicted mortality for those who had pessimistic attitudes after adjusting for age and medical status. Kuhl (2000) states that cognitive representations of behavioural responses are associated with personal meaning, which can channel behaviour.

2.3   Illness Perceptions

Many theories have been developed to understand health related beliefs (Ogden, 2000). Several models have integrated these theories/approaches to predict health related behaviours such as the Health Belief Model (Becker et al., 1974), the Protection Motivation Theory (Rogers, 1983) and the Theory of Planned Behaviour (Ajzen, 1991). On the other hand, Leventhal and colleagues (Leventhal et al., 1980) defined *illness beliefs* which provide a framework to explain how a patient understand and manages the illness. Leventhal and colleagues integrated illness beliefs into CSM of Self-Regulation (Figure 2.1) to describe the relationship between the patient's cognitive and emotional representation of their illness and their coping strategies. The proposed framework successfully describes illness behaviour as

the dynamic that focuses on both emotional and cognitive components in the context of

illness threat (Leventhal et al., 2003).
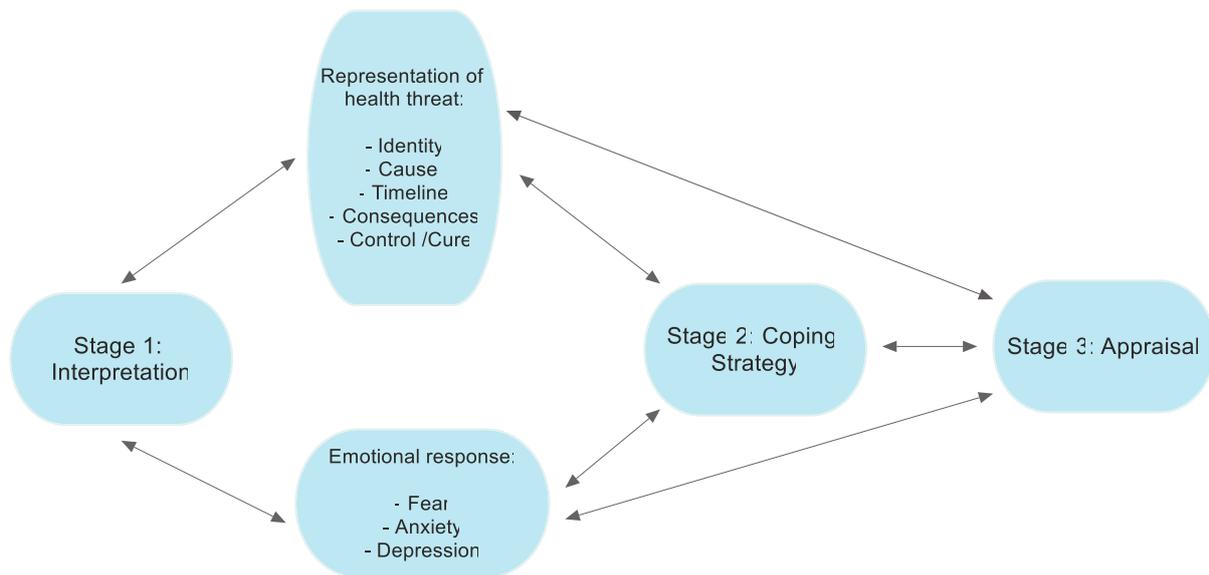
Figure 2.1: *Leventhal's Self-regulatory model*

Adapted from *Health Psychology, 5th ed.* (p. 221), by J. Ogden 2012, Open University Press. McGraw

Hill Education. Copyright 2012 by Jane Ogden.

People have mental representation about a given health threat. They develop beliefs regarding

their condition. These beliefs play a significant role in their coping behaviour and the way

they manage their illness. These illness beliefs can change, illness perceptions can also

change Leventhal et al., 1980). When people experience new symptoms or diagnoses, they

consider it as a health threat. The mental representation of the health threat determines a

person's response to their condition. The person's medical knowledge and past illness related

experiences, for instance, family member with a similar condition commonly have an impact

on the representation of health threat and illness perceptions people hold. They can actively

cope with the health threat according to illness beliefs they form. Therefore, illness

perceptions are a key concept of the CSM (Leventhal et al., 1980). The model suggests that

people cope with the health threat and/or illness in similar to the way they cope with other problems in life. According to the model, the person attempts to solve the problem to achieve the 'normality' (problem-free state) back again. In the context of health, the problem refers to a new symptom or diagnosis of an illness. People develop coping strategies to reach the 'normality' (problem-free state) through illness perceptions they hold (Leventhal, 1984).

In the context of the CSM of self-regulation, people experience problem-solving processes in three stages: interpretation, coping, and appraisal (Leventhal et al., 2003). In the first stage, interpretation, an individual may face the problem (i.e., illness) through symptom perception and/or social message. Symptom perception influences how the individual makes sense of the illness-related symptom/s. For example, an individual may indicate that they feel pain in the chest and their symptom perception may be influenced by mood and cognitions. Also, the individual may obtain information related to their illness through other people. The social message includes formal diagnosis through the doctor or advice of family members and friends based on their personal experiences. Informal information related to illness based on others' personal experiences is considered as 'lay referral system'. For example, the individual may ask for advice of a friend who had a similar cough. Social messages- the individual receives will likely affect the way they make sense of the problem (i.e., illness). The mental representation of the problem will affect the way of making sense of the problem and engaging in an appropriate coping strategy that is parallel with the illness perceptions (Leventhal, 1984).

The individual builds illness perceptions within five different dimensions (Leventhal, 1984). *Identity* of illness: individuals generally associate their illness condition with their symptoms and labels to identify the condition. When the individual is diagnosed with an illness, they may also start developing ideas about their symptoms. The identity component of the illness

perceptions is important since patients' beliefs related to symptoms of their illness can be very different than views of health care professionals who treat the illness. The patients can misattribute symptoms which may affect the treatment applied (Petrie & Weinman, 2006). *Causality*: newly diagnosed individuals start developing different causal beliefs about reasons for their illness such as stress and pollution. Causal beliefs can have an impact on the individual when seeking a treatment for the illness. For example, if a person believes that smoking is the reason of having a heart attack, they will be more likely to stop smoking. Also, causal beliefs can influence emotional response in some illness conditions especially when a person blames themselves for their condition (Petrie & Weinman, 2006). Causal beliefs are an important concept in research as well as treatment. *Timeline* represents predictive beliefs related to the duration of a condition. Most patients evaluate their condition as acute or chronic, however, some patients may perceive their conditions as cyclical (Petrie & Weinman, 2006). Beliefs related to timeline may influence several outcomes, for instance, patients who had a belief that their illness is chronic have shown a higher level of medication adherence (Aflakseir, 2012). *Control/cure*: beliefs about controllability include how a patient perceives their control over their condition (personal control) and to what extent they believe the treatment will control their illness (treatment control) (Petrie & Weinman, 2006). Controllability has been positively associated with more efficient coping strategies (Hagger & Orbell, 2003) which are critical in illness management. *Consequences*: Patients hold beliefs about the consequences of their illness representing how these may affect them physically and socially (Hale et al., 2007). Beliefs related to illness consequences also reflect how the patients perceive their illness in terms of severity (Petrie & Weinman, 2006). Those patients who had perceptions of serious consequences about their illness have shown more emotional distress, less social functioning and tendency to use avoidant coping strategies (Hagger & Orbell, 2003).

2.3.1 Measurement Tools

To determine the dimensions of illness perceptions, Leventhal and colleagues originally used semi-structured interviews (Leventhal et al., 2003). However, most studies have recently used quantitative illness perception measurement tools to investigate correlates of illness perceptions after the development of Illness Perception Questionnaire (IPQ) (Weinman et al., 1996), Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) and Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent et al., 2006).

Patients' perceptions and thoughts about their illnesses may be influenced from their culture, therefore ensuring validity and reliability of illness perception measurement tools in different clinical and cultural contexts is critical for its utility (Chen et al., 2008). Both IPQ-R and Brief IPQ have been established as valid and reliable measurement tools (Leysen et al., 2015). As the tools allow researchers to change the dimensions of illness causality and illness identity to represent a specific illness, cultural contexts or groups (Moss-Morris et al., 2002), many researchers have used this opportunity to conduct translation and adaptation studies. However, translation studies differ in terms of translation process and reporting psychometric characteristics of the translated version of the tool.

2.3.1.1 Revised Illness Perception Questionnaire (IPQ-R)

The Illness Perception Questionnaire (IPQ) was developed to measure cognitive representations of illness. It consists of five dimensions; identity, causality, timeline, consequences, and cure/control (Weinman et al., 1996). The IPQ has been revised by adding more items to assess illness coherence (understanding of illness), perceptions of cyclical timeline, and emotional representation. The original questionnaire was also improved by separating the cure/control scale into two subscales; treatment and personal control (Moss-

Morris et al., 2002). IPQ-R include over 80 items and it has 3 sections, 1) statements about illness symptoms and whether the specific symptoms are experienced (e.g., pain, breathlessness, sleep difficulties etc.) (Answers are limited to *yes/no*), 2) patient's views about the illness on 5 Likert type questions (Answers ranges from *strongly disagree* to *strongly agree*). This section mainly includes statements related to dimensions of *illness coherence, controllability (personal and treatment), timeline (chronicity/cyclical), consequences, emotional representations*. 3) Causality sections includes possible beliefs about the illness (e.g., stress, hereditary, diet etc.) (Answers ranges from *strongly disagree* to *strongly agree*). Additionally, there are 3 items where patients are asked to rank order the most important cause according to given choices.

IPQ-R is a multidimensional scale aiming to measure illness perceptions in the context of dimensions described above. The scale has demonstrated good psychometric characteristics (Moss-Morris et al., 2002). The authors reported test-retest reliability results over three weeks and six months period with acceptable values (ranging from .46 to .88). They provided evidence for discriminant validity showing the illness perceptions did not overlap with negative affect. Also, the scale had predictive validity for illness adjustment. Results of factorial analysis provided support for the illness perceptions' theoretical framework. As the scale is generic, Moss- Morris and colleagues stated the scale can be adapted according to a specific illness (i.e., by changing the symptoms in the first section according to a specific illness and/or by changing the causal beliefs according to culture) (Moss-Morris et al., 2002).

Although the translation process differs, to date, IPQ-R has been translated into 17 languages and adapted to several cultures including Chinese, Swedish, Slovenian, Italian. The scale has been redesigned to represent specific conditions such as hypertension, asthma, chronic fatigue syndrome (The Illness Perception Questionnaire, n.d.). There are studies translated

and adapted the scale into different languages (Arabic [Al-Smadi et al., 2017; Noureddine & Froelicher, 2013] and Danish [Jørgensen et al., 2009]), yet their versions are not available on the 'Illness Perceptions Questionnaire' website. It should be noted that most translation studies have used forward and backward translation with multiple professionals who have had relevant language skills. However, misinterpretation of the instructions and confusing translation have been criticised, therefore carefully wording of the items have been advised (Broadbent et al., 2011).

By using forward and backward translation, Armay and colleagues developed the Turkish version of IPQ-R for use in patients with cancer. They provided evidence for test-retest reliability for three weeks period. Also, findings showed support for criterion validity and structural validity (Armay et al., 2007). However, Brzoska and colleagues tested the factor structure of the Turkish version of IPQ-R in patients with cardiovascular disease and diabetes. In order to obtain a good model, they reported several modifications such as deleting some of the items due to low factor loadings (personal control, treatment control and timeline cyclical factor) and they suggested to reconsider the wording of some negative statements to increase semantic equivalence of the translated version (Brzoska et al., 2012).

2.3.1.2 Brief Illness Perception Questionnaire (Brief IPQ)

Questionnaires that include more items such as IPQ-R may be more comprehensive but may not be suited to certain situations, for instance, when target group is elderly and/or when patients have limited time available. Therefore, Broadbent and colleagues (2006) designed brief version of IPQ-R to be used in various patient populations. It has eight new items and one item (causality) taken from the IPQ-R. Answers of eight items are evaluated on a 0 to 10 response scale. Five of these items represent cognitive dimensions; consequences, timeline,

personal control, treatment control, and identity. Whilst two items represent emotional dimensions which are concern and emotions, and one item refers to illness coherence. The causality scale which is adapted from IPQ-R consists of an open-ended question asking to list three most important causes. Like the IPQ-R, the Brief IPQ is a generic tool, therefore Broadbent and colleagues have suggested to adapt the scale to specific diseases, in other words, the word 'illness' in the scale can be changed to a particular illness such as asthma, hypertension etc. Similarly, the word 'treatment' in the scale can be also changed to a specific treatment depending on the illness for instance, dialysis for renal patients (Broadbent et al., 2006).

The Brief IPQ was developed from IPQ-R rather than in-depth interviews. Single items on Brief IPQ are expected to obtain information related to a particular domain. These have been considered as limitations of the Brief IPQ (Van Oort et al., 2011) yet well-designed single item measures can be successfully used with lesser chances of method variance which is mostly an issue in multiple item measures in psychology (Gardner et al., 1998).

According to a systematic review study, most studies that have used the Brief IPQ did not include causal beliefs into their analysis as it is time consuming to interpret findings, whereas those who did include the causal item categorised the causal beliefs and reported the most common responses. Besides, only few studies reported association between causal beliefs and illness outcomes. Future studies are suggested to include the causal item into the analysis by categorising responses and to examine associations with demographic factors and/or illness outcomes, which may indicate validity of causality item (Broadbent et al., 2015).

When equivalent dimensions were analysed, the Brief IPQ showed a good level of relationship with IPQ-R (Broadbent et al., 2006). Findings also indicated support for test-

retest reliability, predictive and discriminant validity. The Brief IPQ specifically is a useful tool when illness perceptions should be measured in a short period repetitively. Also, it is less burden for those who may have difficulty in answering long questionnaires (Broadbent et al., 2015). As it is short and allows easily interpreting scores, the Brief IPQ has been commonly used in different contexts including heart failure (Timmermans et al., 2017), fibromyalgia (Homma et al., 2018), chronic kidney disease (CKD) (Jansen et al., 2013) and cancer (Karataş et al., 2017). Most studies that used the Brief IPQ were conducted in Western and European countries (Broadbent et al., 2015). However, the scale has been translated into 25 languages (e.g., Chinese, Dutch, Danish, Croatian, Norwegian) and adapted to various cultures (Broadbent et al., 2015). Additionally, the scale has been translated into Arabic (Alzubaidi et al., 2015; Mohammed et al., 2015), Turkish (Karatas et al., 2017) and Tai (The Illness Perception Questionnaire, n.d.). There are number of translation that studies have successfully used Brief IPQ, these studies however are variable in completeness of details as per the translations process of the scale. It is not clear whether translated versions are all semantically equivalent to the English version. Nevertheless, illness perceptions may differ according to language, illness, and culture, hence, studies translating and adapting Brief IPQ are suggested to provide validity related evidence (Broadbent et al., 2015).

Several studies translated Brief IPQ into Turkish (Karataş et al., 2017; Oflaz et al., 2014). Detailed information about the translation process and psychometric findings of the Turkish version of the scale were reported by Karataş and colleagues (2017). After the forward and backward translation process and a pilot study, the Turkish version of the scale was used with patients with cancer. The results of factor analysis demonstrated emotional representations involved consequences, illness identity, concern and emotions on the other hand, cognitive representations included personal control treatment control, and illness coherence. The authors modified personal control and illness coherence and removed the timeline from the

factor analysis since it overlapped on the loadings. Whilst they reported an acceptable value for internal consistency (.85). The reason for the Turkish version of the Brief IPQ showing a different factor structure than the English version may be related to the impact of culture as well as the illness characteristics (Karataş et al., 2017).

2.3.2   Illness Perceptions in CKD

Since the CSM of self-regulation has been developed, illness perceptions have been analysed in various illnesses including chronic, acute, mental and physical disorders. Research examining illness perceptions have focused on a specific illness context as perceptions may vary according to characteristics of a disease (Dempster et al., 2015). Regardless of illness type, illness perceptions of primary care patients and those who are living with long terms conditions have been widely examined. Negative illness perceptions have been linked with severe somatic symptoms (Zhang et al., 2014), psychological distress and poor quality of life (Wu et al., 2014) including physical and mental health outcomes (Frostholm et al., 2007). A wealth of literature has investigated the relationship between illness perceptions and emotional and behavioural consequences of illness (Petrie et al., 2007). Review studies have been helpful in clarifying broadly how illness perceptions are associated with several outcomes such as adherence (Kaptein et al., 2008; Kucukarslan, 2012), quality of life (Foxwell et al., 2013; Petrie et al., 2007) and psychological wellbeing (Richardson et al., 2016).

When diagnosed with CKD, some patients may have a chance to prepare themselves for dialysis and for the change in their lifestyle. There are two dialysis modalities, these are haemodialysis (HD) and peritoneal dialysis (PD). HD is predominantly performed at health centres while PD is mainly performed at home setting by patient (Yang et al., 2021).

Regardless of dialysis modality, the preparation period can positively affect the adaptation and coping process (Wu et al., 2015). On the other hand, some patients may have worries about their condition, and beliefs that they have little control over their conditions. Although early stage of pre-dialysis phase involves mostly taking medicines and following a diet, treatment is still an important aspect for pre-dialysis patients at the early stage of the illness (Jansen et al., 2010). Patients in the pre-dialysis phase have been shown to have lower perceptions of treatment control than dialysis patients despite dialysis patients having higher perceptions of illness consequences (Jansen et al., 2013). The patients' symptoms may be related to the way they view their illness (Rees et al., 2018). Therefore, interventions addressing illness cognitions in the early stage of illness may be effective (Jansen et al., 2010). However, illness perceptions (illness coherence, personal and treatment control) may also vary among dialysis patients (Jansen et al., 2013). This shows that their views are also changeable when they start receiving dialysis treatment.

Psychological distress has been shown as one of the important experiences in CKD which may be associated with illness perceptions (Griva et al., 2010). Patients receiving HD with depressive symptoms were found to have negative illness perceptions in the dimensions of illness identity, illness coherence and timeline, control/cure. Additionally, dimensions of illness coherence, consequences, and personal control were found to predict depression (Chilcot, et al., 2011a). Similarly, a prospective study has indicated negative perceptions of illness coherence, treatment control, consequences and cyclical timeline were related to greater depressive symptoms in patients receiving dialysis (Chilcot et al., 2013). In one study, the dimension of treatment control was even found to predict survival when controlling for depression level (Chilcot et al., 2011b).

An individual's ethnicity can potentially influence their interpretation of symptoms and as a result, it can affect illness perceptions (Kim et al., 2012). Cultural groups have been found to report negative illness perceptions therefore, they may be more likely to have difficulties in management of their illness (Lip et al., 2004). A study examining illness perceptions in diabetes patients has demonstrated that illness perceptions differed among Europeans, South Asians and Pacific Islanders (Bean et al., 2007). For instance, patients from a Pacific Islander background reported greater identity and consequences perceptions than other ethnic groups, and European patients reported longer timeline perceptions compared to other ethnic groups. However, kidney failure related illness perceptions of patients from cultural and ethnic groups are poorly studied (Calvin et al., 2019). Patients from different cultural backgrounds receiving HD treatment have been found to have different illness perceptions. For instance, Korean patients were found to have greater emotional distress, whereas, patients from African American background were found to have higher negative perceptions of personal intervention or medical treatment (Kim et al., 2012). Future research on illness perceptions in kidney failure have been recommended to include diverse cultural groups including Caucasians (Kim et al., 2012).

Generalisation of the findings to different populations related to illness perceptions and experiences requires replication studies in different societies. Research on illness perceptions in diverse cultural groups can also be informative for health care systems to identify culture-specific illness perceptions of immigrants in other majority countries (Brzoska et al., 2012). Overall, there is need for further research to consider illness perceptions in cultural/ ethnic groups and validate their results in specific patient groups (Noureddine & Froelicher, 2013). It should be noted that research on illness perceptions started with in-depth interviews in White majority populations. Therefore, in-depth interviews on illness perceptions in other

populations have been recommended to better conceptualise the patient experiences in cultural/ethnic groups (Alzubaidi et al., 2015).

2.4 Cultural Aspects of Health and Illness

Culture has been defined various ways in the literature. Although there may be some differences in defining culture, it has been agreed that culture involves shared and/or learned experience by group of people (Birukou et al., 2013). It mainly consists of socially transmitted knowledge, belief, habits, morals, behaviour and patterned feeling, ways of thinking that are characteristics of members a particular society (Bailey & Peoples, 1998; Harris, 1975). As culture consists of learned experiences, it may change over time. Research on cultural evolution have highlighted transmission via human interaction and social learning (Bentley & O'Brien, 2011). This has been suggested as basis for cultural complexity and variation (Boyd & Richerson, 2005; Hrdy, 2009). People continue to acquire knowledge and learn from others, and also improve what they have learnt and transfer these things to the next generation, which will be improved again and will be transferred again. This leads to rapid cultural evolution over time, which is the process that explains adjustments to a particular environment (Boyd & Richerson, 2005). The degree of how fast this change occurs has been suggested to be related to selectivity in social learning along with the impact of cultural/technological complexity (Bentley & O'Brien, 2011). Therefore, culture is not considered as static. According to anthropologists, culture consists of multiple variables influencing aspects of life experience, these include economic, religious, political, psychological, and physical circumstances (Kleinman & Benson, 2006). Culture is seen as a process in which regular activities and conditions involve emotional reaction and moral meaning for members of a particular group. Within the cultural context, the members make sense of psychophysiological responses (Moerman, 2002), interpersonal relationships (Dion

& Dion, 1993), religious practices (Peña, & Frehill, 1998), common-sense interpretations
(Zou et al., 2009), individual and collective identity (Hong et al., 2001).

Psychological science enables researchers to study various topics by using diverse
measurements and methods to study populations, contexts, and events (Nápoles & Chadiha,
2011). The diversity of study populations is critical in the research to ensure that the
processes examined apply equally to diverse groups (Medin, 2017). However, psychological
research has heavily focused on study samples from Western, educated, industrialised, rich
and democratic (WEIRD) societies, yet WEIRD samples do not perfectly represent most of
the populations in the world (Henrich et al., 2010). Participants recruited from 'WEIRD'
cultures have been widely accepted to be norm (Nielsen et al., 2017). Researchers may
implicitly think that these samples are 'standard' to be representative, however, it is wise to
question to what extent findings obtained from these samples can be generalised to other
societies (Henrich et al., 2010). Rad and colleagues have suggested that psychological
science should aim to clarify aspects of human behaviour that are universal and how the
culture and context leads to variations (Rad et al., 2018). Researchers should feel encouraged
to reconsider the importance of culture and context in every stage of the research process
including data collection, analysis and presentation of the findings. Although criticisms have
been raised repeatedly, there is little evidence on experiences of diverse samples. It has been
stated that 96% of the samples in psychological research came from countries representing
only 12% of the population across globe (Nielsen et al., 2017). However, there are
implications of using WEIRD samples for instance, interventions designed and policy
developments will be less likely to address non-WEIRD societies (Nielsen et al., 2017). In
the context of health, for instance, much research on treatment burden has been conducted in
Western societies. It is known that illness and health can be understood and experienced

diversely in different geographical locations. Therefore, it is necessary to test the validity of the measures developed in Western societies in patient populations from different cultural backgrounds (Sav et al., 2017).

Literature provides evidence on cultural differences and culture related beliefs in the context of health. Health beliefs and behaviours are affected from (normative) cultural values that relate to personal experiences, attitudes, cognitions to specific cultural context (Baumann, 2003). It is well-acknowledged that illness experience cannot be studied in the absence of important aspects such as social, cultural and personality perspectives (Brown, 1995; Engebretson, 2003; Smith & MacKenzie, 2006). Illness experience is subjective therefore understanding culture and its role on self and perception are crucial. As mental representations of illness tend to be rich and complex in terms of content that is shaped by culture, these perceptions may be difficult to understand for those who are not familiar with a particular culture (Hagey, 1984). Cultural context has been shown to greatly influence many aspects of our lives such as beliefs, attitudes, actions related to illness which have implications on health status. This makes it essential to examine critical elements of cultures that shape normative behaviour that shapes how a person thinks and acts in a particular context (Helman, 1990). To obtain insight in order to improve healthcare services appropriately for cultural groups, information can be collected through individual interviews and scales measurements which elicits information on patterns and normative behaviours (Bates et al., 1997).

Cultures differ in causal attributions about health and well-being; these attributions may provide sources for sense making about illness along with features of individual experiences that vary. For instance, individuals from Western cultures were shown to report symptoms

with duration, severity and frequency. Also, they were found to focus more on internal attributes that may contribute to development of the symptoms (as cited in Baumann, 2003). A study conducted among Turkish and German patients indicated that Turkish patients had more pessimistic attitude regarding their illness compared to German patients who tended to attribute their illness to external factors (Franz et al., 2007). Similarly, another study concluded that Turkish patients (first and second generations) more frequently attributed their illness to external factors (e.g., fate, God's will) and they had less personal control over their treatment compared to German patients (as cited in Kizilhan, 2012). Besides, Turkish patients who were more likely to "minimize" their illness were unable to cope with illness related difficulties compared to German patients who rather managed to "mentally digest" and did recognise and appreciate information about their illness. (Özelsel, 1994).

With the impact of cultural beliefs, understanding and interpreting health related experiences may not differ only among patients but also among healthcare professionals. A study conducted between healthcare professionals in Puerto Rico and New England indicated that Puerto Ricans found pain expression of patients appropriate therefore Puerto Ricans perceived pain expression seriously and they believed that patients had severe pain that required treatment. However, healthcare professionals in New England perceived pain complaints of patients as "overly emotional" which mostly did not lead to consideration for treatment (Bates at el., 1997). Cultural values are playing a critical role in behavioural responses, and this makes it significant to consider cultural beliefs to develop efficient healthcare provision (Leininger, 1995).

In some cultural groups, health is viewed as both personal responsibility which can be managed by individual's actions and something that God defines for people. These interpretations might be also observed while patients attribute their illness to stress and

everyday life obstacles (Papadopoulos, 1999). On the other hand, beliefs related to God's willing and/or fate have been negatively associated with sense of control in patients with cancer (Iskandarsyah et al., 2014). However, those patients who believed their illness was 'God's will' reported more perceived recovery while those who perceived bodily weakness as cause of their illness had more difficulty in terms of psychological recovery (Kohli & Dalal, 1998).

Expression of bodily symptoms (somatisation) has been suggested to be related to availability of particular healthcare services. For instance, availability of psychiatric services for only patients whose conditions are severe might make people stress bodily symptoms to visit healthcare professional, this facilitates receiving attention for their problem (Kawanishi, 1992). Beiser and Flemming (1986) stated that South Asians were more likely to emphasise somatic symptoms rather than depression symptoms which led them to consult healthcare professionals due to bodily symptoms. They suggested that most South Asians with clinical depression concurrently experienced bodily symptoms. Cross-cultural studies indicate that some cultural groups may be more likely to use healthcare services for somatic symptoms rather than emotional distress (Ryder et al., 2008; Simon et al., 1999; Yen et al., 2000). For instance, Vietnamese men were found to have more somatic complaints that healthcare professionals found it difficult to explain. Emotional distress has been suggested to highly associate with somatic symptoms, particularly those that are mostly unexplained in ethnic and cultural groups (Kirmayer et al., 1998).

Cultures vary in terms of distinguishing physical and nonphysical sides of the self (Angel & Williams, 2000). Views and perspectives on illness observed in different cultural contexts (e.g., egocentric and sociocentric) differ as members of cultural groups make sense of their illness, and treatment differently (Baumann, 2003). Cross-cultural researchers have suggested

that health beliefs differ between egocentric cultures and sociocentric cultures. Western societies (e.g., Europeans, North Americans) value more biomedical explanations of illness highlighting mind-body dualism (Duncan, 2000). On the other hand, sociocentric cultures hold slightly different meanings regarding mind-body, medical, spiritual, religious, social and emotional aspects (Landrine & Klonoff, 2001). Differentiating mind from the body is commonly observed in Western societies. In other words, Western individuals are likely to distinguish mind and body when they talk about their symptoms. For instance, they may indicate that they feel "stressed" or "depressed" and attribute nonphysical factors to their feelings. Whilst individuals from different cultures do not clearly distinguish physical and emotional symptoms (Kleinman et al., 1985). Physiological processes of illness development are greatly emphasised in those cultures that distinguish individuals from their social environments (Landrine & Klonoff, 2001). Physical difficulties have been greatly associated with emotional responses, at the same time, emotional distress can be expressed in the form of physical symptoms. Overall, cultural factors, emotional responses and self-perception are indisputable part of the subjective experience that should be further studied (Angel & Williams, 2000).

Cultural differences also play a role in access to healthcare. These differences attributed to factors related to causal beliefs, nature of symptoms, curability and trust towards healthcare professionals (Uskul, 2010). Group differences have been frequently attributed to cultural characteristics. This is common as culture is a broad term including rules, structures, traditions and values in a given society (Shweder & LeVine, 1984). However, when the term, culture, is used broadly, it lacks specific contents and concepts to clarify how culture determines a person's perception of health and illness in a given context (Uskul, 2010). When studying subjective illness experience, the use of established theories of culture has been suggested to have more potential to explain the cultural influence of health and illness related

perceptions and actions. Individualism-collectivism framework is commonly used in cultural studies (Uskul, 2010). For instance, Western societies (e.g., United Kingdom, United States) have been represented with individualistic culture where self is greatly dominant and self is considered to be independent aiming to achieve personal autonomy (Oyserman et al., 2002). Whereas Eastern cultures (East Asian societies) are greatly represented with collectivism where self is considered to be interdependent and defined through social relations within a particular social context (Markus & Kitayama, 1991). For instance, a cross-cultural study comparing people from Asian, European American, and Asian American cultural background indicated that individuals differed in terms of using social support (Kim et al., 2008). This may be one of the important tendencies that should be considered when individuals attempt to make sense of physical symptoms through social environment as it may help to interpret somatic symptoms (Kirmayer & Young, 1998). Individual with Asian origin have been shown to be less likely to seek social support (e.g., explicitly sharing stressful event) compared to European American, however, they received the benefit of implicit social support where they were emotionally comforted without explicitly sharing the cause of stressful event (Uskul, 2010).

Spirituality, family relations, physical and mental well-being have been shown as interrelated aspects to health among Maori individuals in New Zealand, hence, problems in one of these aspects may be attributed as a cause of an illness (Durie, 1994). Early studies conducted in most rural Turkish populations indicated that this group was greatly influenced from cultural beliefs and used religious practices for healing in the context of psychiatric disorders (Ozturk & Volcan, 1971). For instance, beliefs related to "God's will" and "evil eye" which have been frequently associated with psychological and physical difficulties and personal failures (Ozturk & Goksel, 1964). Similarly, a qualitative study conducted among Greek Cypriots living in the UK demonstrated religious related attributions, participants used cultural

discourse while sharing experiences, for instance, *marazi* represents depressive symptoms and sadness that harms a person physically or mentally. They also made reference to the importance of social relations as lack of social relations might be linked to stress and worsened health status (Papadopoulos, 1999). Taken together this evidences aspects of culturally determined attributions for health and well-being, as well as sharing some similarity to other cultures where social relations are important.

Individuals from collectivist cultures may be more likely to be influenced by spiritual and philosophical orientations of the culture that determine social relations with others and the physical environment (Vitell et al., 2016). Therefore, they would have a more holistic view in making sense of illness experiences rather than greatly focusing on the physiological process of illness development which might be more likely to be observed in individualistic cultures (Uskul, 2010). Collectivism emphasises social responsibility, achievement, and desire to fulfil social obligations in the context of interpretation of illness. A study examining past illness experiences indicated that individuals who saw themselves as relational (collective) were more worried about social outcomes of illness, their concerns included being a burden to someone else and being unable to fulfil social responsibilities (unable to work) (Uskul & Hynie, 2007).

Cultural differences in the perception of self and world will be reflected on health and illness experience (Uskul, 2010). For instance, those from individualistic cultures may be more likely to emphasise the physical body as it can be considered as a goal within an individualistic culture, on the other hand, in collectivistic cultures, a healthy body is more likely to be considered as a resources that helps one to fit into social (collectivistic) context (Uskul & Hynie, 2007). Causal beliefs related to illness may vary depending on features of

cultural values. Particularly, it has been suggested that most frequent causes reported tend to be different between cultural groups (Uskul, 2010).

2.5   Cultural Influence on Illness Perceptions

Several models have been used to understand illness behaviours, for instance, explanatory models have been used to gain deeper understanding of illness beliefs and behavioural responses (Baumann, 2003). Explanatory models have investigated cultural factors as related to health beliefs (i.e., illness narrative) by examining how a person makes sense of somatic, social and psychological experiences within a given cultural context (Kleinman et al., 1985). For instance, explanatory models of diabetes among individuals from Latino backgrounds demonstrated that the individuals reported economic and family problems as causal attributions for diabetes (Poss & Jezewski, 2002). It has been suggested that family relationships are important that can serve as buffer to cope with stressful life events from the perspective of individuals from Latino background (Luyas, 1991). On the other hand, studies informed by self-regulation theory have used quantitative methods to categorise illness perceptions (Meyers et al., 1985; Weinman et al., 1996). This approach is helpful to identify predictive associations between illness beliefs and actions.

Acknowledgment of cultural influences on health and illness helps to better understand self-regulation process (Baumann, 2003). The self-regulation process includes both personal and collective experience (Vohs & Baumeister, 2004). In order to clarify illness experience and factors that shape this experience, it is critical to understand how an individual views the world. Individuals who are actively involved in problem solving attempt to interpret and make sense of bodily changes. This makes it clear that cultural values are also involved in and play a role in self-regulation process. Individual's mental representation and experience

of illness is influenced by cultural values as processing information (e.g., diagnosis) is determined by both the internal and external environment (Baumann, 2003). A person attempts to identify and make sense of somatic experiences in different ways such as by categorising to determine implications. This categorisation may be affected by previous personal experience, and/or through seeking healthcare advice. Cultural values are critical in this process, and it helps to clarify the interpretation based on normative beliefs (Baumann, 2003).

The critical role of culture should be studied in a particular context to unearth beliefs and behaviours that are related to a specific social context (Helman, 1990). It is important to define culturally shaped schemas that can explain illness discourses and labels. Cultural values are observed in schemas and shape individuals' interpretation of symptoms and feelings and behavioural responses. With its impact on individuals' schemas, cultural values and beliefs determine how an individual interprets healthy or ill, acceptable or deviant, and normal or abnormal (Angel & Williams, 2000). Defining illness perceptions and related behaviours as pure product of cognitive schema would not be accurate. Instead, culturally defined cognitive aspects of illness experience would allow better sense-making of health behaviours, at the same time, they can potentially elicit emotions such as distress, or anxiety. Hence, emotional symptoms regarding illness experience may be clarified when it is considered in parallel with the cognitive aspect. This is due to fact that what a person feels as emotion such as fear, is likely to depend on what is determined as threatening by cultural factors (Angel & Williams, 2000). The socio-cultural environment plays a role in perception of health and illness by guiding how a person will feel and react in the case of physical changes. Therefore, it would not be wrong to assume that subjective illness experiences may be shaped by the socio-cultural environment.

Leventhal and colleagues advanced that Common Sense Model (CSM) of self-regulation
(Leventhal, 1984), more specifically, perception of disease as interpersonal as well as an
intrapersonal process. Personal, cultural, and social, factors are assumed to have an impact on
the components of illness perception. Moreover, contextual factors are also involved in
sources that may affect problem solving processes which are critical for disease management.
Nevertheless, contextual factors are not necessarily influencing illness outcomes directly.
Overall, Leventhal and colleagues highlighted the importance of contextual variables in
understanding illness perceptions. For instance, cultural and social aspects of health
behaviours indirectly influence changes in illness perceptions and responses (Leventhal et al.,
1997). For instance, research examined illness and treatment perceptions and found that
social pressures may reinforce specific perceptions of health threat and particular coping
procedures (strategies) for disease management (Leventhal et al., 1997).

Domains of illness perceptions that form the CSM of self-regulation seem universal across
different societies despite cultural factors shaping characteristics of the domains of illness
perceptions (i.e., identity, duration, consequences, timeline, controllability) (Baumann, 2003).
Similar cultures may share aspects of illness perceptions in a particular context. For instance,
Latino cultures that share language including Latin America and Caribbean populations tend
to share similar illness perceptions (Baumann, 2003). Moreover, it has been suggested that
somatisation of emotional distress is commonly observed in some cultural groups where
psychological concepts are not well-developed (Mechanic, 1995). These cultures tend to
attribute somatic experience of emotional distress to illness as they are less likely to
emphasise conditions related to emotional distress (Al Busaidi, 2010). Nevertheless, cultural
values can determine concepts related to emotional representations of illness and this may

modify symptom experience, procedures adopted and other aspects of self-regulation process (Baumann, 2003).

Self-regulation models are frequently criticised for representing mental processing within individuals and ignoring the contextual factors that may influence the process itself (Ogden, 1995). However, self-regulation models that highlight both perceptual and conceptual components of the process also consider how individuals relate to their environment (Leventhal et al. 1997). There are several models aiming to predict health behaviour such as Health Belief Model (Becker, 1974), Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the Theory of Planned Behaviour (Ajzen, 1991). These models generally consider a person who makes informed decision by evaluating pros and cons in relation to the utility of behaviour. These processes can be considered as initial phases in self-regulation where a person sets behavioural goals, yet these models do not allow including emotional processes-they fail to consider that self-regulation is dynamic process that may reshaped overtime (Leventhal et al., 2016). This distinguishes the CSM of self-regulation from other models and makes it useful while studying health behaviours (Cameron & Leventhal, 2003). Characteristics of health threat and resources present in the social and cultural aspects determine coping procedures (strategies) that adopted. In the CSM, self-regulation is both a definition of the process that shows what the content is and what is being regulated. This characteristic differentiates the CSM of self-regulation from other approaches used to study health behaviours such as Health Belief Model (Cameron & Leventhal, 2003).

Social and cultural influences on self-regulation have been well-recognised in the CSM (Brownlee et al., 2000; Cameron & Leventhal, 2003; Leventhal et al., 1998). It is acknowledged that social and cultural determinants are involved in individuals' health and

illness perceptions. Leventhal and colleagues and assumed greater cross-cultural similarity in attributes among Western societies yet they have suggested that cultural differences affecting variance in domains of CSM is likely (Leventhal et al., 1997). Leventhal and colleagues highlighted two ways to illustrate socio-cultural impact in illness perceptions. Firstly, they have indicated that culture is a resource to provide linguistic material to categorise illness related events, secondly, they have stated that social relations can affect the interpretation of information regarding somatic experience and adoption of particular procedures (coping strategies) for illness management. It has been suggested that other individuals can play a role in establishing the five dimensions of illness perceptions. Hence multiple resources including family, healthcare professionals and peers can shape an individual's illness perceptions. This provides a deeper insight into the self-regulation process (Leventhal et al., 2003).

Perceived relations with others such as connection, have been associated with symptom expression and the emotional representations that are elicited by symptoms (consequences). Cross-cultural studies not only indicate differences in causal beliefs related to illness but also demonstrate variance in beliefs related to illness consequences. Causal beliefs observed in Western societies seem to be more related to the physical world while in collectivistic contexts, metaphysical and connectedness with others appear to gain more importance in relation to causality (Uskul & Hynie, 2007). Leventhal and colleagues defined self-regulation of health and illness in terms of its own dynamic context where management of illness can be considered as shared work that includes loved ones and family members. They clearly suggested illness related behaviours and attitudes are better explained within its socio-cultural context as social aspect of the illness experience cannot be underestimated. Receiving information, sharing thoughts about diagnosis and treatment and even emotion regulation includes others in the process of self-regulation (Leventhal et al., 2003). It is recognised that

socio-cultural factors can determine illness beliefs, attitudes and actions which are important components of self-regulation model of health and illness (Leventhal et al., 1984).

Most models studying health and illness are developed and tested in Western societies that represented mainly the individualistic framework. This case raises questions on generalisability of the models to societies that likely are collectivists. Therefore, testing established models in a variety of cultures by emphasising socio-cultural factors is encouraged to gain a clear picture of the nature of and interrelations between illness perceptions, behaviours, and cultural beliefs (Uskul, 2010). Examining illness perceptions within individualism-collectivism framework, one could expect to observe how illness beliefs may be shaped by individualistic or collectivistic cultural characteristics of a particular socio-cultural context.

2.6   Methodological Rationale of the Research Programme

It is known that cultural values may shape illness beliefs which have been closely associated with illness experience. Illness perceptions of Turkish Cypriots patients with kidney failure have not yet been studied. Given the recommendations of previous research and the fact that the target patient population is an under-represented cultural group, this programme of research will adopt a mixed-methods approach including qualitative interviews to gain an in-depth understanding, and a quantitative measure to observe the potential change of illness perceptions and outcomes over-time.

Mixed-methods research utilises strengths of both quantitative and qualitative methods. This combination can facilitate obtaining a complete understanding about an issue or events rather than using either quantitative or qualitative approach to understand one aspect of the problem

(Creswell, 2015). It is crucial to think about the philosophical assumption that will be associated with mixed-methods research as it is not only informs procedures but is also influenced by the research problem and researchers' perspectives. Critical realism has been used in some mixed-methods research as it is one of the standpoints that allow researchers to integrate different data sources and interpret the findings. Generalising findings is not a priority for critical realist perspective, instead it highlights the importance of events in a particular context. Critical realist researchers can also use theoretical frameworks however, they still believe that they can only partially know about reality which emphasises the recognition of others' perspectives (Shannon-Baker, 2016). Critical realist standpoint will be used for this research program as it offers to understand experiences of the research population and identify and explain the association between variables within the socio-cultural context.

Taking critical realist perspective informed by Leventhal's (1984) illness perception framework of CSM of self-regulation, this programme of research aims to integrate qualitative and quantitative data to understand experiences of Turkish Cypriot patients receiving HD treatment. As there is no evidence available about this population, conducting qualitative study firstly will provide insight about how this patient group experience kidney failure. Additionally, the qualitative study will indicate to what extent questions related to illness beliefs framed by the quantitative measure of illness perceptions are clear for the patient group. This is important as it will guide further steps of this research programme.

Mixed-methods research can be conducted with a longitudinal methodology. A methodological review study reported the types of longitudinal mixed-methods research and their procedures (Plano Clark et al., 2015). The review suggested that a variety of forms have

been used to conduct longitudinal mixed-methods research and there are differences in terms of implementing studies and interpreting the findings. Plano Clark and colleagues (2015) did not offer a typology of logical longitudinal mixed methods designs. However, according to the terms they used, this programme of research aims to use procedures of prospective longitudinal (exploratory sequential) mixed-methods design. The qualitative study in a single time point will inform the follow-up quantitative measure that will be collected at three different time points (Figure 2.2). Illness perception researchers particularly those studying patients with CKD have suggested to utilise longitudinal methodology as it can increase our understanding about change in perceptions and associated illness outcomes.

1st phase
- A qualitative study with patient group
- Data collection and analysis (theme development)

2nd phase
- Using qualitative data analysis to identify variables to measure (based on the themes)
- Identifying specific quantitative research questions

3rd phase
- Applying quantitative measures to the patient group
  - Data collection at Time 1, Time 2 and Time 3
  - Quantitative data analysis
- Qualitative systematic review (in parallel with the quantitative study)
- A qualitative study with healthcare professionals (in parallel with the quantitative study)
  - Data collection and analysis

Figure 2.2: *Prospective Longitudinal (Exploratory Sequential) Mixed-Methods Design of the Research Programme*

In summary, by using the illness perception framework as a lens, this research programme intents to understand the experiences of Turkish Cypriot patients receiving HD. An exploratory sequential mixed methods design will be used. This involves collecting qualitative data first to achieve an in-depth understanding, which will help to identify variables for the quantitative measures. After identifying the variables and quantitative research questions, the quantitative measures will be implemented longitudinally at three different time points. This will help to describe illness perception trajectories of the patients. At the same time, qualitative systematic review will be conducted to understand illness perceptions of patients receiving dialysis, the findings of this review can be compared with findings of first qualitative study. This discussion may reveal whether the target patient group experiences are similar to experiences of other dialysis patients in different settings. Additionally, another qualitative study will be conducted in parallel with the longitudinal quantitative study. This qualitative study will aim to understand perspectives of healthcare professionals in relation to patient experience. The following chapter will give overview of methods adopted to meet aims of the research programme.

Chapter 3: General Methods

3.1   Introduction

The aim of this chapter is to provide a general overview of the methodological approaches used in this research programme. The programme of work includes several studies designed to explore the experiences of Turkish Cypriot patients receiving haemodialysis (HD) including how this is shaped by illness perceptions.

Mixed-methods research is suitable approach to reach informative, complete, and comprehensive findings (Johnson et al., 2007). Mixed-methods approach has been widely described as research which mixes quantitative and qualitative methods to collect and analyse the data in a single or series of studies. Main assumption of the mixed-methods research is that it allows answering some research questions in elaborative way compared to a single method research (either quantitative or qualitative method). Researchers may use mixed-methods for several aims such as validating findings, generating data, and to increase understanding with the complementary approach (Creswell & Plano Clark, 2018; Dures et al., 2011).

As both qualitative and quantitative methods have strengths and weaknesses, combining both methods can be helpful to address complicated multi-dimensional events such as long-term conditions (Nicca et al., 2012). Integrating quantitative and qualitative methods facilitates to adopt holistic approach in data collection and analysis which in turn helps to generate conceptual framework, to corroborate quantitative results by relating the information obtained from qualitative study (Onwuegbuzie & Leech, 2004). In a good mixed-methods research, limitations of different methods should not overlap while their strengths should be

complementary (Curry et al., 2009; Johnson & Turner, 2003). By integrating different types

of data, researchers can enhance their understating about complex health issues.

A mixed-methods programme was selected to balance mapping of patterns with in-depth

inquiry (Doyle et al., 2016; Tariq & Woodman, 2013). The thesis includes the following

studies:

- Illness perceptions of Turkish Cypriot patients receiving haemodialysis treatment: a
  qualitative study (Study 1)

- Illness perceptions of patients receiving dialysis for the treatment of kidney failure:
  systematic review of qualitative studies (Study 2)

- Trajectories of illness perceptions in patients with kidney failure being treated by
  haemodialysis or peritoneal dialysis (Study 3)

- Perspectives of Healthcare professionals in North Cyprus on psychosocial care needs
  of patients receiving dialysis (Study 4)

This research programme adopted a mixed-methods approach that used an exploratory

sequential design with longitudinal methodology. As the patient group has not been studied

earlier, designing a qualitative study at the first phase helped gain an in-depth understanding

of patient experience. Patients receiving dialysis tend to report various challenges due to

treatment burden (Sav et al., 2017; Song et al., 2019). A systematic review was included in

the research programme to understand to what extent the patient group reported similar

experiences to patients receiving HD in different regions. Additionally, a prospective

longitudinal study was designed to observe changes in illness perceptions and associated

illness outcomes overtime. Variables to measure were identified by analysis of the qualitative

study at the first phase. In parallel to the longitudinal study, another qualitative study was

designed to understand the views of healthcare professionals on patient experience. The aim of involving healthcare professionals was to further the applied use of the findings.

3.2   Sample

All participants recruited were Turkish Cypriots who live in Northern Cyprus. Turkish Cypriots can be considered as a minority ethnic group underrepresented in health research. Several cultural/ethnic groups have been living in Cyprus. Greek Cypriots and Turkish Cypriots have been majority groups, respectively. Although Cypriot culture has been influenced by Turkish and Greek cultures from mainland Turkey and Greece, respectively, Cypriot culture is different. Religious practices may differ, however, Greek Cypriots identify themselves as Orthodox Christian, whereas Turkish Cypriots identify themselves as Muslim. Although Greek and Turkish Cypriots share many socio-cultural characteristics, spoken languages and adopted faiths are different in these communities. Turkish Cypriots speak Turkish with Cypriot dialect whereas, Greek Cypriots speak Greek with Cypriot dialect. After the announcement of the independent Republic of Cyprus in 1960, conflicts between two groups emerged, leading to division. Unfortunately, Cyprus is currently a divided country. Greek Cypriots mainly live in Southern, which the Republic of Cyprus governs, and Turkish Cypriots mainly live in Northern Cyprus, governed by the Turkish Republic of Northern Cyprus (Arbuckle, 2008) (Figure 3.1).

Figure 3.1: *Map of Cyprus*

Retrieved from "List of cities, towns and villages in Cyprus" (2022)

Cypriot culture has been considered as collectivist, however, research has suggested that

Turkish Cypriot culture is associated more of a vertical collectivist compared to Greek

Cypriot culture (Zorba, 2015). Individuals with collectivist cultures tend to prefer

interdependent relationships and consider group goals prior to one's own goals. Cultures

associated with vertical collectivist particularly tend to emphasise hierarchy by complying

with authorities and increasing group cohesion (Shavitt et al., 2011).

3.2.1   Patient Group

The target population of this research programme was patients receiving HD treatment in

Northern Cyprus. To date, this patient group has not been studied. Also, the experiences of

Turkish patients receiving HD have been poorly studied in Turkey, with only limited research

from this area. Consistent with the literature, available research indicates that Turkish patients

receiving HD experience emotional distress (Tezel et al., 2011). Limited research has

investigated illness perceptions of Turkish patients receiving HD treatment (Karabulutlu &

Okanlı, 2011). However, illness outcomes in kidney failure have been generally investigated by using illness perception framework, particularly in Western societies (Griva et al., 2009; Kim & Evangelista, 2010; Pagels et al., 2015). Nevertheless, evidence shows illness perception framework have been used cross-culturally and domains appear to be stable across different groups (Hajmohammadi & Shirazi, 2017; Seyyedrasooli et al., 2013). As the illness perception framework has been helpful to describe experiences of cultural groups, the studies of this research programme were informed by illness perception framework of CSM of self-regulation (Leventhal et al., 2003; Parfeni et al., 2013).

The number of patients who commenced dialysis treatment in Northern Cyprus was 59 in 2019. In the same year, there were 220 patients receiving dialysis (i.e., haemodialysis [HD] or peritoneal dialysis [PD]). Although Northern Cyprus has a small population, the incidence and prevalence of kidney failure treated by dialysis are high in Northern Cyprus (Connor et al., 2013). Before commencing dialysis (i.e., HD or PD), patients typically receive pre-dialysis treatment in Northern Cyprus. In 2019, there were only three dialysis services in three different cities (i.e., Nicosia, Kyrenia and Famagusta). Therefore, the first qualitative study sample included participants from three services. In 2020, another state hospital in a different city (i.e., Morphou) had started to provide dialysis services. The prospective longitudinal study included participants from four state hospitals in total. All patient data were collected between January 2019 and November 2021.

3.2.2   Healthcare Professionals

Evidence highlights the treatment burden and its demanding consequences on patients receiving HD (Ng et al., 2020). Treatment burden and complex illness outcomes experienced by patients receiving dialysis remain as an issue. Therefore, this research programme aimed to gain insight into this issue by collecting data from patients receiving dialysis and

healthcare professionals who work at the nephrology department in Northern Cyprus. As patients receiving dialysis, particularly HD treatment, frequently see healthcare professionals in the hospital setting, it is essential to understand the views of healthcare professionals on patient experience. Planned studies aimed to understand patient experience by identifying the challenges and needs of patients. Healthcare professionals (doctors and nurses) who work at nephrology departments were invited to participate in the interview study. In 2021, there were four dialysis services in four different cities (i.e., Nicosia, Kyrenia, Famagusta and Morphou). Data were collected from all services to understand the perspectives of healthcare professionals who work at nephrology departments. It is hoped that this research programme will describe patient experience and provide suggestions for future interventions supporting both patients and healthcare professionals who work at the nephrology department in Northern Cyprus.

3.3   Study Methodology

Parts of this research programme were undertaken during the Covid-19 pandemic. Due to Covid conditions, local healthcare practices in Northern Cyprus have also been negatively affected, similar to different regions across the globe. For instance, patients receiving pre-dialysis treatment had difficulty regularly attending face-to-face hospital appointments. Such circumstances also influenced the scheduling of commencing dialysis treatment. On the other hand, kidney transplantation surgeries have decreased due to the limited usage of hospital facilities in 2020. Data were collected according to local healthcare recommendations regarding Covid conditions since 2020. The data collection method had started face-to-face in 2019 (Study 1) and then it was changed to via telephone with the advice of the local ethics committee in 2020. In Study 3, baseline data collection was completed face to face (in 2020), and 6 months and 12 months follow-up were completed through telephone (in 2021). In the meantime, data collection for Study 4 were competed face to face by taking precautions

regarding Covid pandemic such as performing antigen test before and after interviews. Study 4 was planned to be conducted through online platform (i.e., Zoom meetings), however, local healthcare professionals in nephrology department were not quite familiar with online meetings and they did not find it feasible. Hence, they requested face to face interview by taking precautions. The local ethics committee was informed about the request and permission was obtained for face to face data collection for Study 4 with condition of taking precaution.

3.3.1   Qualitative Interviews (Study 1 & Study 4)

Qualitative methods in health research have gained importance as it allows researchers to understand how individuals make sense of their condition. There are different methods of collecting qualitative data, however, the most commonly used methods in psychology consist of one-to-one interviews and focus groups (Marks & Yardley, 2003). Qualitative interviews allow participants to share their experiences and unearth perceptions and attitudes that may not have been observed earlier (Braun & Clarke, 2006).

One-to-one interviews have been used to understand the lived experiences of patients with long-term conditions. This method has been helpful to know how patients make sense of their condition and experiences (Braun & Clarke, 2014). Unlike quantitative methods, researchers can collect rich data to gain insight into the patient experience. Qualitative interviews can provide an in-depth understanding of the phenomenon of interest rather than testing hypotheses and predictions. Qualitative interviews in health research are used commonly to identify the needs of individuals who receive treatment in medical settings. In addition, they may help enhance the patient experience by informing healthcare practices (Daly et al., 2007). For example, kidney research has frequently used one-to-one interviews to understand

patient experience and perceptions regarding illness and treatment adherence (Karamanidou et al., 2014; Rees et al., 2018). Considering the patient group has not been studied before, it was expected to obtain rich information by conducting one-on-one interviews.

Qualitative interviews in health research have been critical to understanding the perspectives and perceptions of healthcare professionals in clinical settings (Andersen-Hollekim et al., 2021). Data provided by healthcare professionals are crucial as it can contribute to tailoring interventions in clinical settings. Healthcare professionals' views in Northern Cyprus have not been reported yet like the patient group. Conducting one-to-one interviews with healthcare professionals who work at the nephrology department seemed appropriate since it provides the opportunity for interviewees to feel more comfortable expressing their thoughts and experiences. By conducting one to one interviews with nurses and doctors who work at the nephrology department in Northern Cyprus, it was hoped to gain insight into local healthcare practices regarding psychosocial care needs of the patients. Nevertheless, qualitative data can help understand how well current support is working and to offer recommendations for service development as well as health policy (Pope et al., 2002; Yuan et al., 2022).

Interviews can be conducted in different forms, including structured, semi-structured and unstructured. All questions in structured interviews are asked to participants, and guideline is followed precisely. Therefore, data in structured interviews are collected straightforwardly. Interviewer and interviewee are less likely to interact as questions are designed to focus on the topic and maximise consistency. Structured interviews are frequently used in survey research for theory-testing (May, 1991). On the other hand, in unstructured interviews, questions are asked in inconsistent form and are not pre-determined (Stuckey, 2013). In semi-structured interviews, questions are pre-determined and are not strictly followed in order.

Depending on the discussion, answers for some questions may come up; in this case it is not required to ask questions on these issues in the topic guideline. The interviewee usually leads the discussion as they can freely express their thoughts and experiences, however, the interviewer makes sure that the topic of interest is discussed in the detail required. Hence interviewer input is vital in shaping the discussion. For instance, the interviewer may ask questions that are not pre-devised but may seem relevant to the interviewee's experience. While designing questions for the interview topic guideline, researchers tend to determine probes that may include examples and prompts to facilitate discussion to obtain rich data at the interview. Therefore, semi-structured interviews can be considered as flexible though possessing a structure in terms of including pre-devised questions and probes that aim to address the research question.

There are various qualitative data analyses techniques used to analyse qualitative interviews. Commonly used techniques include interpretative phenomenological analysis (IPA), grounded theory (GT), thematic analysis, and qualitative content analysis (QCA). These methods may differ on epistemological assumptions and analytical techniques guiding the research process in terms of designing a research question, sampling, data collection methods. Thematic analysis and QCA are frequently recognised as methods that allow researcher to use theoretically flexible techniques. QCA has been viewed as a method that can only produce descriptions of the phenomenon of interest, therefore it can be considered as the *least* interpretative qualitative data analysis technique among approaches mentioned above (Braun & Clarke, 2020). On the other hand, approaches like IPA and GT are theoretically informed methodologies that offers a framework for qualitative data analysis. For instance, IPA represents phenomenology- theoretical framework – that focuses on understanding how individuals experience and make sense of the world. Research questions aim to gain understanding on personal experience and sense-making process on a particular

context. Therefore, sample sizes tend to be small and homogenous, representing more idiographic approach to identify unique characteristics of each case (Smith et al., 2009). On the other hand, there are several different approaches using GT. It has been suggested using a GT approach particularly when research questions relate to social processes and factors that shape particular phenomena (Charmaz, 2014). One of the key characteristics of GT is that data collection and data analysis continue concurrently. This theoretical sampling-developing analysis informs participant recruitment. Saturation can be described as the point at which theoretical sampling/ data collection stops as there is no more new insight can be obtained according to impression of researcher (Braun & Clarke, 2019a).

Thematic analysis has been frequently used to analyse qualitative data, particularly in interview and focus group studies (Braun & Clarke, 2021). Approaches to thematic analysis have been distinguished (Braun & Clarke, 2019b). These are *coding reliability, codebook* and *reflexive thematic analysis*. Coding reliability adopts a (post)positivist paradigm therefore, this approach focuses on the accuracy or reliability of the coding process. Researcher subjectivity or bias is perceived as a critical issue that negatively affects the reliability of the analysis. With this approach, researchers aim to produce "objective" knowledge that is believed to be repeatable (Boyatsiz, 1998). Postpositivist perspective views reality as singular which is observable independently from the researcher (Creswell & Plano Clark, 2018). Themes may be developed before or after data familiarisation, and they are usually based on data collection questions (e.g., questions asked in the interview). In other words, themes are frequently understood as topic summaries that overview what participants have said about a particular topic. Such themes tend to be short as they summarise the responses of participants. The coding frame (or codebook) is used during analysis by multiple coders who work independently. Then coding reliability is calculated to establish the level of agreement between multiple coders (O'Connor & Joffe, 2020). Agreement on a theme represents the

assumption that "theme is meaningful" (Braun & Clarke, 2021). On the other hand, codebook

approaches can be understood as standing somewhere between coding reliability and

reflexive thematic analysis (TA) in analysing qualitative data. It includes a structured coding

process through codebook or coding frame and theme development as topic summaries (like

coding reliability). Also, it recognises researcher subjectivity as an inventible source for

research (like in reflexive TA). Framework (Ritchie et al., 1994) and template (King, 2012)

analyses can be considered using the codebook approach. Researchers do not typically

calculate intercoder reliability in this approach; instead, the codebook can be used to report

the analysis and inform the coding process (Braun & Clarke, 2021).

To analyse qualitative interviews in this research programme, thematic analysis informed by

Braun and Clarke approach (Braun & Clarke, 2006; 2019b), which is now known as reflexive

TA, was used. Reflexive TA is a flexible method to analyse qualitative interviews by

identifying patterns of meaning across the dataset. This technique allows observing

similarities and differences within an aspect of the research topic. Rather than summarising

data, it will enable the researcher to describe participants' experiences with interpretation and

provide a story that exceeds participants' responses. Unlike GT, using saturation – theoretical

sampling – is not consistent with reflexive TA's approach to qualitative data. Despite this

saturation is commonly used as rationale for sample sizes in different types of TA

approaches, though it is problematic in reflexive TA research as it gives impression that

researcher should discover and reveal themes that are already exist out there. However,

conceptualisation of qualitative research in reflexive TA encourages to work on generating

knowledge as there is always chance to shape our understanding (Mason, 2010). There is no

clear way to justify sample size (participant group) in reflexive TA. Researchers are

recommended to reflect on "information richness" of participant group and how it may be

consistent with aims of the research. For instance, thinner data would require larger sample

size (data set) to have sufficient information power (Malterud et al., 2016). On the other hand, the coding process does not require multiple coders as the quality of analysis is not dependent on the agreement of multiple coders. Using a single coder is typical in this approach. However, quality in reflexive TA can also be achieved through multiple analysts if it aims to increase reflexivity and interpretative depth rather than an agreement between analysts. Themes are considered analytic outputs generated after coding the entire dataset. Themes in reflexive TA represent a shared idea or central organising concept, that is, they are not "topic summaries". Researchers do not discover themes, instead they produce themes by analytic engagement with data set, personal positioning, assumptions and reflection (Braun & Clarke, 2021). Reflexive TA is a suitable data analysis technique where the researcher aims to describe shared meaning within the dataset. Therefore, reflexive TA was used to analyse qualitative interviews in the research programme. Although this technique is flexible, researchers should determine whether they will use inductive (bottom-up approach), deductive reasoning (top-down approach which a theoretical framework guides analysis), and semantic and/or latent coding. Also, researchers should think about their epistemological assumptions as this will shape their analysis and report writing. For instance, experiences can be framed directly as language reflects experiences in the essentialist approach. According to the constructionist approach, experiences are socially produced. Therefore, the constructionist approach highlights socio-cultural context that allows making sense of individuals' perceptions (Braun & Clarke, 2006). Studies of the research programme were guided with a critical realist approach. Therefore, analyses of the qualitative interviews were completed by a critical realist standpoint, which assumes reality exists; however, observing reality independent of observer (e.g., researcher) is impossible (Sturgiss & Clark, 2020).

Reflexivity is the foremost characteristic of reflexive TA. It is critical in every phase during the analysis. A researcher should be aware of their position and/or relationship to the research

topic and how they contributed and shaped the analysis with their socio-cultural values, educational background, and experiences. The researcher's subjectivity is crucial for quality reflexive TA. Researchers should be aware of and present their perspectives. It has been suggested to be critical and engaged to be reflexive during the research process (Braun & Clarke, 2021). The researcher is expected to reflect on their understanding, personal positioning, relationship with participants, expectations, and assumptions regarding the research topic. These have been recognised as personal reflexivity (as cited in Braun & Clarke, 2021). Reflections and thoughts related to methodological choices can be considered as functional reflexivity. On the other hand, disciplinary standpoint can be regarded as disciplinary reflexivity. Different types of reflexivity have been suggested however, there is limited evidence on how to do reflexivity and include reflexivity in research reports. It has been recommended to use a reflexive journal during the research process. It helps researchers to note their insights, thoughts, experiences and observation during interviews. These notes facilitate reflexivity by being more critical and increasing the researcher's awareness of their input. It is expected that all types of reflexivity will intersect and shape analysis during the research process. Reflexivity should be included in research reporting (Braun & Clarke, 2021). As recommended, a reflexive journal was kept for both qualitative interview studies of this research programme.

According to Braun and Clarke's guideline, reflexive TA has six phases. These are *1- familiarisation with the data, 2- coding the data, 3- generating initial themes from the codes and coded data, 4- reviewing and developing themes, 5- defining, naming and refining themes,* and *6- writing up the report*. In the first phase, data (e.g., audio-recorded interviews) are transcribed, read, and re-read to note initial ideas about interesting and relevant sections to the research question. In the second phase, initial codes are generated systematically for the entire data set. In the third phase, the researcher goes through all codes and groups them

into different categories depending on the aspect of the research topic represented. At this stage, some codes may be discarded, for instance, if they seem not to be relevant to the research topic. In this phase, initial themes are developed based on clustered codes. In the fourth phase, the researcher reviews candidate themes developed in the third phase. The themes are checked against the dataset to ensure that participant responses support them. Some themes may be merged, re-named and/or discarded at this phase. Themes are reviewed against supporting codes and data extraction and whether they seem to be related to each other to describe the research topic. Themes should represent a distinct aspect of the research topic, at the same time, should be meaningfully related to each other. At this phase, generating a thematic map is helpful to clarify the analysis. In the fifth phase, the researcher defines each theme by providing a 'story' that identifies focus of each theme and its relation to the research question. The researcher refines, re-names themes if necessary, and revise the thematic map. The researcher identifies whether the theme can be supported by sub-theme(s), which is one of the aspects of the theme. It is vital to name themes clearly, but titles should make sense and include the researcher's interpretation. The last phase involves writing up the final version of the analysis. Data extracts should support the presentation of narrative analysis to provide examples of the 'story' for the reader. The narrative analysis describes patterned meaning across the dataset and includes interpretation to answer the research question/s. The narrative analysis should be presented with previous research findings. In other words, the analysis should be contextualised with previous evidence (Braun & Clarke, 2006).

Analysis of qualitative interviews of the patient group was conducted manually. Data analysis of qualitative interviews of healthcare professionals included manual coding, and then analysis was completed in NVivo software (version 12).

3.3.2   Systematic Review (Study 2)

Illness perceptions have been frequently examined in several long-term conditions, including heart related conditions, diabetes, and kidney failure (Broadbent et al., 2018). Although quantitative examination of illness perceptions has dominated the literature, there is emerging evidence on qualitative studies examining illness perceptions in chronic conditions (Wu et al., 2015). It is acknowledged that qualitative methods can unearth experiences, thoughts and attitudes. Hence, it can provide an in-depth understanding of the interest of research. There have been several qualitative studies investigating illness perceptions in kidney failure. The first study of this research programme intends to qualitatively describe illness perceptions of Turkish Cypriot patients receiving HD treatment. A systematic review of qualitative studies was planned to synthesise illness perceptions in patients receiving dialysis. With the review's findings, it was hoped to understand to what extent perceptions and experiences of Turkish Cypriot patients seem to overlap with patients' experiences in different regions. The synthesis would also be helpful to guide future interventions in a clinical setting to enhance experiences of patients receiving dialysis. This review would be the first study qualitatively synthesising experiences of patients receiving dialysis within illness perceptions framework.

Traditional literature reviews have been widely used to summarise available evidence representing a body of literature. Researchers may use (traditional) literature reviews for several reasons, such as -to present an overview on a topic, -to indicate a historical aspect of the development of evidence on a topic, -to determine lack of knowledge, similar and different views on a topic, and -to describe relationships between key constructs from the available evidence (Rozas & Klein, 2010). Although traditional or narrative reviews help define an issue, they are limited in informing healthcare practice as they are mostly subjective and primarily rely on the researcher's knowledge and skills. Traditional literature reviews are frequently based on sources selected from available studies. This increases the chances of risk

of bias or systematic error. Therefore, it makes it challenging to achieve reproducibility and lets findings heavily rely on the understanding and explanations of the researchers. In traditional reviews, authors summarise the previous evidence rather than analyse and synthesise the results.

To change practice in a clinical setting, it is beneficial to have clear recommendations based on extensive knowledge. Therefore, single study findings are generally not sufficient to inform healthcare practice (Gough et al., 2013). Also, it is acknowledged that not all published studies are of high quality and reliable, they may have used inappropriate statistical procedures and/or may not have conducted the study with lack of transparency, leaving the study as questionable work. Consequently, literature reviews have improved by increasing transparency in each stage, such as during the search process, data collection, assessment, and synthesis (Aromataris & Pearson, 2014).

As traditional literature reviews are considered quite limited in terms of reproducibility, the requirement of a more structured approach has been highlighted for the review process. The systematic review has been considered a practical alternative approach, where applicable, as it offers a comprehensive, unbiased synthesis of knowledge based on considerable evidence that investigated the same topic. In a systematic review, a straightforward, systematic approach is used to identify studies to minimise bias, facilitating providing reliable evidence informing the future decision-making process (Higgings & Green, 2011). A systematic review of evidence, when conducted with transparency, has the power to influence healthcare decisions and policy. Systematic reviews help to reveal international evidence, examine new practices, describe conflicting findings and inform future research and/or practice (Munn et al., 2018). It is expected that systematic review will be reported explicitly. For instance, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement

describes a checklist for a researcher to follow during research reporting to increase the quality of the review (Page et al., 2021). Conducting systematic reviews includes building a search strategy, study selection, critical appraisal and data extraction, which independent reviewers typically complete to reduce the risk of bias (Aromataris & Pearson, 2014). Although systematic reviews are conducted with different methodologies, there are well-defined characteristics of systematic reviews that are internationally recognised. These include:

- Clear research question/s and objectives
- Well-defined inclusion and exclusion criteria to determine eligible studies
- Comprehensive and explicit search strategy to identify relevant studies
- Quality assessment of eligible studies
- Analysis of extracted data
- Reporting the analysis and methodology explicitly and transparently

Conducting a systematic review will be depended on the research question. For example, a systematic review may synthesise evidence on treatment effectiveness by reviewing randomised controlled trials (RCT) (Picariello et al., 2017a). On the other hand, there are systematic reviews conducted to synthesise qualitative evidence on patient experience (Reid et al., 2016). The reviews may differ depending on the designs of included studies and the type of extracted data. For example, quantitative focused systematic reviews frequently include meta-analysis to identify the strength of relationships of variables or to synthesise the effect of an intervention. On the other hand, systematic reviews of qualitative studies aim to synthesise a group of individuals' perceptions, attitudes, and/or experiences. Also, there are mixed-method systematic reviews that include meta-analysis (quantitative) and qualitative synthesis of the previous evidence (Hnatiuk et al., 2019).

Before starting to review, researchers are expected to develop a protocol for their review study. The protocol should include information on research questions to answer, identified keywords that will be used for search strategy, database indexes to search, inclusion criteria for eligible studies, and data analysis technique used to synthesise the evidence. Depending on the aim and topic of interest, the protocol for systematic reviews is registered in well-known databases. For instance, reviews interested in the effectiveness of interventions are registered in the Cochrane Library. On the other hand, reviews interested in health-related outcomes are frequently registered in the PROSPERO database. The protocol for a systematic review of the research programme was registered on the PROSPERO database (ID: CRD42020202272). The steps for conducting a systematic review are as follows broadly:

Review question and inclusion criteria: Unlike traditional reviews that summarise available evidence, systematic reviews aim to answer specific research questions. Identifying a clear research question is crucial and the first step of the review. There are different approaches to formulate a research question and develop a search strategy. Research questions for quantitative reviews have been frequently informed by PICO (Population, Intervention, Counter-intervention, Outcome) tool. As the focus and scope of qualitative reviews (also known as qualitative evidence synthesis or systematic review of qualitative studies) are different, the PICO tool may not be ideal for qualitative evidence synthesis. For instance, questions of qualitative evidence synthesis may include additional/other interests such as setting or context. Therefore, several frameworks have been developed to guide qualitative evidence synthesis research questions. These include but are not limited to SPICE (Setting, Perspective, Intervention or Phenomenon of Interest, Comparison, Evaluation) and SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) (Flemming & Noyes, 2021). A suitable tool also helps clarify concepts used during the search. This is critical as it will aim to capture relevant studies by indicating inclusion criteria explicitly. Using such a

tool in the review is necessary to decrease the chances of potential bias. For instance, authors will identify relevant studies based on the concepts rather than focusing on findings of primary studies. The systematic review of the research programme utilised SPIDER framework as it has been shown as a good alternative tool for qualitative evidence synthesis (Cooke et al., 2012). Cooke and colleagues (2012) adapted components of PICO were adapted to qualitative research and developed SPIDER tool. Considering smaller sample sizes in qualitative research, 'Population' was reframed as *Sample*. 'Intervention' on the other hand, was changed with ***Phenomenon of Interest*** as it is more suitable for aims of qualitative research which may include behaviour, experiences, perspectives etc. Instead of 'Comparison', ***Design*** was used referring to study design and theoretical framework may influence analysis and facilitate capturing qualitative studies in the search. Instead of 'Outcomes', ***Evaluation*** was added acknowledging subjective constructs of qualitative synthesis. Also, ***Research type*** was added in the framework which may be useful for mixed method reviews (Cooke et al., 2012).

Searching for relevant studies: By adhering to the framework used to clarify review question, reviewers develop a search strategy. This search strategy should be comprehensive enough to capture relevant studies. Reviewers spend some time doing a preliminary search with early versions of the search strategy to ensure comprehensiveness. Initial search can be conducted in PubMed and SCOPUS databases using keywords of identified concepts. Reviewers may include more keywords throughout this search or change and/or remove some keywords from the search strategy. Once the reviewers agree on the final version of the search strategy, the reviewers run the search strategy in pre-identified databases after registering the protocol. Manual search is also conducted by checking reference lists of retrieved papers. Usually searching process also include 'grey' literature. For instance, unpublished studies, including preprint papers, conference presentations, doctorate/master

thesis, can be reached through Web search engines and databases for dissertations. Also, reviewers may contact experts who study the topic of interest.

Study selection and quality assessment: Relevant studies are retrieved and checked against inclusion criteria, then reviewers identify eligible studies. For instance, reviewers check whether the primary study recruited the target population, measured or examined topic/variable of interest etc. Once independent reviewers determine the eligible studies, the quality of the eligible studies should also be assessed independently. Critical appraisal is vital as some studies may be poorly conducted or reported, leading to bias in synthesis. In addition, this process evaluates studies regarding methodological limitations, trustworthiness and credibility (Soilemezi & Linceviciute, 2018). Different quality assessment tools are used depending on the design of primary studies. For instance, Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018) has been commonly used to assess the quality of qualitative studies. In contrast, Effective Public Health Practice Project (EPHPP) tool (Thomas et al., 2004) is one of the quality assessment tools frequently used for health-related quantitative studies. Those primary studies that show low quality and/or conducted questionably are generally excluded from the review.

Data extraction and synthesis: When the quality of primary studies have been assessed, relevant data should be extracted in pre-defined form. There are readily available extraction tools designed for qualitative and quantitative studies (Joanna Briggs Institute, 2014). The data extraction form can be pre-designed by reviewers. Reviewers extract information on the research sample, study design, setting, year, research aim, main findings, etc. Relevant citations may also be retrieved during data extraction to ensure relevant studies are not missed. Once data have been extracted, researcher/s use a data analysis technique suitable for the review question and the type of data extracted. For example, a review may aim to estimate the overall effect of an intervention (e.g., psychotherapy approach), whereas another

review may aim to understand patients' and healthcare professionals' experiences. A quantitative focused review may statistically combine previously applied intervention to estimate the intervention's overall effect, which is typically done by conducting meta-analyses. On the other hand, another review may only present a narrative summary by interpreting the synthesis or may present both analyses. Data synthesis can be completed by using various methods. It is strongly recommended that reviewers consider several points when deciding on an approach to use. These include review questions and epistemology that underpin the synthesis, resources, knowledge and skills of the review team and type of data (e.g., richness, qualitative/quantitative, etc.) (Booth et al., 2018, Flemming & Noyes, 2021).

The systematic review included in the research programme was qualitative evidence synthesis (systematic review of qualitative studies). There are approximately 30 different approaches that can be used to synthesise qualitative evidence (Booth et al., 2016). Commonly used methods are meta-ethnography, thematic analysis, and framework synthesis. Although they share several similarities, their approach to analysing qualitative data is different, and each has strengths and limitations. Thematic synthesis interprets primary research findings and provides new insights not clearly indicated by primary research. It allows reviewers to inductively code data and develop descriptive themes, leading to analytic themes if data is sufficiently rich (Thomas & Harden, 2008). This approach has been practical to describe beliefs, attitudes, experiences of individuals with disease and those who have received a healthcare intervention (Naidoo et al., 2020; Walker et al., 2019). However, if reviewers' qualitative skills are limited, the analysis produced may be simple and superficial, which does not provide a higher level of explanation of the topic of interest (Flemming & Noyes, 2021). On the other hand, framework synthesis uses an apriori framework to synthesise extracted primary research findings. The main purpose of framework synthesis is

to integrate findings that represent a particular context. Therefore, it uses mainly deductive approach and is primarily suitable when existing framework can be used in review (Booth et al., 2016; Flemming et al., 2019). Moreover, meta-ethnography is also one of the approaches used frequently in qualitative evidence synthesis. It also aims to interpret a body of work and provide new explanations and theories. However, meta-ethnography mainly aims to develop a comparative understanding (Heyvaert et al., 2016). In other words, it is helpful to highlight similarities and differences between critical findings and translate these to develop themes (Atkins et al., 2008).

The aim of the review, type of data, philosophical assumption adopted (i.e., critical realist standpoint) and qualitative skills and experiences of the reviewer led to use reflexive TA to synthesise primary research findings in the systematic review of this research programme. As it is a flexible method, reflexive TA has also been used in qualitative evidence synthesis (Stewart et al., 2020). When undertaking the review study, it was hoped to integrate primary research findings and explain them within the illness perception framework. At the same time, it was expected to provide synthesis representing patients' voices. The synthesis was produced by using inductive and deductive reasoning at different levels. Overall, the aim of the review, flexible nature of reflexive TA, type of data, and the fact that the reviewer already had the experience of this method due to interview study (Study 1) made it feasible to utilise reflexive TA in the review study in this research programme. The analysis was completed in NVivo software (version 12). *Qualitative Interviews* section provides detailed information on the phases of reflexive TA. Details on how these phases were applied in the synthesis are provided in Chapter 5.

Interpretation and implication for future practice: Findings of the analysis are summarised, interpreted, and contextualised. Based on the findings, it is critical to provide recommendations and implications for future research and practice. To achieve this, the synthesis should be presented clearly with coherence, and suggestions should be supported by data analysed (Aromataris & Pearson, 2014).

3.3.3   Prospective Longitudinal Study (Study 3)

Longitudinal designs in health research are essential to understand changes in health-related perspectives and illness outcomes over a period of time. Longitudinal designs are particularly helpful to assess the association between risk factors and the prognosis of the disease, and the consequences of treatments over different lengths of time (Caruana et al., 2015). Longitudinal designs have been rarely used in illness perception research, particularly in patients with kidney failure. However, available research in the literature has highlighted that illness perceptions can change overtime, and patients may report different illness outcomes in kidney failure (Tasmoc et al., 2013). Therefore, a quantitative measure was used with longitudinal design to identify illness perceptions trajectories in Turkish Cypriot pre-dialysis patients and those who already receive dialysis (i.e., HD or PD). As data are collected multiple times from particular groups overtime, longitudinal designs have advantages over cross-sectional survey designs. Longitudinal survey studies are helpful to explain within-person as well as between persons change overtime (Caruana et al., 2015).

Longitudinal data can be described as data collected from a group of cases on several variables overtime. This description represents the notion that variables are repeatedly measured. The data are collected to provide information about individuals' behaviour and attitudes regarding the research topic on several separate occasions (i.e., known as 'waves')

(Ruspini, 2003; Taris, 2000). Types of longitudinal designs have been differently defined in social research. Menard (2002) describes four widely used longitudinal designs: *total population designs, repeated cross-sectional designs, revolving panel designs*, and *longitudinal panel designs.* Researchers measure the whole population multiple times in total population designs. In repeated cross-sectional designs, independent probability samples are drawn and measured multiple times. These samples will typically consist of different cases at different measurement periods. This design is also known as trend studies (Ruspini, 2003). On the other hand, in revolving panel designs, researchers collect data from a sample retrospectively or prospectively, then drop some of the cases and recruit new cases instead. However, researchers measure the same sample in longitudinal panel design at each measurement period. In the longitudinal panel designs, it is expected that sample size will vary at each measurement period due to missing values (e.g., dropouts and/or death of participants). This design typically is applied prospectively, and it is the only design that allows observing changes at an individual level. In retrospective panel design, participants are asked to recall events, whereas participants are measured over a period of time in prospective panel design (Ruspini, 2003). In both retrospective and prospective panel design, missing data can be observed due to several factors. For instance, participants may fail to recall events, attitudes and behaviours and/or participants may be unwilling to respond to some questions. Although longitudinal (panel) designs should not differ in data quality, retrospective panel designs may be at higher risk for sampling bias (Menard, 2008). According to the definition of Menard (2002), the quantitative study of this research programme used a longitudinal (prospective) panel design. Prospective panel designs have been suggested as providing the most reliable data on understanding change in attitudes and behaviour overtime as participants are measured while they actually exist. Therefore, prospective panel designs have been recognised as the most truly longitudinal study (Ruspini, 2003).

Various types of prospective panel designs can be applied in social and health research. Cohort panels, representative panels and linked panels are commonly used forms of prospective longitudinal (panel) designs. In *cohort panel* design, a group of individuals who experience the same life event are followed within the same time interval overtime (Caruana et al., 2015). Cohort studies have been recommended, particularly when studying populations whose experiences are likely to change overtime. Such studies are helpful as they provide information on -change of psychosocial events between measurement periods (waves), -differences and/or changes at the individual level (intra-individual) and between individuals (inter-individual) and -patterns of these changes overtime. Observational longitudinal data also helps to identify 'potential' causes of behaviours. Although prospective panel designs have been shown as powerful in providing reliable data on change in behaviours and attitudes overtime, there are several disadvantages associated with this design. For instance, prospective panel data collection is quite time-consuming. One of the problems frequently occurs is a reduction in sample size through each time point of data collection (wave). This may be due to the inability to follow up some cases. Participants may drop out from the study, and they may refuse to respond to survey questions and/or some participants may die. Hence some will not be able to continue to measurement in consecutive waves. On the other hand, participants may condition survey questions (panel conditioning), which may affect their responses in consecutive waves through changing behaviour or the quality of the responses provided (Rajulton, 2001). Participants may learn new information between waves or experience something new. They may react differently in the next wave because they already had survey experience at the previous wave/s (Ruspini, 2003).

Successful recruitment and retention of participants have been considered critical, particularly in prospective longitudinal (panel) designs. Several strategies have been

suggested for longitudinal studies to maintain the retention rate as high as possible. According to Killien and Newton (1990), these include a *combination of clinical knowledge with study phenomenon*, representing the involvement of clinical staff in the research team, which can significantly inform research design, data collection process, and instruments to use. In the early stages of the research programme, a local nephrologist was contacted to build a relationship with the local nephrology department and become familiar with the process to access the target population. Throughout this process, the local nephrologist had involved in the supervisory team, this had informed the research design and data collection procedures.

Moreover, *establishing relationship between researcher and participants* has been shown another critical factor that may affect retention rate. The researcher had already contacted some of the participants due to the invitation to participate in Study 1. During the prospective longitudinal study, she had regular visits to the nephrology department to meet with the local nephrologist. Therefore, most patients, particularly those who received HD treatment, become familiar with the researcher. This somehow has helped to accept to participate in the study in the first place, also it seemed to help maintain the commitment to study. The researcher systematically followed up the participants for the subsequent waves. The first wave of data collection was completed face to face in the hospital setting. Due to Covid conditions, second and third wave data collections were conducted by telephone.

There are several methodological concerns that are unique to longitudinal survey studies. Data collection methods, tracking participants, maintaining communication with them, and changing procedures overtime are some of the main concerns particularly associated with prospective longitudinal (panel) designs. If not considered, these can appear as methodological limitations (Lynn et al., 2019). Literature provides evidence on alternative approaches and strategies in combining different data collection modes in longitudinal studies

(Brown et al., 2019). Mixed-mode data collection has been frequently used in longitudinal survey studies to increase the response rate. For instance, there are prospective longitudinal studies that started face to face data collection and then changed it to telephone interviews or used mixed-mode data collection strategy by asking participants about their preference (e.g., face to face or telephone) (Juster & Suzman, 1995; Couper & Ofstedal, 2006). To maintain retention rate at second and third waves, in the prospective longitudinal study of this research programme, the researcher requested an appointment in case participants were busy answering questions. Then she re-contacted participants via telephone on the agreed time and date. Data collection through telephone seemed to facilitate answering questions for most participants. They explicitly stated that they felt more comfortable expressing their feelings. Furthermore, to maintain the retention rate as high as possible, the research team agreed to contact and re-invite patients to the third wave in case they responded to questions at the first wave but failed to participate in the study at the second wave unless they explicitly rejected to join at the second wave.

Perceived costs and benefits related to participation have been associated with commitment to a longitudinal study. Maintaining participation may be related to one or multiple benefits, including altruistic attitudes (helping others), an opportunity to reflect on one's experiences, and share concerns (Killien & Newton, 1990). Similarly, it was observed that participants in the prospective longitudinal study were keen to respond to questions in the questionnaire. Some questioned the benefits of participation in the study, and they were verbally reminded that identifying patient experience is important to provide better support in the future. However, during telephone contact, most participants expressed their satisfaction regarding being asked about their wellbeing. They perceived the participation in to study as an opportunity to share their concerns, feelings and experiences related to treatment. Some participants at the third wave of the study even stated that they were willing to be contacted

again for future studies. Participation in the study may have therapeutic value for some participants.

Longitudinal data can be analysed with various statistical models. Although statistical techniques used will depend on the type of data and research questions, primarily used models include generalised estimating equation, linear panel analysis, and latent curve modelling such as multilevel models. Longitudinal data are commonly analysed in well-known statistical packages such as Mplus software, SPSS, Stata and SAS. Nevertheless, new technologies on statistical software and packages are still developing to make longitudinal data analysis feasible and accessible. For instance, Jamovi as open statistical software provide an opportunity to run some growth curve models (The Jamovi project, 2021). Growth curve models are helpful to observe trajectories or patterns of change in outcome (Menard, 2008). Therefore, the prospective longitudinal study of this research programme used the growth curve model approach through the multilevel modelling technique. Details of instruments and the statistical procedures conducted for the longitudinal data can be found in Chapter 6.

3.4   Summary

This research programme aimed to understand illness perceptions in Turkish Cypriot patients receiving dialysis. Therefore, individual studies were design to address research questions. Distinct research questions were developed for each study, aiming to understand different aspect of patient experience. This was best suited to a mixed-methods research programme. The studies of the research programme utilised several methods including qualitative interviews, systematic review, and prospective quantitative data collection. By using diverse methods, it was hoped to provide broad understanding considering different aspects of patient experience. This could make novel contribution to understanding of patient experience in Turkish Cypriot dialysis population.

Chapter 4: Illness Perceptions of Turkish Cypriot Patients Receiving Haemodialysis Treatment: A qualitative study

4.1   Introduction

It is clear that chronic kidney disease (CKD) is a worldwide public health issue. There are five different stages in CKD depending on the function of kidneys. Patients receive kidney failure (KF) treatment when kidneys are not able to function (Stage 5) (Levey et al., 2020). Treatment for KF is complex and research examining illness perceptions in cross-cultural settings is limited. As healthcare infrastructure differs, there are large variations in psychological care that patients receive. This chapter aims to report on a qualitative study which examined illness perceptions of Turkish Cypriot patients receiving haemodialysis (HD) treatment.

When people are diagnosed with KF, they require kidney replacement therapy (KRT). Dialysis is one form of KRT that helps the body artificially regulate metabolic waste instead of the kidneys (Foote & Manley, 2008). Dialysis treatment can be undertaken at home or in hospital/ centre. There are two types of dialysis, peritoneal dialysis (PD) and haemodialysis (HD). Patients tend to make their decisions about dialysis modality with their doctors. Worldwide, most patients with KF tend to receive HD at hospital/ centres (Robinson et al., 2016; United States Renal Data System [USRDS], 2017). Overall, this makes dialysis as leading KRT across globe. HD is a life-saving intervention but one that is burdensome for patients (Jones et al. 2018; Tong et al. 2009).

One of the factors makes dialysis treatment difficult is time spent during sessions. For instance, patients receiving HD at centre generally have reported to feel socially restricted due to spending approximately 4 hours for each session, three times a week. (Hagren et al.,

2011). The patients' life experience is likely to be affected in different aspects because of treatment burden from dialysis. Patients who receive dialysis tend to report symptoms such as dry skin, itching, nausea, fatigue, chest pain, and joint pain, lack of energy, muscle soreness, sleep difficulties (Weisbord et al., 2005; Unruh et al., 2003; 2004). Cognitive impairment can be also experienced depending on the disease severity in patients receiving HD (Kurella et al., 2004). Symptom burden has been negatively associated with health-related quality of life (HRQoL) (Kimmel et al., 2003).

Given the nature of HD itself and associated lifestyle changes, it is unsurprising that psychiatric morbidity is common (Kimmel et al. 1998b; Levenson & Glocheski 1991). Patients receiving HD tend to report depressive symptoms with the symptom burden (Weisbord et al., 2005). It is well determined that depression is prevalent in patients receiving HD (Shirazian et al., 2017). Whilst prevalence estimates vary across studies due to issues with methodological approach, one thing that is clear is the relationship between depressive symptoms and patient outcomes in physical and psychological domains, as well as overall survival (Chilcot et al. 2018; Fan et al., 2014; Farrokhi et al., 2014; Perales Montilla et al. 2016; Wang et al. 2012). Depression has been shown to predict mortality in patients receiving dialysis (Silva et al., 2014). Patients who have depression tend to report lower quality of life (QoL) in psychological, physical and social aspects (Bujang et al., 2015). Moreover, HRQOL representing physical and psychological health has been associated with mood among patients receiving HD (Perales et al., 2016). Such findings have spurred interest in the psychological factors that might precede or be closely related to the experience of mood on HD.

4.1.1 Theoretical Framework

The Common Sense Model (CMS) of Self-Regulation is a well-known theoretical framework that has been used to describe how patients manage their condition. According to the model, patients hold a group of beliefs related to their condition which are suggested to shape illness perceptions and illness management (Leventhal et al., 1980). The way patients perceive the health threat determines how they respond to their condition (Leventhal et al., 1984). Illness beliefs represent the patient's illness cognitions (Leventhal et al., 1980). CSM of Self-Regulation includes three stages, interpretation, coping and appraisal. In the first stage (interpretation), the patient develops illness cognitions. The mental representation of the health threat will determine how the patient understands their condition (Leventhal et al., 1984). Patients develop illness cognitions within five domains. Identity represents symptoms of the illness and how the patient's ideas about the label of their condition. *Causality* represents cognitions the patient holds about causes of their condition (e.g., genetic). *Timeline* refers to beliefs and ideas about the duration of the condition. *Control/Cure* refers to whether the patient believes their condition is controllable or curable. *Consequences* refer to beliefs that the patient holds about the impact of their condition (Leventhal et al., 1980). Patients develop different cognitions related to same condition, therefore the management of their condition may differ (Petrie & Weinman, 2006). Illness perceptions may change over-time, leading to both inter and intra individual variation (Bonsaksen et al., 2015).

Illness perceptions can be measured using either the revised Illness Perception Questionnaire (IPQ) (Moss-Morris et al. 2002) or a shorter version- the Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent et al. 2006). This has given rise to numerous studies that quantify illness experiences and relate them to a board-range of psychological and clinical outcomes though qualitative exploration is lacking (Chilcot, 2012). Research demonstrates the relationship between illness perceptions in HD and quality of life (Nabolsi

et al., 2015; Patel et al., 2002), diet adherence (Kim & Evangelista 2010; Seyyedrasooli et al., 2013), depression (Chilcot, 2012; Peterson et al., 1991), and mortality (Parfeni et al., 2013).

Oflaz and colleges (2014) translated the Brief IPQ into Turkish language and used in sample of patients with myocardial infarction. However, Karataş and colleges (2017) were one of the first to comprehensively look at the factor structure of the scale in Turkish speaking patients. Although studies of illness perceptions in Turkish patients are limited, there are a handful of studies from Turkey quantitatively examined illness perceptions in patients receiving HD. The findings indicated negative illness perceptions were associated several outcomes such as disability, lower quality of life, and higher risk for developing anxiety and depression (Krespi & Kuntuz 2017; Karadag et al. 2016; Yildirim et al. 2013; Yorulmaz et al. 2014).

4.1.2   Rationale

Whilst both Turkey (Stel et al. 2011) and Cyprus (Connor et al. 2013) have high incidence rates of KF, Cyprus in particular is a distinct cultural context. Historically, it has been governed by both Greek and Ottoman Turks. Consequently, the population mix is different, genetically, from that of either Turkey or Greece (Connor et al. 2013) and so it may be problematic to generalise illness experiences across patients based in these regions. Turkish-Cypriots are a distinct group, largely clustered within the North of the country where dialysis care has been expanding in the past decade. The mix of genetic, economic, sociocultural and environmental issues make it important to differentiate illness experiences in an increasingly common illness setting for Turkish-Cypriots. Although the majority of Northern Cypriot patients with KF (91.1%) start KRT by in-centre HD treatment (Connor et al. 2013), illness perceptions of those patients have not been studied to date. To address this issue, this study used qualitative methodology to identify and explore the illness perception of Turkish-

Cypriot patients receiving HD. Qualitative methods facilitate obtaining insights about patients' values and beliefs which determine illness perceptions, they may help to better understand experiences of patients (Tong et al., 2014; Tong & Craig, 2016). Therefore, a qualitative methodology was selected as they are useful to describe previously unidentified contexts (Tong et al. 2014) and offer a mechanism for unearthing depth of experience including unexpected findings (Vandermause et al., 2017).

4.1.3   Aim

This study was designed to use qualitative one to one interviews to understand illness perceptions of Turkish Cypriot patients receiving HD, for the first time.

4.2   Methods

This study obtained ethical permission from both Lefkosa Dr Burhan Nalbantoglu State Hospital, Department of Inpatient Treatment, Ministry of Health in Turkish Republic of Northern Cyprus (YTK 1. 01-629-19-E. 1114) and Health, Science, Engineering and Technology Ethics Committee with Devolved Authority in University of Hertfordshire (LMS/PGR/UH/03879).

4.2.1   Design

Semi structured, face-to-face, one to one, in-depth interviews were conducted. After reviewing the literature, a previously developed interview topic guide was used (Sharma et al., 2019). The tool was prepared by several professionals including specialists in health psychology, nephrology, qualitative research and psychological counselling. It included components of Brief IPQ (Broadbent et al., 2006) and the Multimorbidity Illness Perceptions Scale (Gibbons et al., 2013). The tool has 10 questions focusing on illness-related

experiences. The questions include but not limited to "Do you know what the cause of your kidney disease is? How did you gain this information?", "How does kidney disease impact your day– to day life?", Do you think having kidney disease has affected your mood?". Prompts and examples were used where appropriate to encourage participants to share their experiences.

4.2.2 Participants

In 2019, there were three governmental hospitals provide HD treatment in North Cyprus. Nurses who work at Renal Service identified potential participants. Written participant information sheets were provided to patients at the Renal Services. By using purposive sampling, potential participants were invited to participate in the study. The participant information sheet included detailed information about the study such as objective of the study, advantages/disadvantages of the participation, and contact details of the researcher. In total, 20 patients were invited to participate in the study, 15 of them accepted. The refusal rate of participation in the study was only 25%. Majority of those (n=3) who declined to participate said they had a busy schedule and did not have spare time for the study. An appointment was requested with those who agreed to participate in the study. Before starting to do the interview, participants were reminded the study only aimed to understand illness-related experiences of patients receiving HD, and that they had right to withdraw from the study without providing an explanation at any time during the data collection. The participants were also informed that their data would be treated confidentially and anonymously. They were then asked to read and sign the informed consent form. The participants were provided with a copy of the signed informed consent. After completing the interview, they were provided with a debrief sheet in which they could find contact details of

the psychological service of the state hospital if required. All participants were Turkish

Cypriots and identified as Muslims.

4.2.3   Inclusion and Exclusion Criteria

To obtain detailed information related to the experiences of the patients receiving HD the

inclusion and exclusion criteria below were applied.

The inclusion criteria:

•   Turkish Cypriot patients receiving HD who are fluent in Turkish.

•   All patients who are over 18 years old

•   All patients who have dialyzed for a minimum of six months.

•   Patients who not suffer from any major extrarenal comorbidity.

The exclusion criteria:

•   Patients with mental health problems (under referral or treated within over a last year)

were excluded. This aimed to prevent further distress in these patients. Also, it was

recognised that patients with previous involvement in mental health services might already

hold different beliefs towards their illness that should be investigated separately.

•   Patients with specific intellectual difficulties (that influence capacity to consent) were

excluded. This was due to possible difficulties related to effective communication. This did

not include patients with specific learning disabilities such as dyslexia, however, it did

involve patients with disorders in which language skills and cognitive function are limited.

•   Patients with life expectancy of less than one year were excluded, such as those who

received end of life care.

4.2.4   Data Collection

Most participants preferred to complete the study at their home while few participants (n = 2) completed the study before their HD session in a private room at the Renal Service. Only in one interview, was the partner of a participant present. The interviews were conducted in three different cities; Nicosia, Kyrenia and Famagusta in North Cyprus. Majority of the participants were from Nicosia as it is the capital city and its hospital has a larger capacity. Interviews were conducted between March and April in 2019. In total, 15 semi-structured interviews were conducted. The interviews were audio-recorded with the permission of the participants. The interviews took approximately 35 minutes. All interviews were conducted in Turkish. The interviewer was Turkish Cypriot closely familiar with Cypriot culture and was not known to any participants (BK). She has experience in qualitative methods in health research at postgraduate level. Before discussing the questions on the interview topic guide, the participants answered questions about demographic information such as age and dialysis vintage. Later, nurses who work at the Renal Service were consulted to confirm the participants' multimorbidity status.

4.2.5   Data Analysis

One of the interviews was excluded from the analysis according to inclusion/exclusion criteria. The interview was excluded from the analysis since the participant already had diagnosis of major depressive disorder and was receiving treatment for it, which was ascertained during the interview. Fourteen interviews were audio-recorded and transcribed verbatim. Analysis was completed with a critical realist perspective. Transcripts were inductively analysed by using a reflexive thematic analysis (TA). Consolidated criteria for Reporting Qualitative health research (COREQ) tool was used to report findings comprehensively (Tong et al. 2007). To ensure a quality reflexive TA, a 15-point checklist of

criteria was used (Braun & Clarke, 2013). Reflexive TA is quite flexible, and its active

coding process continues for the entire dataset. Unlike the other types of TA such as coding

reliability (Boyatzis, 1998) and codebook (King & Brooks, 2017) approaches, themes are

generated at later stages in the reflexive TA (Braun & Clarke 2006, 2013). Calculation of

inter-rater reliability scores is not recommended unless a suitable epistemological approach

(realist/positivist) is used (Braun & Clarke, 2013). When realist/positivist assumption is used

in the analysis, it is expected that a reality in the data can be accurately captured through

coding. However, the reflexive TA does not require two or more independent coders to

increase reliability in coding as the subjectivity of the researcher is acknowledged. Positivist

assumptions supporting coding reliability approaches often restrict the flexibility of TA. On

the other hand, codebook approaches may share broad qualitative philosophical perspective

with reflexive TA, however, the development of the themes in codebook approaches are

more like theme development stage in coding reliability approaches. The main interest of this

study was to understand the illness experiences of patients receiving HD treatment.

Considering the epistemological standpoint (i.e., critical realist) and experiential-type

research question of this study, using reflexive TA was appropriate to explain patterned

meaning across the dataset (Braun & Clarke, 2013) with the current sample size (n = 14).

Transcription and all stages of the analysis were completed in Turkish (the original language

of the interviews). The entire dataset was read multiple times to become familiarised with it.

Initial notes were taken for potential codes. Codes that have a similar phrase were merged to

prevent overlapping where applicable. A few codes that did not occur in most of the

transcripts were discarded since they were not quite relevant to the research topic. Similar

codes were then gathered together to see whether they were able to construct a meaningful

subtheme/s and theme/s. Codes were re-checked to ensure they are distinctive. The codes and

all relevant data extracts were put together to identify themes. This process was indicative for

the later stage of analysis. After theme development, all codes were re-checked for the entire dataset to ensure that they represent the patients' experiences and to confirm they have a good fit with the themes developed. After reviewing identified themes, one of the themes was re-named to better represent supporting codes.

Coding in reflexive TA reflects the subjectivity of the researcher, and this subjectivity can't be checked by another researcher, however, theme development can be weaker or stronger therefore, a more experienced researcher can be consulted about thematic framework (Braun & Clarke, 2013). Another researcher checked the applicability of the thematic framework on the transcripts, it was ensured that themes and subthemes were meaningful to answer the research question. The local supervisor checked the analysis in the original language and checked quotations in both languages (Turkish and English) to ensure semantic equivalence.

There is a debate about whether the translated data still hold the same meaning in both original and translated languages (Regmi, Naidoo, & Pilkington, 2010). To avoid problems and potential restrictions such as meaning loss, recent studies have recommended delaying translation by staying in the original language as much as possible (Temple & Young, 2004; Van Nes et al., 2010). Therefore, the analysis was completed in the original language (Turkish) and it was then translated into English. Once translated into English, another researcher checked the applicability of the thematic framework across the transcripts by reviewing 20% of all interview data. Any differences were resolved through discussion.

4.3   Findings

The current study attempted to understand the illness experiences of the participants receiving HD. Table 4.1 describes the demographic and clinical characteristics of the sample.

Table 4.1: *Demographic and clinical characteristics of the participants*

Participants	Gender	Age	Dialysis vintage		Comorbidity status
			PD	HD	
P1	M	76	5 y.	8 y.	Ischemic heart disease
P2	F	64	-	1 y.	Ischemic heart disease
P3	F	77	-	4.5 y.	Hypertension
P4	M	81	-	7 y.	Hypertension & Lymphoma
P5	M	77	-	12 y.	Ischemic heart disease & Hypertension & Peripheral vascular disease
P6	F	61	-	7 y.	Hypertension & Thyroid disease
P7	F	48	-	2 y.	Diabetes & Hypertension & Amputee
P8	M	75	-	6 m.	Hypertension & Rheumatoid arthritis
P9	M	76	-	2 y.	Hypertension & Diabetes & Ischemic heart disease
P10	M	79	-	3 y.	Hypertension
P11*	M	58	8.5 y.	6 y.	Hepatitis C
P12	M	82	-	8 m.	Hypertension
P13	F	78	-	2 y.	Diabetes & Cervical cancer
P14	F	48	-	2 y.	Hypertension

*had kidney transplantation (7.5 y.). y: years; m: months.

Table 4.2 summarises the themes and subthemes developed as a result of the analysis which was conducted both at semantic and latent levels. The participants' illness appraisal was an important aspect of their illness experience as it included the process of sense making and expectations of prognosis. With the consequences of HD, the participants' life experiences were affected in different aspects. The participants mainly discussed physical and emotional changes they experienced. Another critical aspect of the participants' experience was around their active coping strategies which helped them to cope with the burden of HD and illness-related difficulties. Three themes and relevant subthemes are discussed in more detail below with illustrative data examples. Quotations from the interviews were presented both in the original language and English translation in order to aid readers with relevant language skills to have context at source.

Table 4.2: *Summary of thematic analysis*

Themes	Subthemes
1. Illness appraisal	1.1 Sense making
	1.2 Causal beliefs
	1.3 Expectations for the future
2. Life changing effects	2.1 Physical
	2.2 Emotional and cognitive
	2.3 Social restrictions
	2.4 Normalising haemodialysis
3. Active coping strategies	3.1 Religious /spiritual attitudes
	3.2 Social Support
	3.3 Cognitive reframing

4.3.1 Illness Appraisal

This theme relates to how participants' respond to interpret their condition. It included 3

subthemes focusing on causal beliefs (causality), views and expectations related to the future

process (timeline & concern) and sense-making (identity).

4.3.1.1 Causal beliefs

The participants did not have a clear idea about the cause of their illness therefore, most did

not indicate any specific cause:

> herhangi bir nedeni yok herkese olabilir yani yemekten ya da beslenmeden dolayı
>
> herhangi bir nedeni yok [there is no a specific reason, it (CKD) can happen to anyone,
>
> so it is not because of a food or dietary, there is no cause], male participant, 76.

> işte ben de bilmiyorum neden… heralde (doktorların) bir bildikleri var [I have no idea
>
> why it (CKD) developed... Perhaps they (doctors) know], female participant, 48.

Some of the participants had few assumptions based on their medical background. For instance, some believed the treatment they received for another health problem triggered CKD:

> grip oldum, öksürük falan, 5 gün hastanede yattım. Ateşim yoktu, verilen antibiyotik böbreği bozmuş ve keratin 6,33 oldu bir anda… öksürük için kullanılan antibiyotik böbreği bozdu [I had flu and cough, I stayed 5 days in the hospital, I didn't have a fever, the antibiotics that they gave me damaged the kidney so my creatine value reached 6.33 suddenly… the antibiotics used for the cough deteriorated my kidney], female participant, 77.

Another participant who also believed that the wrong treatment was the cause of his kidney disease said:

> benim sızılarım vardı… mide doktorum sana kuvvetli bir ilaç vereceğim dedi… 3. Güne çok kötü oldum… karaciğerin yarısı gitmiş… böbrekler de gitmiş [I had pains… the doctor whom I visited for my stomach said to me that he will give me very strong medicine… my condition was really bad on 3rd day… half of my liver and my kidneys deteriorated], male participant, 75.

Similarly, another participant reported that:

> bana dediler ki senin tansiyonun var, yüksek tansiyon. Hap verdiler, iki ay o hapı kullandırdırlar… Meğerse benim tansiyonum yok…yanlış tedavi… X'deki (başka hastanedeki) doktor söyledi [they (doctors) told me that I have hypertension. They prescribed pills, they made me to use those pills for two months… But I don't have hypertension… wrong treatment… The doctor from X (another hospital) said so], female participant, 48.

Likewise, few participants believed that the treatment he received for hypertension led to kidney disease:

doktora götürdüler beni, bir ölçtüler tansiyonumu 12 e 24… hap verdiler… tansiyon hapı kulan dedi bana… ondan olmuş olabilir [they (my children) took me to a doctor, they (doctor) measured my tension… it was 12:24… they (doctor) prescribed me a pill… he (doctor) told me to use the pill for hypertension… maybe it (kidney disease) occurred because of that], male participant, 81.

yüksek tansiyonum vardı benim … senelerdir tansiyon hapı içerdim… 3 tane 4 tane günde… ondan diye bilirim ki böbrekler bozuldu [I have had hypertension… I have used pills for hypertension for years… 3 or 4 per day… I know that they are the reason my kidneys deteriorated], male participant, 77.

On the other hand, some participants assumed hypertension was the cause of their illness:

ben anlayamıyorum neden … ben işteydim birden tansiyonum çıktı… böbrekmiş… hastanede 3 ay yattım ve o günden diyaliz hastası oldum [I don't know why… I was at work, suddenly my tension increased… it was a kidney problem… I stayed at the hospital for 3 months and I am dialysis patient since then], female participant, 61.

ansızın tansiyonum çıktı 19'a geldim doktora, dedi ki böbreklerin iflas etti [my tension suddenly increased to 19, I went to see a doctor, he told me that my kidneys deteriorated], male participant, 58.

Despite not sure about it, hereditary was also among the causes some participants assumed:

doktorun demesine göre kalıtımsal olabilir, annemde babamda böyle bir hastalık yok… ama benim bir ufağım, kardeşim var onun da başladı… o henüz diyalizde değil ama diyettedir [according to what doctor said, it can be related to hereditary, my mother and father did not have kidney problem but my younger brother just started to

develop kidney problem, but he is not on dialysis yet, he is on a diet currently], female participant, 64.

Overall, there was no consensus regarding the perception of causality among the participants. Where offered, explanations were varied with no core cluster of attributions made.

4.3.1.2 Sense-making

The participants believed they did not receive sufficient explanation related to their condition especially at the diagnosis process where patients require much information about the CKD and dialysis:

daha fazla bilgi edinmek isterdim… yeterli değildi… hastaları bilgilendirmeleri lazım düzenli [I would like to get more information… it was not sufficient… they (health care professionals) should inform patients regularly], female participant, 61.

ben öğrenmek isterdim (diyalizi)…seni makineye yollayacağız dediler… ben sordum… gidersen göreceksin dediler [I would like to learn about it (dialysis)… they (health care professionals) told me "We will send you to the machine" I asked…they told me "You will find out when you go"], female participant, 48.

Another participant mentioned that she did not have any idea of dialysis:

beni katater takılması için bir yere yolladılar, onu bile bilmezdim, gidince öğrendim ne olduğunu [they (health care professionals) sent me somewhere to put in a catheter, I didn't even know what it is, I found out later], female participant, 64.

Other participant said the only thing she knew that she should start to receive dialysis to survive:

bana birşey anlatmadılar… bana birtek böbreklerimin iflas ettiğini, diyalize

bağlanmazsam 3 gün, 4. Gün … hayatına son verirsin dediler [they (health care

professionals did not explain at all… they only said my kidneys deteriorated and if I

don't receive dialysis… on 3rd or maybe on 4th day I will die], female participant, 48.

Most participants reported their kidneys deteriorated quickly although they did not have

symptoms earlier. That is, the process of getting the diagnosis was short. With the severity of

the condition and with the critical attitude toward local health care, most participants

attempted to get confirmation about the diagnosis and treatment. Therefore, they visited

healthcare centres in Turkey and south Nicosia (Republic of Cyprus) other than local

hospitals:

İstanbul'da bir profesörden randevu aldık ona gittik… sonra Güney'de doktora gittik

ama o da söyledi artık birşey yapılamayacağını ve diyalize başladım [we booked an

appointment from a professor in Istanbul, we visited him… then we went to a doctor

in South (Nicosia) but he said there is nothing to do and I have started to dialysis

treatment], female participant, 64.

Another participant also wanted to get confirmation whether the dialysis was the only option

for this condition:

yengem Türkiye'de doktordur, beni orda başka bir doktora götürdü, o da diyalize

devam etmek gerektiğini söyledi [the wife of my brother is a doctor in Turkey, she

took me another doctor there, he also said that I should maintain dialysis treatment],

male participant, 79.

4.3.1.3 Expectations for the future

Participants were hopeful for the opportunity of kidney transplantation surgery. Although most participants' age was critical for the kidney transplantation surgery, they hoped for an opportunity for the transplantation. However, those who were eligible in terms of their age did not accept the transplantation suggestion from their own family. They had a negative opinion about getting a kidney from their partners/children. The reason for rejecting the donation from the family members was the fear of possible damage to the well-being of the relative by making him/her 'deficient'. As transplantation may end the necessity of dialysis, this could mean to obtain the normality back again hence, deceased donation was at the forefront for most:

oğlum bana dedi ben vereceğim, dedim kabul etmem! Ben yaşadım yaşayacağımı zaten, oğlumu da yarım yapamam… şimdi kızım diyor, 18 ine gelince ben vereceğim diyor… asla! Öleceğimi bilsem bile gene çocuklarımdan almam… ama hastanede adım var [my son said to me that he will give his kidney to me, I said to him that I do not accept! I have lived this much anyway, I cannot make my son half also… now my daughter has started to say that she will give me a kidney when she is 18 years old… never! Even if I know that I will die I will not accept a kidney from my children… but I am on the list (for transplantation) at the hospital], female participant, 48.

Similarly, another participant refused his children' attempt to check blood test to find out whether they can donate:

çocuklarım istedi bana versinler, hayatta almayacağımı söyledim… hiç kontrol bile ettirmedim uyar mı diye [although my children offered to donate their kidney, I told them I would never accept it… so I didn't even allow them to do the tests], male participant, 76.

Another participant hoping for transplantation from cadaver said:

kadavradan olursa… inşallah! çünkü eşimi tehlikeye atmak istemem, çocuklarımı hiç istemem [if it (transplantation) happens through cadaver…God willing! Because I don't want to put my partner in danger, and particularly my children at all!], female participant, 64.

The participants argued about their feelings as well as expectations related to future. They were afraid of being dependent on someone else in future when their condition worsens. As they were physically independent, the idea of losing independence was worrying them. Regardless of holding positive or negative views about their condition, the fear related to the possibility of being dependent as well as being a burden on somebody else was prominent:

bir korkum var, şimdi bazı gün oğlum/ hanım bazen de iyi hissedersem kendim (diyalize) giderim, ama ilerde yalnız gidemeyeceğim günler olacak ve beni hastaneye götürmek zorunda kalacaklar, geleceğimle ilgili birtek bundan korkarım, getir götür çok zor [I have only a fear, sometimes my wife or my son takes me to dialysis, or sometimes when I feel good I go to dialysis alone, but I will have days that I will not be able to go to the hospital alone in the future, therefore, they (wife or son) will have to take me to dialysis, this is the only fear I have related to my future, it will be very difficult to take me hospital and bring back home], male participant, 76.

Another participant expressing her fear of being dependent on someone else said:

mesela annem yatalak değil ama bakıcısı var. Eşimin annesi yatalak oldu… o yaşamak değil bence [for instance, my mother is not bedridden, but she has a caregiver. My partner's mother has become bedridden…it is not living life, I think], female participant, 64.

On the other hand, the participants also expressed their fear related to possible complications during dialysis sessions that they may face. Based on their own or other patients' experiences,

they had assumptions about possible complications such as, low blood pressure and pain. For instance, one participant who often experienced intense pain during the dialysis said:

yani öyle bir hale gelin artık ki (diyalize) gideceğin gün korkarsın, yani bugün ne olacak diyalizde diye düşünürsün… ağladığım, bağırdığım günler olurdu ağrıdan [you start to feel fear on the day that you will go to dialysis, you start to think about what might happen today at the session, there were days that I was shouting and crying because of the pain I had], male participant, 77.

Another participant who was also concerned about dialysis-related possible complications said:

devamlı korku içindeyim… diyalizden çıktığımda yürüyemem, tansiyonum düşer [I am always in a fright… I cannot walk when I finish the dialysis session, my tension goes down], male participant, 58.

Although it was not explicitly expressed, some participants had anxiety of death. One participant even refused to use the word *death*, instead, she used the word *white house* to represent life after death and she said:

ya iyi olacağız ya da beyaz eve gideceğiz, başka çare yok [either we will be fine or we will go to the white house (life after death), there is no other option], female participant, 78.

One of the participants mentioned some parts of a conversation she had with his son:

oğluma diyorum… oğlum mürvetini göreyim de öyle öleyim diyorum [I am saying to my son that I may die after seeing you getting married], female participant, 48.

Similarly, another participant said:

bunlar (diyaliz ile ilgili zorluklar) kolay değil bir insan için… yani o akibetin bizi (diyaliz hastalarını) beklediğini biliriz [these (complications related to dialysis) not

easy for a person to experience… so we (dialysis patients) know that consequence (death) is waiting for us], male participant, 77.

There was disagreement in terms of expectation of prognosis across the interviews. Those who had a more positive overview of their condition were optimistic about the future process of their illness:

güzel günler bekliyoruz ki gelecek güzel olsun… bazı arkadaşlarım (diğer hastalar) ölsek de kurtulsak diyor… bu yanlış bence [we expect beautiful days so that we will have beautiful future… some friends (other patients) wish to die to get rid of this disease… this is a wrong idea I think], female participant, 61.

Similarly, another participant who had positive attitude said:

sağlık diliyorum… elimden ne geliyorsa yaparım sağlık için [I wish for health… I am ready to do anything for health], male participant, 75.

On the other hand, those who negatively evaluated their illness were quite pessimistic about the progression of their disease so that they had negative expectations regarding their condition in the future:

çok kötü günlerin beni beklediğine inanırım, çok kötü günler… Çünkü benden kötü olanların durumunu görürüm [I believe there are very bad days waiting for me in future, very bad days… because I see those who are in worse condition now], male participant, 76.

böyle gidecek artık…hastane bize son duraktır sonrası mezarlık [things will go in this way from now on… the hospital is the last stop for us], female participant, 77.

Another participant described dialysis as a *medical dressing* which only helps to survive because the *wound* would never get healed meaning kidneys would not get back to normal functioning:

bu işin tedavisi yok… yapılan pansuman gibi birşey… bu iş (diyaliz) başladıysa gittiği yere kadar gider… bu işin tamiri yok… kırığı onarmak gibi birşey değil ki doktor seni iyileştirsin… bu işin geriye dönüşü yok… yani doktor seni tedavi edemez [there is no treatment for it (kidney failure)… (dialysis) treatment is like a medical dressing… if this (dialysis) has started, it will continue as long as it takes… there is no way to fix it… it is not like fixing the broken part of the body where a doctor could heal you… there is no going back… so the doctor cannot treat you], male participant, 82.

4.3.2 Life Changing Effects

This theme represents the changes the participants' experienced as their life experienced changed with the HD. These changes were discussed in different aspects. This theme was dominant across the interviews and it included 4 subthemes describing physical, emotional changes, social restrictions and normalising HD.

4.3.2.1 Physical

Most participants experienced several physical changes after they started to receive HD treatment. Persistent exhaustion and fatigue were a common complaint. It was considered as a significant obstacle to maintain social activities and to be an active person. The participants agreed exhaustion was an observable effect in their life which changed their routine hence they experienced themselves as someone different who was unable to do things in the same way as in the past. For instance, fatigue associated with otherwise day-to-day activity:

tam olarak iş yapamazsın… bir yere yürümek istediğinde yorulursun… temizlik yapmak istediğinde de yorulursun [you cannot do your things properly… you feel tired when you feel like walking somewhere… you also feel tired when you want to clean], female participant, 48.

yorulurum, (ev işi) yapamam zaten… bir kilo bile kaldıramam [I am exhausted, I cannot do it (housework) anyway… I cannot even lift one kg weight] (female participant, 48).

One of the participants described his experience of exhaustion saying:

diyalizi alıyoruz, yoruluyoruz, ertesi güne bile yansıyor, sabah yorgun kalkıyoruz [we receive dialysis, we become exhausted, it even affects next day so you get up exhausted], male participant, 76.

Another participant tried to describe how exhaustion influenced him as whole:

özellikle diyalizden çıktıktan sonra 1-2 saatte ancak toparlanıyorsun, (diyaliz) adam akıllı yorgunluk verir, hatta beyin yorgunluğu bile verir [you need a couple of hours to put yourself together particularly after the dialysis session, it causes exhaustion, even mental exhaustion], male participant, 77.

The participants also reported they felt weak and powerless:

halsizlik var… yürüyememe var… güçsüzlük var [I feel weak, I cannot even walk, I feel like I don't have strength], male participant, 75.

Another participant mentioned she tended to feel weaker particularly on the last day before the dialysis session:

Pazartesi özellikle Salı günü evden çıkmak istemem, her yerim şişer, sesim de değişir çok kötü olurum diyalizi almadan önce [on Monday especially Tuesday, I don't feel like going outside, all parts of my body swell, my voice even changes, I feel so bad before receiving dialysis], female participant, 64.

Weakness was also obvious across the data as the participants' life experience mostly affected by it:

enerji kalmaz, bazen dışarı çıkacağım, arabayı sürecek gücüm olmaz [there is no energy, sometimes when I want to go outside, I do not have the energy to drive the car], female participant, 77.

Most male participants particularly stated how weakness was closely associated with their sexual life:

seksin azaldığını hissederim, gücün yok [you feel that sexuality decreases, you do not have strength], male participant, 76.

bazı fonksiyonlar (cinsellik) değişir, gerçekten değişir… ve bu değişikliklere alışmak hiç kolay değil [some of the functions (sexuality) changes, really changes… and it is not easy to get used to these changes at all], male participant, 77.

For the male participants, this was quite an important indicator of the negative change, and likely made those participants have a negative view about themselves. This was considered as 'negative self-concept' which may be a cognitive change hence it is discussed in detail below.

4.3.2.2 Emotional and cognitive

Participants' negative views about themselves were noticeable across the dataset. A participant reported:

benim için bu hayat değil ama yaşıyorum… işte [this is not a life for me, but I am living… like this], female participant, 48.

They expressed to feel not normal functioning individual:

normale döneceksin diye birşey yok… olmaz [there is no such thing that you can get back to normal… no way], male participant, 82.

The participants expressed feeling less than normal, describing this as "half" of themselves after they started to receive HD:

> değiştim… aynı değilim… yarıbuçuk değil de buçuğun buçuğu oldum [I have changed… I am not same anymore… not even a half, I have become a quarter of the quarter], male participant, 75.

They associated these feelings with weakness. They explicitly indicated that they do not feel strong as they felt before the HD treatment. 'Feeling half' and 'feeling of not being a normal person anymore' were identified as a negative self-concept. Notably, male participants related to these feelings to their negatively affected sexual life. When they explained their *feeling of less than normal*, some also said they were not sexually active anymore:

> kendini *yarım* hissedersin, seksin azaldığını hissedersin, gücün yok [you feel yourself *half*, you feel that sexuality decreases, no strength], male participant, 76.

On the other hand, some female participants linked being 'half-person' with an inability to do housework and disengagement with the social activities:

> aynı değilim artık… (diyalize başlamadan) evvel, gezmeye giderdim [I am no longer the same person… I used to go out for trips (before starting to dialysis)], female participant, 78.

For some participants, the first months of the HD treatment were quite demanding. Some described themselves as *a dead person* at the beginning of the treatment. They felt like they did not function as a normal person at all, because of the burden of HD:

> böyle yaşamaktansa öl daha iyi... bir anda bu kadar güçsüz düşmek… öl gitsin artık o demektir [instead of living like this, it is better to die... suddenly losing all your strength... it means to die], female participant, 77.

This evidences the overlapping nature of physical and emotional/cognitive symptoms in that they are interconnected.

With the physical and cognitive changes, the participants also mentioned experiencing emotional changes. Anger emerged as one of the most obvious emotional changes that participants experienced. Most participants experienced more intense anger at the beginning of the HD treatment:

> ilk zamanlar çok sinirlenirdim [in the beginning, I used to be very angry], male participant, 76.

Particularly, the participants reported getting angry when they noticed their inability to complete a job because of fatigue:

> hele ilk başta… ağrın olur… ansızın sinir olursun [especially at the beginning… you are in pain… suddenly you feel angry], male participant, 77.

Frustration was mainly related to the fact that HD is an apparent obstacle negatively influencing the life experience:

> elim ayağım kesilir… bir iş yapamam canım sıkılır [I don't have strength at all… I cannot do any job I feel frustrated], male participant, 58.

Some said that they could not even control over their anger:

> (HD) insanı çok değiştiriyor… biri sana birşey dese hemen bağırıyorsun [it (HD) changes the person a lot… if somebody says something, you immediately start to shout], female participant, 48.

HD was necessary treatment, at the same time, it caused some changes in their life, therefore the participants felt frustrated. Intense frustration at the beginning of the treatment was related to the sudden change they experienced. Considering the majority of the participants' kidneys suddenly deteriorated, they had to start to receive HD immediately. They did not have sufficient time to be psychologically prepared for the treatment:

> bayağı hızlı oldu, o zamanlar ne yaşadığımı ne olduğunu pek hatırlamam, kızım yanımdaydı, o anlattı sonradan çok sinirli olduğumu, onlara o dönem hep kızdığımı [it was quite fast, I do not remember well how I felt and what I experienced that time, my

daughter was next to me, she told me later that I was really angry and I was getting angry at everyone], female participant, 64.

Some participants did not have time to discuss the dialysis treatment options and expectations related to the future process:

benim öksürüğüm vardı... 5 gün hastaneye yattım... 2 veya 3 gün sonra … (doktorlar) diyaliz dediler... öfkelendim hastaneden çıktım [I had cough... I stayed at the hospital for 5 days... 2 or 3 days later... (the doctors) they said that I should start to receive dialysis... I was really angry, I left the hospital], female participant, 77.

This unexpected experience seems like a critical factor that caused intense anger at the beginning since the participants suddenly become 'sick' who had to receive HD to maintain their life.

This sudden change also led to sadness especially at the beginning of the HD treatment:

ilk seneler Kıbrıs'ta o kadar insanın içinden bir beni mi buldu bu hastalık diye düşünürdüm [first years, I was thinking, among all the people in Cyprus, why this illness found me], male participant, 76.

After a while, the participants accepted the necessity of the treatment (please see section 3.2.4). However, sadness seems as dominant emotion among the participants regardless of their dialysis vintage:

insan illaki üzülür… üzülmez mi? ben buyken bu oldum demez mi insan [of course, the person feels sad… is it possible not to feel sad? You tell yourself that I was like that before… now I am like this], male participant, 75.

Another participant mentioned she also had to deal with unwanted thoughts (death) along with sadness:

insan illaki düşünüyor… düşünüyorsun işte… üzülürsün… bazen yattığım yerde düşünürüm… neler gelmez aklıma!, bu sefer uykum kaçar… çocuklarm daha bekar,

ya bana bişey olursa… [the person surely thinks about it… so you think… you feel sad… sometimes I start to think when I am in the bed… many thoughts! And I lose my sleep overthinking… my children are still single, what if something happens to me…], female participant, 48.

Sensitivity was observed as one of the recurrent emotional changes across the interviews. Mostly female participants explicitly expressed to become sensitive after HD treatment:

daha uysal biri oldum… mesela birşey olduğunda hemen ağlayabilirim… ara ara… yaşlar gözümden akar işte [I have become softer person… for instance, I can cry immediately when something happens… sometimes… my tears flow], female participant, 64.

Another participant mentioned about feeling easily offended:

değiştiriyor seni… en ufak birşeyden kırılıyorum, en ufak birşeyden alınıyorum [it (CKD) changes you… I can be broken from even the smallest thing, I can be offended by the smallest thing], female participant, 48.

As the participants experienced emotional distress regarding the diagnosis of the illness and the requirement of the treatment, they naturally expressed their emotional burden more and they attributed this as 'becoming sensitive':

ruh halini darmadağın eder… psikolojik, duygusal yönden insanı çok etkiler bu hastalık [it (CKD) destroys your mood… this illness really influences the person in terms of psychological and emotional aspect], male participant, 76.

For some participants, HD treatment caused even a big emotional change that they distinguished their emotional status as before and after the treatment:

hastalığımdan sonra oldu ben şimdi mesela hasta insan göreyim… acı çeken insan göreyim ağlarım, duygusal oldum sanki… eskiden cenazede bile ağlamazdım, şimdi ağlıyorum… belki diyorum kendi çektiğimden mi acaba ama duygusal oldum sanki

[this happened to me after the diagnosis of my disease, now if I see a sick person…

those who suffer… I cry I have become sensitive, I think… I didn't even cry at a

funeral before, I cry now… maybe I feel in this way since I am suffering from this

illness... but I have become sensitive, I think], female participant, 61.

On the other hand, one of the participants expressed becoming indifferent particularly related

to dietary recommendations. Although the participants knew HD treatment was critical for

their survival and they attended dialysis sessions, some did not strictly adhere to the food

restrictions which is another important aspect for the illness progression and treatment:

geçen gün, aldım muzumu gittim diyalize, başlamadan yerim diye düşündüm, hemşire

aldı masaya koydu, çünkü bize yasak, alma muzumu dedim ben yiyeceğim, ve bir

güzel aldım yedim, diğer hemşire başladı bağırsın 'potasyumdur, kalp kasılır', yahu

benim potasyum değerim limitin altındadır, bırak dedim karnım aç öleceğime tok

ölürüm (gülerek), yani bu kadar vurdumduymaz oldum ben artık [I took a banana and

went to dialysis (hospital), I thought I can eat it before it (dialysis) starts, a nurse took

it and put it on the table, because it is forbidden for us, I said to her: 'Don't take my

banana, I will eat it' and I took it and ate it, another nurse started to shout: 'it has

potassium, it causes heart contractions!', my potassium level is under the limit, I said

to her: 'instead of dying hungry, I will die my belly full' (with laugh), so I have

become indifferent now], female participant, 77.

4.3.2.3 Social restrictions

The participants felt that they were socially restricted since they had to attend dialysis

sessions 3 times a week. The time they had to spend at the hospital for the dialysis sessions

limited their engagement in with the social life. Although most were retired, they felt they

had limited time to arrange activities that they were otherwise interested in:

mesela ben şimdi Türkiye'ye gitmem gerek çok önemli işlerim var ama gidemiyorum [for instance, I now should travel to Turkey, I have very important things to do but I cannot travel], male participant, 75.

The fact that dialysis sessions are scheduled three times a week was also an obstacle for holiday trips:

biz (eşim ile) emekliyiz şimdi gezeceğiz diye düşünüyorduk ama haftada 3 gün diyaliz varken nasıl gezeceğim? Bir kere Paris'e gittik ama iki gün sonra dönmek zorunda kaldık çünkü ertesi günü diyaliz günüm vardı. Ben gezmek istiyorum ama gezemiyorum [we (with my wife) are retired, we were thinking that we would go for trips when we were retired, but how do I go for trips when I have dialysis 3 times in a week? Once we went to Paris, but we had to return after two days since I had dialysis on the next day. I would like to go on trips, but I cannot], male participant, 76.

Therefore, some of the participants had to re-schedule their planned holidays:

istediğim yere tatile gidemem. Gitsem gittiğim yerde diayliz servisi aramak zorundayım. Mesela kızımın İstanbul'da evi var, eskiden çıkıp giderdik. Şimdi nasıl gideceğim, gidemem, o yüzden tatili burada yapacağız… kültür gezilerine Doğu'da (Türkiye'de) isterdim katılayım ama kısmet olmadı [I cannot go anywhere I want for a holiday. If I go, I need to search for a dialysis centre. For instance, my daughter has a house in Istanbul (Turkey), we used to go there. How will I go there now? I cannot, therefore we will have a holiday here (North Cyprus) … I wish I could join cultural trips in East (Turkey) but it wasn't meant to happened], female participant, 64.

Additionally, fatigue and weakness restricted the participants' social activities:

yürüyemem, dışarı da çıkamam, araba süremem… devamlı ağrılarım olur… mesela eskiden biraz bahçe ile uğraşırdım çünkü severdim bahçe ile uğraşayım [I cannot walk, I cannot go outside, I cannot drive a car… I always have pains… for instance I used to take care of my garden, I used to love take care of it], male participant, 77.

As the participants frequently felt fatigued, they did not feel powerful enough to be socially active:

> önceleri sinemaya giderdim, heryere giderdim… tabi şimdi gidemem öyle yerlere artık… (diyaliz) etkiler [I used to go to cinema, to everywhere, (before starting to dialysis) … of course I am not able to do these kinds of activities anymore… (dialysis) affects me], female participant, 78.

Although the primary focus was around the participants' perception of their own social lives, they also mentioned how dialysis negatively affected the family's routine also:

> bütüngün evde hanımla, dışarı çıkamayız… sadece sen değil ailen de mağdur olur [we are always at home with my wife… so it is not only yourself, but your family is also affected by this], male participant, 77.

> hastanede yatırım, evde de yatırım, bütün hayatın alt üst olur, sadece benim değil karımın da [I lie down at the hospital, I lie down at home, your life becomes upside down, not only mine but also my wife's], male participant, 76.

4.3.2.4 Normalising haemodialysis

The participants reflected dialysis as part of their lives. They somehow normalised the fact that they had to attend dialysis regularly. The significance of acceptance of the dialysis treatment was evident in all interviews. The participants clearly stated how acceptance of the treatment is critical to survival:

> bazı arkadaşlarım var öleyim de kurtulayım diyor… yanlış! … komşumun bir oğlu vardı bir yıl olmadan çocuk öldü çünkü psikolojik olarak kendini bıraktı… sigara içmemesi lazım içiyordu… dinlemedi… (diyaliz tedavisini) kabullenmen lazım!

[Some of my friends say *let me die and get rid of it* … wrong! … My neighbour had a son, it didn't take even a year, he died because he was not good psychologically… he shouldn't smoke but he was smoking… he didn't listen… you must accept it (dialysis treatment)!], female participant, 61.

Most recognised possible consequences in case not accepting to receive dialysis treatment regularly:

bu hastalığı kabul etmeyen ölür… bir adam vardı yanımda yatırdı… ben senin gibi değilim derdi bana. Diyalize gelmek istemezdi, şimdi öldü [whoever did not accept this disease died… there was a man who was on the next bed at the hospital (for dialysis) … he was telling me: 'I am not like you'. He didn't want to receive dialysis, he died later], male participant, 76.

Although they stated acceptance is vital for the treatment, they found dialysis demanding. The participants knew they had to attend dialysis sessions to maintain their lives hence, they felt like they were forced to adjust to the HD. Their motivation for the adjustment was to decrease the possibility of negative outcomes such as, worsen kidneys, and accordingly extended dialysis sessions:

bu işe mahkumsunuz… mecburen giderim… ama görürüm bazıları gitmek istemez, ama bu iş kaytarmaya gelmez, aksi takdirde 4 saat diyaliz süresi 5 saate çıkabilir… böbrek kötüleşebilir, o yüzden kaytarmamak lazım, evet zordur ama başka çaresi de yok [you are obligated to… I go to dialysis because I have to… but I see some patients do not want to go, but dialysis cannot be skipped, otherwise, you might end up spending 5 hours instead of 4 hours in the dialysis session… the kidney may worsen, that is why, you should not skip, yes it is difficult but there is no other cure], male participant, 82.

One of the participants similarly emphasized the cost of not attending the dialysis sessions:

> gelmezsen (diyalize) hasta olursun… mecbur alıştık [if you don't come to dialysis session you become ill… we are obligated to get used to it (dialysis)], male participant, 58.

The majority of participants reported feeling obligated to adapt to HD treatment as there was no alternative option:

> alışırsın ister istemez, başka çaresi yok, alışmamak diye bir durum yok [you get used to it of necessity, there is no other choice, there is not a chance of not getting used to it], male participant, 76.

One of the participants seemed powerless to do anything but get used to dialysis as there was no alternative treatment other than HD treatment:

> düşmeye gerek, düştükten sonra başka çare yok (hastalığa yakalandıktan sonra tedaviye alışmaktan başka bir şansın yok) … iyiliğimiz için katlanacağız [there is no alternative way other than getting used to the treatment after you diagnosed with an illness… we will bear with it for our wellbeing], female participant, 78.

Similarly, another participant who wishes to get better health recognised dialysis as the only treatment:

> eskiden haftada 2'yi şimdi 3 oldu… gelmeye devam edeceğiz… iyileşmek istiyorum… mecbur geliyoruz… doktorlar gelmek zorundasın demese gelmeyeceğim [It (dialysis) was twice in a week not it is now three times in a week… we will continue dialysis treatment… I want to recover… I am obligated to come (for dialysis) … If doctors would say *you do not have to come*, I would not come (for dialysis)], male participant, 75.

As other patients become part of the participants' lives, the illness experiences of those patients were also important for the participants. Across the interviews, the participants

emphasised the influences of the other patients' conditions. Comparison with other patients' condition also acted to normalise both some positive and negative elements of life on HD. Some participants appreciated their condition when they witnessed worse conditions:

> diğer hastaları görürüm, eli ayağı tutmaz… öyle olmadığım için kendimi rahatlatmaya çalışırım [I see other patients, they are feeble… I try to feel better as I am not like them], female participant, 64.

One of the participants mentioned about her reaction towards younger patients:

> genç hastaları görünce ben kendi derdimi unuturum [when I see younger patients, I forget my problems], female participant, 77.

On the other hand, some experiences with patients acted to confirm the temporary nature of HD, something which has to be accepted. For instance, one participant who lost a friend (another patient) who received dialysis said:

> diyalize gittiğimizde yan yana yattığımız arkadaşı ertesi gün göremediğimizde, ne oldu diye sorarız, öldü derler, sapasağlam sohbet ettiğimizin ertesi günü insanlar ölür [when I didn't see my friend (another patient) who normally lie down next to me (at the hospital for during the dialysis session) and I asked what happened to him, they (health care professionals) told me that he was dead… those in good health status, we chat normally but they can die the next day], male participant, 77.

Similarly, the participants felt uncomfortable when they talked about other dialysis patients who lost their lives:

> zordur söylemesi ama…orda ben bir iki tane malesef ölen insan gördüm… bunun kaçınılmaz son olduğunu anlarsın [it is hard to say but… I have seen some people who died there (dialysis service) … you understand that this is the inevitable consequence], male participant, 82.

4.3.3   Active Coping Strategies

This theme was generated to represent coping strategies the participants adopted to cope with the burden of HD. These strategies were summarised in 3 different subthemes which include religious/ spiritual attitudes, social support and cognitive reframing.

4.3.3.1 Religious/ spiritual attitudes

Attitudes related to fate were recurrent and represented the idea of '*it is meant to happen*'. The participants highlighted the role of fate by indicating how they had limited control over their disease because of fate:

> ne yapalım oldu… benim elimde olan birşey değil, kaderde varmış [what I can do… it is not something that is in my hand, it was in my fate], female participant, 48.

For some participants, belief in fate even facilitated the acceptance of the illness and the treatment:

> zaten Allah'tan gelen birşeydir, kullardan gelen birşey değil ki… kabulleneceksin ki hayatın daha normal geçsin, başka çaresi yok… [it (illness) is something that comes from God, it is not something that comes from the people (servants)… you have to accept it to have a more normal life, there is no other option], male participant, 76.

Similarly, another participant believed that complying with destiny would make it easier:

> ne yazılıysa olur, bunu değiştirecek bir durumumuz yok… o yüzden kaderine razı olacaksın ve bu iş böyle yürüyecek başka çare yok [whatever is written will come true, we are not in a position to change this… hence, comply with your destiny and things will carry on according to its track, there is no other choice], male participant, 81.

Another participant reported that his belief in fate comforts him psychologically:

şükür ediyorum… kadere inanan birisiyim… takdiri ilahi diyorum… ben inanıyorum

ve bu beni rahatlatıyor [I thank God… I am someone who believes in fate… I think

this is the will of God… I have faith and this makes me relief], male participant, 75.

The participants explicitly expressed their gratitude toward God for not being in a worse

condition. Thanking/appreciating for the current status was perceived as a way of avoiding

from the negative thoughts about the illness:

Allah'a şükür edeceksin… yoksa düşündük sonra daha kötü olur [you should say

thank God… otherwise, it gets worse if you keep thinking about it], male participant,

81.

Similarly, the participants also prayed God to not to be in a worse condition in future:

her zaman dua ederim, kurbanım Allah'a beni yatalak yapmasın, ona dayanamam [I

always pray God that I do not want to have to become bedridden, I cannot bear with

it], female participant, 48.

The participants had difficulties as their life experience was influenced, however, they were

still thankful for their health status because there is always a possibility that their condition

can worsen:

çok şükür! Hep böyle kalsın da birşey değil [thank God! there is no problem if our

condition remains steady], male participant, 77.

buna da şükür diyorum… elim ayağım tutuyor… evin işini yapıyorum belki başkası

olsa yapmaz [Thank God for this… I am physically strong… I do housework maybe

someone else could not do it], female participant, 61.

As participants had an idea about other patients' conditions, they compared it with their

condition and prayed for not being in worse condition like others:

şimdi görüyorum diğer hastaları, eli ayağı tutmaz, Allah onları göstermesin! Öyle olmadığım için kendimi rahatlatmaya çalışıyorum [I see now other patients who are not in good physical health (physically dysfunction), May God protect us from a worse condition! I am trying to relieve myself as I am not like that], female participant, 64.

4.3.3.2 Social support

The participants mainly received social support from the families. This encouraged them to cope with the illness and the burden of HD. Many mentioned their families helping them in daily life such as taking them to the hospital for dialysis or regular appointments, making their food and sharing the housework:

eşim de değişti benimle birlikte, mesela önceden problem yaptığı şeyleri şimdi yapmaz, şimdi görür beni hastayım gitmez dışarı pek, evdedir…mesela yemek yapamazsam bir problem yok… bazen bulaşıklara da yardım eder… çok destektir bana, beni 17:00'de bırakır (diyalize) sonra gelir akşam alır… çocuklarım da çok evhamlıdır, kesinlikle beni yalnız bırakmazlar beni [my husband also changed with me, for instance, he was making a problem related to some things earlier, he now doesn't do, now he sees me that I am sick, he doesn't go outside much, he is often at home… for instance, if I am not able to make food, he doesn't have any problem with it… he even helps to wash the dishes… he supports me a lot, he takes me to dialysis service at 17:00 and later he comes and picks me up… my children are also worrier, they never leave me alone], female participant, 64.

A participant who had PD treatment for 5 years before he started to HD treatment mentioned how his wife was helpful to assist with PD at home:

ilk başladığımda hanıma dedim *sen öğren peritonu (PD) ben istemem*, kabul etmedim ilk. Hanım gelip yapardı, bağlardı beni makineye [when I first started, I told my wife: *you learn PD, I don't want to learn how to do it*, I didn't accept it in the beginning. My wife used to prepare it for me and help me with it.], male participant, 76.

Similarly, another participant stated support she got from her daughter:

kızım işten çıkıp beni götürür sonra işten çıkıp beni almaya gelirdi, çok zor, çünkü 4-5 ay arabayı hiç sürmedim ilk başta [my daughter used to leave from work to take me to dialysis service, and leave again work to bring me back home after dialysis, it was so difficult, because I didn't drive my car for 4-5 months at first (when started to dialysis)], female participant, 77.

As the participants didn't have the same lifestyle any longer such as diet, some participant reported how their family also adapted to these changes. These participants recognised family members' adaptation to these changes as support. This had a positive impact on coping with the demands of the illness:

eşim çok destek bana… ben tuzsuz yerim diye o da tuzsuz, yağsız yer… çocuklarım da destek bana [my partner supports me a lot… he eats without salt and fat since I eat my food without salt and fat… my children also support me a lot], female participant, 61.

As mentioned earlier, most participants experienced many negative events such as physical (e.g., fatigue, pain) and emotional difficulties (e.g., anger, sadness), one of the participants described the change in his life experience as:

düşün ki güzel bir yaşantı yaşıyorsun sonra ansızın maddi olarak iflas ediyorsun, etkilenirsin, bu durumda da (hastalıkla beraber) vücudun iflas eder… bu da sizi etkiler [imagine that you have a great life and suddenly you are financially broken, this affects you... also in this situation (when suffering from CKD) your body is broken/ deteriorated... this also affects you], male participant, 77.

However, the same participant highlighted the importance of family support to enhance

mood: onları (aileyi) düşünürsün, çocuklarla bir araya geldiğinde, üzerinden atarsın

(olumsuzlukları) [you think about them (family) when you come together with

especially children, you get rid of it (negativities)], male participant, 77.

Similarly, gathering with family members and spending time together facilitated the coping

process:

torunum var, evli, 2 çocukları var, bazen hanımı gelir alır beni yemeğe gideriz…

bazen kızım gelir alır beni bazen onun evinde kalırım, oradaki küçük torunlarımla da

vakit geçiririm, çok sevinirim [I have a grandson, married with two kids, sometimes

his wife takes me out for a dinner… sometimes my younger daughter takes me her

house, I stay with them, I spend time with my young grandchildren, I become very

happy], female participant, 78.

Another participant stated she accepted to receive dialysis treatment because she had

children and she felt their support:

ben ilk hastalandığımda, oğlum duvara yumruğunu vurdu, *anne benim için kalk dedi,*

bırakma kendini, ilk defa oğlumu ağlarken gördüm, ikisi (çocuklar) de bana çok

düşkün… dedim kalkacağım başka çaresi yok… o zaman dedim doktora, benim iki

tane çocuğum var ben tedavi olmak istiyorum [when I become ill first, my son

punched the wall and said, *mother! please get up for me, stay with me!* I saw my son

crying for the first time, both (children) are fond of me very much… I said to myself I

should be strong, no other choice… then I said to my doctor that I have two children

and I want to receive treatment], female participant, 48.

4.3.3.3 Cognitive reframing

Across the interviews, the participants shared an attempt to have a positive attitude about their condition. They used several ways to develop a positive attitude about their condition. Some focused on their satisfaction with current capabilities they had. As they found those capabilities adequate, they were satisfied with it:

> arabamı kullanıyorum… diyalize kendim gidip geliyorum… şimdiye kadar bir sorunum olmadı…kendi işimi kendim görürüm [I can drive my car… I go to dialysis sessions by myself… I haven't had any problem yet… I do the errands by myself], male participant, 76.

> ilk hasta olduğumda ki hastaneye yattım, evime geri gelemeyeceğimi sandım… şimdi arabamı kullanabiliyorum, istediğim yere gidebiliyorum, yani birşeyleri kendi başıma yapabildiğimi farkettiğimde daha iyi hissettim [when I was first sick and stayed in the hospital, I thought I will not be able to come back home… I drive my car now, I go anywhere I want, I mean when I realise that I can do things by myself I felt better], female participant, 64.

For some, not having a comorbid condition which could cause extra difficulties was a positive thing and it meant that condition was manageable, and this led to satisfaction:

> diyabet yok… bazen başka hastalık da olunca hepsi (belirtiler) birleşir ama benim öyle bir problemim yok…bu gibi hallerden uzağım, belki uzak olmam da yardımcı olur ama belli bir derdim yok, tek sıkıntım 4 saat, ama sonra değişen birşey yok… idare ederiz [I don't have diabetes… sometimes when there is another disease, all (symptoms) can be experienced at the same time but I don't have such a problem, the only problem is that it (dialysis session) is 4 hours but there is no difference between pre- and after dialysis session… I am handling it], male participant, 82.

Similarly, another participant reported not experiencing many negative consequences related to dialysis which led a positive outlook related to his condition:

> etkilenme gibi birşey yok bende, hiç sorunum yok nasıl girersem diyalize öyle çıkarım [I am not affected, I do not have any problem, I get out from dialysis session as nothing happened (it doesn't affect me at all)], male participant, 79.

On the other hand, some participants tried to displace the thought of having an illness with another thought. They attempted to do this by avoiding the reality that they were diagnosed with KF and required HD. This helped them to shift their attention from negative thoughts. The following quote belongs to a participant who attempted to perceive dialysis as a job that he should go to:

> kendimi kandırmaya çalışırım, sanki bu hastalık benim işimdir, hastaneye haftada 3 gün sanki işe giderim orada verdikleri yemekleri beğenmem ama verdikleri su da benim maaşımdır (gülerek). Yani polyannacılık oynarım! [I am trying to fool myself as if this (dialysis) is like my job that I should go to. I tried to see it as a job. I do not like hospital food, but I consider the water they (hospital) provide as my salary (with a laugh). So, I am being pollyannaish!], male participant, 76.

One participant said that to generalize the chances of developing the disease and to avoid thinking about the disease may help both to comfort themselves and to maintain a normal life:

> herkese olabilir onu düşüneceksin… onu düşününce teselli bulursun… durup düşünürsen hergün mesela ben şeker oldum ne yapacağım ne edeceğim… olmaz… hayat geçmez… normal hayatını yaşaman gerek ama haftanın 3 günü de buraya (diyalize) geleceksin [it can happen to anybody, you should think in this way… if you do, you comfort yourself… if you start thinking every day, for instance: "I have diabetes, what am I going to do now?" no way… the life will be harder… you should

live your life normally but you should come here (dialysis) 3 times in a week], male participant, 76.

Another participant mentioned when he was trying to avoid thinking about his condition, others were reminding him this fact with the 'get well soon!' wishes. This even negatively affected his engagement with the social life for some time, particularly when he started to receive HD at the beginning:

hele ilk zamanlar hiç istemezdim dışarıya gideyim. Ben gülerim (iyi bir ruh halinde olmaya çalışarak) dışarda gördüğüm herkes bana geçmiş olsun diyorlardı, bana niye hatırlatıyorlar hastalığımı? Ben kurtulmaya çalışırım, gerçi kurtulamazsın haftada 3 gün gitmek zorundasın [I didn't want to go outside particularly at the beginning. I am smiling (trying to be in a good mood), anybody I used to see outside was wishing me to get well, why do they remind me of my disease? I am trying to get rid of it, yet you cannot get rid of it, you must go (to dialysis) 3 times in a week], male participant, 76.

Others believed that admitting to being sick was like a self-fulfilling prophecy and they did not want to adopt a *'patient identity'*. They thought rejecting the 'patient identity' could protect them from becoming the ill person as a result, this could decrease the possibility of experiencing negative illness consequences:

hiç kafana takmayacaksın, düşünmeyeceksin… ben hastayım dersen kafaya takarsan hasta olursun zaten [you shouldn't mind at all, you shouldn't think about it… If you say that you are sick and if you are obsessed with it, you will end up sick], male participant, 81.

Similarly, one of the participants mentioned that she was distant to the idea of being a patient and she did not internalize this idea yet:

6 bitti 7 yıl olacak halen daha ben bile inanamıyorum hasta olduğuma… psikolojini bırakırsan gidersin… ama kendime bu hastalığı yakıştıramıyorum [6 years completed, it will be 7th year (with dialysis) but I still cannot believe that I am a dialysis patient…

if you give up on yourself, it will be even worse (you should be strong

psychologically) … but I cannot think about this disease becoming suit me], female

participant, 61.

By rejecting the patient identity, she believed she can be psychologically strong and can

protect herself against the burden of HD.

4.4   Discussion

This study is the first to explore illness perceptions in Turkish Cypriot patients receiving HD.

The findings highlight the treatment burden in HD, which is reported consistently by patient

groups across different cultures (Masina et al. 2016; Sharma et al. 2019; Song et al. 2019;

Zamanian, & Kharameh 2015). Importantly, it has also demonstrated unique cultural

influences on illness representations amongst Turkish-Cypriot patients and associated

implications for how patients make sense of and attempt to cope with illness imposition.

Despite negative outcomes and the difficulties of HD, the participants somehow normalised

their life on HD by acknowledging the significance of the HD treatment. This is supported by

the previous qualitative findings suggesting that patients eventually accept the inevitable

requirement and criticalness of HD for their lives (Wu et al., 2015). Dialysis has been

considered as an imposition which may make the patients feel physically and emotionally and

socially restricted. Although the patients tend to describe themselves as victims of the dialysis

(Jones et al., 2018) and they may feel trapped for their health (Wu et al., 2015), they tend to

show an ability to integrate dialysis into their lives (Tong et al., 2009). Considering that

participants took some time to accept the chronicity of the illness, time may be an important

factor for the normalisation process (Reid et al., 2016; Tong et al., 2009). During this process,

the participants made sense of their illness differently. Accordingly, they differed in terms of

future expectations. For instance, they had conflicting cognitions regarding the possibility of transplantation. Most were not eligible for the transplantation as they were older, yet they still had hope. On the other hand, those who may be eligible in terms of age did refuse transplantation suggestion of family members since they were concerned about risking the wellbeing of a family member. Earlier findings have suggested patients with KF tended not easily accept transplantation offer through living donor because of the idea of putting someone's life at risk (Waterman et al., 2006). Patients receiving KRT may struggle in between the feeling of hope and uncertainty of transplantation (Rees et al., 2018). Overall, the participants who shared a positive view related to their condition seemed to have a positive assumption about their condition. This positive assumption mostly transpired from the comparison between their condition and others' who were perceived to be worse off. Despite the demanding nature of the treatment, holding a positive outlook about the illness has been identified as important for patients receiving HD (Sharma et al., 2019; Tong et al., 2009) and indeed in other health settings (O'Brien & Moorey 2010; Van et al. 2012). Patients may develop strategies to benefit from optimism which may also affect their future expectation (Reid et al., 2016).

The findings are consistent with studies in other cultural settings that echo the treatment burden of HD. It is multifaceted and extended to physical and psychological difficulties (Nabolsi et al. 2015; Shirazian et al. 2017). Fatigue is a prevalent complaint among patients with KF (Davison & Jhangri, 2010; Jhamb et al., 2019; Picariello et al., 2017b). A qualitative study indicated patients even had difficulty to differentiate their fatigue-related and illness-related experiences (Picariello et al., 2018). A recent study found at least 1 in 2 patients receiving HD were clinically fatigued (Picariello et al., 2019). Consistent with the previous findings, the participants in this study emphasised how they frequently felt fatigued and how this negatively affected their involvement with social activities (Horigan et al., 2013). In

parallel with a prior qualitative study (Jones et al., 2018; Tong et al., 2009), many reported that they were no longer able to travel and go for holidays because of the fatigue and dialysis session they should attend. Several qualitative studies have highlighted the experience of fatigue as a prominent illness consequence and the perception of fatigue may also be associated with other illness experiences such as mental and physical functioning among patients with CKD (Picariello et al., 2018; Rees et al., 2018). Tong and colleagues (2009) identified dialysis patients particularly feeling intense exhaustion. Negative perceptions related to fatigue and multimorbidity were found to be associated with fatigue severity among renal patients (Chilcot et al., 2017), however, participants in the current study did not attribute their fatigue experience to other condition/s they had.

Emotional distress and cognitive changes were dominant across the interviews. Many stressors including time spent during dialysis, restrictions of dietary and fluid intake may negatively affect the emotional status of the participants (Kittiskulnam et al., 2017). Distress may also be a response to physical and emotional burden of the treatment (Jones et al. 2018). It is well studied that patients with CKD, particularly those receiving HD tend to show depressive symptoms (Bujang et al., 2015; Chilcot et al., 2018a; Cukor et al., 2006; Ng et al., 2015; Shirazian et al., 2017) regardless of culture (Gerogianni et al., 2019; Loosman et al., 2015). Depression has been recognised as a common psychiatrisc illness affecting the majority of patients with CKD (Kittiskulnam et al., 2017). Similar to the findings of Tong et al. (2009), the participants reported feeling less than normal which can be considered as a negative self-concept. Some male participants associated the feeling of being *half* with the inability to maintain sexuality. Negatively influenced sexual desire and/or functioning has been also shown among the common complaints in patients with CKD (Pagels et al., 2015). As physical symptoms continuously experienced and patients become dependent on dialysis, this may result as inconsistency between personal and patient identity. This can make patients

struggle with maintain normality status (Rees et al., 2018; Reid et al., 2016) and their self-esteem particularly when the prognosis is uncertain (Tong et al., 2009). This may explain the participants' negative view of themselves and feeling as though something has been lost in the '*halving*' of their identity/ capacity. Adjusting to this new sense of self is essential and several facilitators emerged.

To cope with the demands of the illness and the burden of HD, the participants developed several coping strategies. Most participants attempted to adopt cognitions helping them to avoid the fact that they had a long-term condition and/or let them appreciate their physical status. By trying to have a positive attitude they shifted their attention from negative thoughts regarding their condition. Maintaining a positive attitude can be considered as an adaptive process to the difficulties of HD (Pelletier-Hibbert & Sohi, 2001). Patients receiving dialysis have been reported to think positively and to engage in activities or exercise also (Tong et al., 2009). Interestingly, the participants in the current study did not report any activities to preoccupy their minds although most were retired. On the other hand, their religious/spiritual attitudes such as belief in fate made them feel that their condition was controlled externally, and this somehow helped them to adjust to HD. The belief that life events are determined by fate does not prevent working for more positive outcomes (Yeoh et al., 2017). Religious faith has been indicated as coping mechanism, letting some patients adopt positive view about their condition (Wu et al., 2015) including Muslim patients who recognise health and illness as a natural part of the life which comes from God (Yodchai et al., 2017). Despite the negative illness outcomes, the participants appreciated their health status as at least extending their life. This concurs with broader literature on patients receiving HD seeing this as a life-line, though a double-edged sword (Jones et al. 2018). Additionally, social support was one of the sources for coping mechanisms. The participants mentioned about family support they received during the illness process. Family support has been recognised as an important

resource for coping with illness difficulties (Sharma et al., 2019). More specifically, encouragement from the family members has been identified as critical for motivation (Picariello et al., 2018). As the participants had similar experiences with other dialysis patients, they referred 'we' word (i.e., other patients receiving dialysis) while describing their experiences instead of personal reference. However, most did not explicitly mention other patients as a source of support. As dialysis patients share renal experiences, they have been found referring to other patients as 'dialysis community' or 'family' hence other patients may be seen as a source of social support (Rees et al., 2018).

Illness perceptions of Turkish patients have been examined in several long-term conditions such as chronic obstructive pulmonary disease (Ekenler, 2017), diabetes (Yorulmaz et al., 2013) and cancer (Yilmaz Karabulutlu & Karaman, 2015). The number of studies analysing experiences of patients receiving HD in the context of illness perceptions is very limited. These mainly used quantitative methods to understand illness perceptions of Turkish patients receiving HD (Karadag et al., 2016; Yılmaz Karabulutlu & Okanlı, 2011; Yorulmaz et al., 2014; Yildirim et al., 2013). Their results have demonstrated the patients tended to perceive their health status as poor as they experience the negative effects of dialysis. To our knowledge, Turkish patients receiving HD have not been examined qualitatively in the context of illness perception framework. Yet the current findings seemed to be in parallel with similar studies which reported several illness outcomes such as fatigue, symptom burden (Akturk & Gul, 2019; Yıldırım Usta & Demir, 2014), and depressive symptoms (Krespi et al., 2008; Ok & Isil, 2019; Turkmen et al., 2012).

4.4.1 Strength and Limitations

The main strength of this study was that being the first to explore illness perceptions of Turkish Cypriot patients receiving HD. The findings are critical as they provide insight about this patient group which has not been studied previously. Additionally, this study included all three hospitals providing HD treatment in North Cyprus thus, patients from each hospital were invited to participate in the study. To enhance the quality of the research in different aspects, we used several checklists such as criteria for a good reflexive TA (Braun & Clarke, 2006), COREQ (Tong et al. 2007), APA journal reporting standards for qualitative research (American Psychological Association, 2019) and Yardley's quality principles (e.g., sensitivity to context, commitment and rigour and transparency) (Yardley, 2000). However, this study is subject to some limitations. Although evidence suggests analysing the qualitative data in its original language is advantageous (Van Nes et al., 2010), there may be a possibility of a loss of meaning when researchers do *transliteration*. That is the process of replacing words of original language with a similar meaning in the target language when the exact equivalent word does not exist (Regmi et al., 2010). Effort was made to minimise the loss of meaning by employing rigorous quality assurance of both the forward translation of data itself and checking the applicability of the translated coding framework to 20 percent of the overall transcripts. Also, we have transparently reported quotations in both original language and English translation in the *Findings* section. However, there might be a chance that some parts of the data extracts might not fully represent the participants' voice. Another important limitation might be related to the fact that only those who were available and willing to share their illness-related experiences agreed to participate in the study. Hence, the findings may not precisely represent experiences of those did not participate in the study. It should be noted that those patients who received mental health treatment within the last year were excluded from the study as they may have different concepts of mental health and sense-making in relation to their illness. This is a limitation as these patients will have important experiences

that can also help shape future psychological care, though more pragmatic to avoid further distress. Future research should seek to consider how those who have engaged with treatment are similar and different in illness perceptions versus those who do not tae up such support.

This study faced some ethical challenge when potential participants were invited to participate in the study. Some questioned whether it was mandatory to participate in the study or not. Therefore, it was ensured that the participants did not feel under pressure to participate in the study. Considering they regularly receive treatment from the Nephrology Service, they could feel pressured to participate. However, the necessary explanation was provided verbally and written indicating that not agreeing to participate in this research will not affect their regular treatment. As this stands as a critical ethical concern, future studies should take this point into account sensitively when they invite patients to participate in a study in a similar context.

4.4.2   Implications for Practice

Illness beliefs and representations closely linked with illness outcomes (Tiggelman et al., 2014) and are amenable to change (Petrie et al., 2002). As such, effective interventions should be explored to decrease negative illness outcomes for those receiving HD in different cultural contexts. Emerging evidence for illness perceptions-based interventions themselves is promising (Sararoudi et al., 2016). The findings advance scope for the importance of integrating cultural coping mechanisms within such interventions to bolster patient adaptation. As this is the first study aimed to explore illness experiences of Turkish Cypriot patients receiving HD, future studies adopting currently used and different methodologies should clarify how this patient group experience their illness. As illness perceptions may

change over time, longitudinal designs particularly may help to identify illness perception trajectories in this patient group.

4.4.3   Conclusion

This study provides unique insight highlighting how Turkish Cypriot patients receiving HD experience their illness physically, psychologically, and emotionally. Importantly, it also unearths important coping mechanisms that facilitate adjustment to a new sense of self. Interventions that help patients understand their condition better and that advance culturally tailored messages about adjustment may be useful to encourage better outcomes. These findings should be considered as an indicator of a need for a holistic approach in health care in North Cyprus.

Literature indicates that patients receiving dialysis may experience similar difficulties due to treatment burden, however, this study provides findings on an underrepresented cultural group. It would be useful to examine qualitative evidence to see whether Turkish Cypriot patients' experiences matches experiences of other cultural groups and patients receiving dialysis overall.

Chapter 5: Illness Perceptions of Patients Receiving Dialysis for the Treatment of Kidney Failure: Systematic Review of Qualitative Studies

5.1   Introduction

The previous chapter considered illness perceptions of Turkish Cypriot patients receiving haemodialysis using a qualitative method. This was because there is limited evidence in this patient group and it was deemed more suitable to use qualitative methods rather than quantitative which is more about mapping patterns not depth. Using qualitative methodology enabled to be familiar and understand the patients' experiences within the socio-cultural context which helped to observe cultural influences on patient experience as evidenced in chapter 4 in the thesis. Qualitative synthesis is useful to unearth patient experience in different health settings. This chapter seeks to utilise systematic review method to identify the extent to which findings reported in chapter 4 map other qualitative studies in this field.

Chronic kidney disease (CKD) is a growing public health concern affecting the general population worldwide (El Nahas & Bello, 2005; Hill et al., 2016). Individuals with kidney failure require kidney replacement therapy (KRT). This can be dialysis treatment or a kidney transplant. The most common forms of dialysis treatment are hospital based haemodialysis (HD) and home based peritoneal dialysis (PD). Life experience of those receiving dialysis is likely to be influenced by treatment burden (Almutary et al., 2013; Tong et al., 2009).

The Common Sense Model (CSM) of self- regulation is a well-known theoretical framework that is commonly used to explore illness management (Leventhal et al., 2016). According to the framework, illness cognitions can be considered within five domains: *identity* (illness symptoms, labelling the condition), *causality* (casual beliefs related to the condition [e.g.,

genetic, fate etc.], *timeline* (beliefs related to chronicity and/or cyclical nature of the condition), *control/cure* (beliefs related to whether the condition is controllable or curable), *consequences* (beliefs and expectations regarding effects of the condition) (Leventhal et al., 1984). Quantitative studies conducted in patients receiving dialysis highlight correlates of illness perceptions that may alter life experience (Griva et al., 2010; Nabolsi et al., 2015; Seyyedrasooli et al., 2013).

5.1.1   Rationale

Existing evidence on illness perceptions in kidney research has used systematic methods to summarise what is known about quantitative data on this area (Muscat et al., 2018; Parfeni et al., 2013). There are no qualitative evidence syntheses that aim to explore illness perceptions using a qualitative method. The findings of the synthesis will not only allow determination of the extent which findings reported in chapter 4 map with other qualitative studies in the same context, but will also inform further research, interventions and clinical practice regarding the illness experiences of patients receiving dialysis.

5.1.2   Aims and Objectives

The review aims to answer the following questions.

Primary question:

1) What does qualitative research tell us about the illness perceptions of patients receiving HD as a treatment modality for kidney failure?

Secondary question:

2) To what extent have illness perceptions of patients receiving HD included the views of patients from different cultural and ethnic backgrounds?

Therefore, the objectives of this systematic review are to:

- Identify which illness perceptions apply to patients receiving dialysis,

- Assess the quality of qualitative research on illness perceptions with this patient population,

- Determine the extent to which qualitative research in this area has been inclusive of patients from different cultural or ethnic backgrounds and

- Draw conclusions to help identify target areas for patient support.

5.2 Methods

The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021) and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement (Tong et al., 2012) to ensure comprehensive and explicit reporting. The PRISMA checklist consists of 27 items regarding reporting of systematic reviews (Page et al., 2021) and ENTREQ includes 21 statements representing five aspects of the qualitative synthesis report; introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings (Tong et al., 2012). The protocol for this study was pre-registered on the PROSPERO database (ID: CRD42020202272).

5.2.1 Selection Criteria

Eligible studies included qualitative studies using the illness perceptions framework of the CSM of self-regulation (Leventhal et al., 1984) to explore the experiences of adults (aged 18 years +) receiving dialysis treatment (HD or PD). Studies needed to be published in the English language with no date restrictions set. Studies were excluded if they did not consider

patients receiving dialysis (any form) e.g. CKD being managed otherwise or studies with paediatric populations.

5.2.2 Data Sources and Searches

A search tool, SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used to develop the search strategy (Cooke et al., 2012). Preliminary searches were conducted to identify all potential key words of the concepts. After preliminary searches, the search strategy created was based on three concepts namely, population, study design and experience. For instance, keywords of 'haemodialysis', 'peritoneal dialysis' were used for the population concept, qualitative study related key words (i.e., interviews, focus groups etc.) were used for the study design and finally, key words such as 'illness perceptions', 'illness beliefs' were used for the experience. Identified key words for the concepts were combined. A broad search strategy was used as noninformative titles can make it difficult to detect qualitative studies in literature (Soilemezi & Linceviciute, 2018).

Both published and unpublished literature were searched between September and December 2020. The search was run again in early 2022 to see whether there is new relevant study that could be included in the synthesis (i.e., before finalising the review write-up). With a sensitive approach, we aimed to reach all relevant studies to include in the synthesis. The following electronic databases were searched: PubMed, Scopus, CINAHL, The Cochrane library, PsychARTICLES, and Web of Science by using free text words and medical subject heading (MeSH) terms relating to concepts. Lateral searches were undertaken such as checking reference lists of primary studies for related articles as well as checking 'Related articles' option on electronic databases where available. Google scholar was also checked for citation searches. Additionally, grey literature was extensively searched through the Centre

for Open Science, Open Grey and Grey Lit. ResearchGate was also checked for unpublished studies. Existing quantitative and qualitative reviews were searched to identify relevant primary studies. As it can be difficult to find qualitative studies (Barroso et al., 2003), relevant journals were also searched by hand.

The researcher screened titles and abstracts and identified studies which did meet the inclusion criteria. Additionally, another researcher screened 20% of the titles and abstracts to ensure that inclusion criteria were applied consistently. Citations from all database searches were imported into Mendeley reference management software. Citations were checked for duplicates, identified duplicates were removed before screening the title and abstracts of relevant studies. Full texts of relevant citations were assessed for inclusion by using a previously designed screening form.

5.2.3 Data Extraction and Quality Assessment

Data were extracted on pre-designed form. Data extracted included general information (i.e., study title, author, year of publication), study design, study aims/research questions, data collection methods (e.g., interview, focus groups etc.), data analysis technique (e.g., thematic, grounded theory, interpretative phenomenological analysis etc.), epistemological standpoint (e.g., essentialist, critical realist etc.), demographic information about participants (e.g., Age, sex, dialysis modality, co-morbidity status) and study findings. Extracted data were checked by another researcher. Any disagreements were discussed and resolved by consensus. During the screening process, we captured studies that included participants on different KRT modalities (i.e., peritoneal dialysis, haemodialysis and transplantation). Only findings related to patients receiving dialysis were extracted. Quotations from individuals not on dialysis were excluded. In case there were sufficient qualitative data, it was aimed to examine any

differential representations of illness from the two dialysis modalities (HD and PD)

separately and combine them if appropriate or report both analyses and as related to the

domains of the illness perceptions framework (identity, cause, timeline, consequences,

cure/control). Among eligible studies, there was one study (Rees et al., 2018) that included

patients with KRT of which only two patients received PD. This was not sufficient data on

patients receiving PD. Considering patient beliefs and experiences may differ depending on

dialysis modality (i.e., HD or PD), we did not merge findings on PD and HD findings. The

synthesis represents only those patients receiving HD.

Two reviewers independently checked eligible studies against the Critical Appraisal Skills

Programme (CASP) Qualitative Checklist (CASP, 2018). The checklist includes 10 questions

to assess the quality of studies in the aspects of the appropriateness of the research design,

participant recruitment, data collection, position of the researcher, the rigour of the analysis,

clarity of presented findings and ethics. Additionally, the comprehensiveness of reporting in

the relevant studies was assessed by using Consolidated Criteria for Reporting Qualitative

Research (COREQ). It assists in clarifying to what extent qualitative studies reported critical

contextual information in the assessment of transferability and transparency (Tong et al.,

2007). Any disagreements between the reviewers were discussed and reached agreement.

5.2.4   Data Analysis

There are number of distinct approaches available to synthesise qualitative research. These

include, but are not limited to, critical interpretative synthesis (Dixon-Woods et al., 2006),

framework synthesis (Oliver et al., 2008), meta-ethnography (Noblit & Hare, 1988) and

thematic synthesis (Thomas & Harden, 2008). Although each method may have its own way

to understand knowledge representing different contexts, some of the approaches, to some

extent, share basic characteristics (Barnett-Page & Thomas, 2009). It is critical to identify the product of the synthesis in relation to context, as this can inform the reviewers to choose the most appropriate method. Thematic synthesis (Thomas & Harden, 2008) combines approaches from both meta- ethnography and grounded theory. It has been commonly used to address questions related to health care intervention need, acceptability, patients' attitudes, and expectations etc. Reviewers inductively examine the experiences of individuals to draw explanations (Ring et al., 2011). Thematic synthesis has been suggested to have great potential to generate hypothesis (Lucas et al., 2007). Considering the current review has focused on patient experiences, thematic synthesis (Thomas & Harden, 2008) may be a suitable approach. However, this review aimed to understand patients' experiences within the illness perceptions framework. Meanwhile it aimed to capture both the diversity and the similarities in patient experience within socio-cultural context. We found that reflexive thematic analysis (TA) (Braun & Clarke, 2006; 2019a) offers the flexibility for this study to use the illness perceptions framework as a lens to interpret patient experiences.

With a critical realist perspective, reflexive TA has been frequently used to analyse primary qualitative studies. Six phases of reflexive TA were followed (i.e., 1- data familiarisation, 2- coding, 3- generating candidate themes, 4- developing themes, 5- refining themes and 6- write-up), with experiential orientation (Braun & Clarke, 2006). With critical realist standpoint (Sims-Schouten et al., 2007), the synthesis was completed in two stages by using inductive and deductive reasoning (Braun & Clarke, 2006; 2012). At the first stage of the analysis (phase 1 to 4), we used *more of a* inductive analytic approach to identify patterns in the data. With the inductive approach, codes are driven by data to represent participants' experiences (Braun & Clarke, 2006; 2012). The researcher extracted each study' findings/results section. Line by line coding was used and identified codes as an iterative process where the researcher repeatedly checked initially identified codes along with

quotations to refine the analysis. The researcher felt engaged with dataset during (initial) coding and did not want to lose links to context while doing the analysis. Therefore, initial coding was completed manually. Once codes were revised, final version of coding was completed in NVivo software (version 12).

Later, the researcher developed candidate themes by grouping codes and discussed the analysis with the principal supervisor who has expertise in qualitative methodologies in health research. The supervisor reviewed the extracted data along with initial findings to ensure analysis has interpretative depth. This process aimed to capture experiences and perceptions of individuals receiving dialysis. The research team discussed whether the initial findings captured both the diversity and the patterns within the dataset. Once the research team agreed that the themes represent the patient experience, at the second stage of the analysis (phase 5), the initial findings were mapped onto five domains of the illness perceptions framework (Leventhal et al., 1984). At this stage, a *more* deductive analytic approach informed the analysis through the existing framework where domains were overarching themes (i.e., timeline, causality, control/cure, identity, and consequences). The deductive approach aims to use existing theory to organise patterns in the data with the assumption that key concepts are already in the data (Braun & Clarke, 2006; Thomas, 2006). As the review included qualitative studies guided by the illness perceptions framework, deductive analysis was conducted in the latter stage to interpret the patient experiences from various health settings with diverse ethnic backgrounds within the framework. To our knowledge, this study for the first time, synthesises qualitative evidence on illness perceptions in HD patients with combined inductive and deductive reasoning. There are studies that have used inductive and deductive approaches within the same level of analysis (e.g., inductive and deductive coding) (Azungah, 2018; Fereday & Muir-Cochrane, 2006; Xu & Zammit, 2020). However, the current study used *more* inductive reasoning at the early

stage in identifying codes and initial themes to ensure participants' experiences are reflected with contextual sensitivity. By this approach, we aimed to decrease potential bias in terms of forcing participants' responses and primary findings into existing concepts of the framework at the early stage of the analysis. Then we completed the last stage of analysis with *more* deductive reasoning. There are qualitative health research studies that have used thematic analysis with a similar approach (Hellqvist et al., 2018; Maine et al., 2017). Using inductive and deductive approaches separately at different levels of analysis enabled interpretation of data within the framework, allowing it to reflect patient experiences.

5.3   Findings

5.3.1   Literature Search

After excluding duplicates, the search yielded 1315 articles as shown in the PRISMA flow diagram (Figure 5.1). We found only 4 eligible articles to include in the synthesis, one was a preprint version ([1] Sharma et al., 2020) determined through the manual searching.

Identification of studies via databases and registers

Identification

Records identified from:

CINAHL Plus (n = 123)
PsycARTICLES (n = 6)
Cochrane (n = 47)
Pubmed (n = 1075)
Scopus (n = 402)
Web of Science (n = 279)

Records removed *before screening*:
Duplicate records removed (n = 621)
Records marked as ineligible by automation tools (n = 0)
Records removed for other reasons (n = 0)

Screening

Records screened
(n = 1311)

Records excluded
(n = 1257)

Reports sought for retrieval
(n = 54)

Reports not retrieved
(n = 4)

Reports assessed for eligibility
(n = 50)

Reports excluded:
➢ Not a qualitative study (n = 11)
➢ Sample did not included patients receiving dialysis (n = 2)
➢ Did not use illness perceptions framework (n = 34)

Identification of studies via other methods

Records identified from:
Open Grey (n = 2)
Manual searching (n = 1)
Citation Searching (n = 27)
Google Scholar (n = 1)

Reports sought for retrieval
(n = 4)

Reports not retrieved
(n = 0)

Reports assessed for eligibility
(n = 1)

Reports excluded:
➢ Did not use illness perceptions framework
(n = 3)

Included

Studies included in review
(n = 4)

Figure 5.1. *PRISMA Flow Diagram*. Adapted from Page et al. (2021)

There are a limited number of studies representing ethnic and cultural minorities in psychological research as samples tend to represent Western, Educated, Industrialized, Rich, and Democratic (WEIRD) societies (Henrich et al., 2010; Nielsen et al., 2017; Rad et al., 2018). However, two of the included studies' samples included individuals who are not representing 'typical' (WEIRD) populations. One of the studies was based in Northern Cyprus and three were based in the UK (Table 5.1). This allowed to examine diverging and converging illness perceptions of patients from a different cultural and ethnic background in the same context. This was a significant opportunity that may increase our understanding about under-represented groups. The included studies used semi structured interviews and focus groups for the data collection (Table 5.1). Most samples included patients receiving HD only ([1] Sharma et al., 2020; [2] Keskindag et al., 2021; [3] Karamandiou et al., 2014). One of the studies included patients who were on different KRT modality such as those receiving PD and those with kidney transplantation ([4] Rees et al., 2018). However, only findings related to HD were included in the synthesis.

Table 5.1. *Characteristics of included studies*

Author (Year), Country, Database/s	Sample (N)	Gender (f/N)	Age range (y)	Cultural/ethnic background and/or religious affiliation, if specified	KRT Modality	Dialysis vintage	Study aims / objectives	Data Collection	Analysis	Language the study was conducted in, if other than English	Method of translation, if applicable
[1] Sharma et al. (2020) UK	Purposive-19	6/19	26 - 87	South Asian -Gujarati and Urdu speakers	HD	>6 mo	To identify the renal specific illness perceptions of South Asian HD patients	Focus groups	Thematic analysis	Gujarati and Urdu	Transcripts were translated into English and then analysed
[2] Keskindag et al. (2021) (North) Cyprus CINAHL, Scopus, Web of Science	Purposive sample - 14	6/14	48 - 82	Turkish Cypriots - Muslims	HD	6 mo – 12 y	To explore patients' beliefs about and understanding of kidney failure in Turkish Cypriot patients receiving HD	Semi-structured interviews	Reflexive thematic analysis	Turkish	Analysis conducted in Turkish then translated into English
[3] Karamanidou et al. (2014) UK PsycINFO, Scopus, Web of Science, CINAHL	NR - 7	4/7	32 -68	3 Afro-Caribbean, 2 Indian origin and 2 Caucasian	HD	2 – 7 y	To explore the experience of renal dialysis patients focusing on patients' beliefs and treatment burden	Semi-structured interviews	Interpretative phenomenological analysis	NA	NA
[4] Rees et al. (2018) UK CINAHL, Scopus, Web of Science	Convenience sample - 11	4/11	28 - 71	NR	PD, HD and Transplantation	>6 mo	To understand the psychosocial effects of ESKD	Semi-structured interviews	Constructivist grounded theory	NA	NA

Abbreviations: UK, United Kingdom; PD, peritoneal dialysis; HD, haemodialysis; mo, months; y, years; NR, not reported; NA, not applicable.

5.3.2 Quality Assessment and Comprehensiveness of Reporting

According to independent assessment of the reviewers, most studies provided -*yes*- as an answer for the questions on CASP qualitative checklist. According to COREQ checklist, the majority of the studies met most criteria for reporting qualitative research in terms of proving contextual details to increase transparency. However, the studies differed in terms of comprehensive reporting as some did not report critical contextual information such as setting of data collection (i.e., hospital, home etc.) and duration of the interview (Rees et al., 2018). Additionally, some studies ([1] Sharma et al., 2020; [2] Keskindag et al., 2021) did not meet some items of the COREQ checklist due to the data analysis method they used. For instance, data saturation is not suitable for reflexive TA approach (Braun & Clarke, 2019a; 2019b), therefore the studies used reflexive TA did not report about data saturation.

5.3.3 Synthesis

At the first stage of the analysis, six themes were identified following inductive thematic analysis, 1) *understanding changes caused by CKD*, 2) *causal beliefs*, 3) *coping with treatment burden*, 4) *treatment beliefs*, 5) *impact of HD* and 6) *adaptation process*. The findings generally showed that patients' experiences were similar, however, differences within the domains were also observed. The patients had difficulty in labelling and making sense about the condition. They were faced with uncertainty where they had inconsistent experiences related to their condition. Life experiences, particularly physical and psychological aspects, were influenced by demands of HD. Struggles to regain normality and changes in functionality influenced perception of self. However, patients used different resources to cope with treatment burden. Cultural values and/or belief system seemed an important factor shaping the coping process. The adaptation process was another aspect of patient experience, it draws on several key concepts in the management of condition such as

acceptance and adherence. At the second stage of analysis, the identified themes were

mapped onto the overarching five domains (i.e., timeline, causality, control/cure, identity, and

consequences) of the illness perceptions framework except one theme, *adaptation process*,

which was presented separately. The findings demonstrated that patients hold beliefs that are

consistent with the beliefs defined in illness perceptions within the CSM of self-regulation

(Leventhal et al., 1984). The relationship between the themes and the overarching themes is

shown in Figure 5.2.
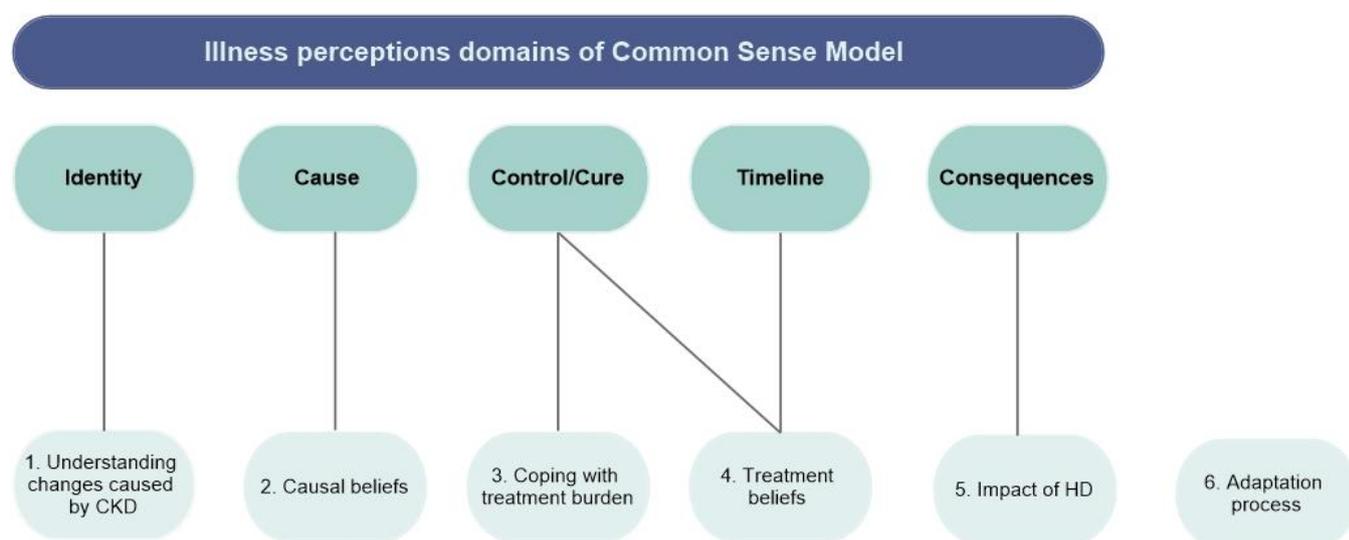
Figure 5.2. *Thematic map of the synthesis*

5.3.3.1 Identity

The identity domain of the illness perceptions framework refers to labels associated with the

illness and symptoms attributed to the illness (Leventhal et al., 1984). In the process of

labelling CKD, patients relied on others to make sense of their condition. Patients considered

other patients as a resource providing information about the symptoms and expectations.

Patients found other patients as a reliable resource as they shared similar experiences

regarding kidney failure. This, however, alone does not necessarily mean that they did not

rely on healthcare professionals. It may indicate that information seeking through other patients may be related to the need for empathy. Other patients had had 'lived' experience, therefore, would 'understand' how changes were experienced. Moreover, patients did seek clarification through multiple health settings. Particularly, at the early stage of the diagnosis, patients wanted to ensure the diagnosis of CKD and requirement of dialysis, therefore, they visited more than one nephrologist:

"*So, to make sure, I went Private. 1,500 to 3,500 I gave. Then they told me it's gone*"
(1)

This may also be related to the fact that the diagnosis process was sudden for many, and it was something that patients did not expect. This stands as one of the barriers to understanding the changes and making sense of CKD:

"*I don't know why… I was at work, suddenly my tension [referring to hypertension] increased… it was a kidney problem… I am dialysis patient since then*" (2)

Patients generally believed that they did not receive sufficient information about their diagnosis and treatment. This was a major factor negatively affecting understanding and sense-making:

"*They don't tell you nothing … unless you go down there and ask them and even then they don't tell you what you need to know …*" (3)

The expectation of patients and information provided by healthcare professionals seem not to match. Depending on cultural differences, some patients had even more challenges such as language barriers. Those who were not fluent in the English language had more difficulty

communicating with healthcare professionals, hence, they had other patients who were more fluent in English to communicate with doctors/nurses on behalf of them.

5.3.3.2 Cause

The causality domain of the illness perceptions framework represents cognitions related to cause of the illness (Leventhal et al., 1984). Patients mostly attributed their condition to risk factors as these were significant contributors for developing CKD. Risk factors mainly included previous health conditions such as, hypertension and diabetes. Additionally, medicine taken as treatment such as antibiotics and pain killers for another health issue were perceived as one of the factors that caused kidneys to deteriorate. On the other hand, some patients believed that stressful life events influenced physical and psychological strength hence, kidney function worsened:

> "*My husband was very ill ... so you know when stress occurs.... everything was too much for me...it was stress related*" (1)

In regards with causal beliefs, there was mismatch between patients' causal beliefs and doctors' beliefs. It was clear that patients had their own assumptions regarding aetiology of their condition. This is despite that they received an explanation from the doctors; they had different opinions about the causes and risk factors that triggered their condition:

> "*As I understand it I think the problem I had was hypertension and possibly also glomerulonephritis, whatever that means ... these are the reasons given to me ...*" (3)

This inconsistency between causal beliefs of patients and the doctors seems to be closely related to perceived lack of information about the condition. As mentioned in the previous section, perceived lack of information was a critical barrier to making sense of the condition. Differences between patients and healthcare professionals' beliefs support the notion that

patients' expectations regarding the information provided were not met and patients were unsatisfied about the explanations. Nevertheless, patients' past experiences were critical to shape their perceptions regarding causality.

5.3.3.3 Control / Cure

This domain represents beliefs regarding controllability of the condition (Leventhal et al., 1984). It also includes cognitions about cure for the condition. This domain was mainly supported by two inductively developed themes, namely, *coping with treatment burden* and *treatment beliefs*. Patients adopted different strategies to cope with the demands of their treatment. Avoiding negative thinking was one of the ways to cope with difficulties. Some patients preferred to ignore or reframe the difficult events to decrease the chances of facing anxiety producing stimuli. They believed, otherwise, it would be difficult to get rid of stress evoking negative thoughts once they let themselves face them:

> "*You don't let it affect your life because if you do, it's gonna get worse*" (1)

However, some patients achieved a positive attitude through adopting positive strategies. These strategies including mindfulness, and gratitude also facilitated coping with the burden of treatment. With mindfulness, patients gained awareness of their own capabilities which helped them regulate their activities and act accordingly in daily life. Similarly, gratitude helped to find the strength to hold a positive outlook. Despite the health issues and challenges they faced, they had sense of gratitude. They appreciated being alive and such health as they enjoyed:

> "*I believe that dialysis is one of the best things that have happened in my life. Um appreciating life, appreciating health…*" (1)

On the other hand, patients found different resources made them feel supported against treatment burden. One of these resources was faith, some patients particularly those from cultural groups even realised that their sense of faith improved with CKD. Their understanding had changed in a way that they considered their condition as mediator to 'feel alive again'. For those mentioning faith, praying was also important to feel optimistic:

> "*I was thinking that I have faith, I am a Muslim… But from one side awaking that faith again in yourself, making yourself alive again…*" (1)

Behavioural strategies such as engaging in physical activities and hobbies were also used among some patients:

> "*I retaught myself how to play the guitar … I think for the first year I read a huge number of books …*" (4)

To cope with demands of the treatment and the condition, support received through the social environment seemed significant. For instance, family relationships were an important reference for feeling supported. Family members were actively involved in patient experiences since diagnosis, even their social roles were re-determined due to caring responsibilities:

> "*he [husband] …. now he sees me that I am sick, he doesn't go outside much, he is often at home… he even helps to wash the dishes*" (2)

Additionally, social support was received through patient dialysis groups. Relationships with other patients were built during dialysis sessions in the hospital setting while sharing experiences. Interactions with others was important for patients so that some defined dialysis sessions as 'therapy'. Depending on dialysis vintage, patients also built long term relationships with healthcare professionals (doctors/nurses) at the hospital setting. Although

they did not always share similar assumptions and expectations related to kidney failure, they knew doctors/nurses for some time, and this made them feel somehow comfortable:

> *"... you do develop these long-term relationships with nurses, doctors ... what you're going through becomes a bit less scary ..."* (4)

This indicates that patients had a multi-aspect relationship with healthcare professionals that included mixed feelings.

Most patients started dialysis with poor physical functioning, they found HD helpful to enhance their health status. Patients recognised the benefits of HD, particularly at early stages of dialysis treatment. Patients considered that HD helped them to survive and maintain their life:

> "*they were taking biopsies of the kidney and so on ... then I started dialyzing and my health improved dramatically after that*" (3)

Some considered that their condition was controlled by a force beyond human power. Some believed that God was the one providing health and illness overall through healthcare professionals. At the same time, patients believed that they should follow the recommendations of the healthcare professionals for their wellbeing:

> "… *without the medication I would have been worse…but I believe in God too. There is one God and if he wants, the treatment, the medication will work ...*" (3)

On the other hand, some patients viewed their condition as a matter of luck. Due to bad luck, they believed they developed CKD and were having to maintain dialysis treatment, and these were perceived as out of their control. Overall, patients shared similar beliefs related to cure of their condition. They commonly believed that a kidney transplant was the only cure:

"*It's only kidney transplant, if available, there is a cure*" (1)

5.3.3.4 Timeline

Patients considered transplantation as a way to be free of dialysis. If they received a kidney transplant, they would not need to receive HD regularly and would not have to experience dialysis related difficulties. Therefore, for some, it may also represent the end of the disease which is related to the timeline domain of illness perceptions. However, kidney transplantation is another form of KRT that still requires following dietary recommendations and having regular hospital visits. Overall, patients held hope for the future that was related to getting a kidney transplant:

> "*I am hoping that one day they will give me a call ... and say oh, there is a kidney for you, you know ... I am looking forward to that ...*" (3)

At the same time, patients felt trapped due to uncertainty. The future was unpredictable as they did not know if or when they would have a transplant. Similarly, their health status was unpredictable due to the long term nature of their condition:

> "*Can't say about your future, you wouldn't know*" (1)

Symptom experience varied at different stages of the disease and this indicates the cyclical nature of the symptoms. Loosing 'friends' from the dialysis group also reminded patients of mortality- this may have also contributed to uncertainty. Maintaining dialysis sessions regularly was not a sole requirement for better health status as symptoms associated with treatment burden may vary. Patients did not have clear assumptions and expectations regarding prognosis. This left them with sense of uncertainty, however, they kept hoping for transplantation which they believed could change their quality of life. It seemed as if they were in the middle of conflict between negativity of uncertainty and positivity of hope.

5.3.3.5 Consequences

The domain of consequences represents the impact of HD on different aspects of life. The burden of HD made it difficult to maintain life, something that was prominent in all studies included in the review. Consequences was one of the domains frequently referred to. Although patients recognised the benefits of HD at the early stage of their condition, they found it demanding as it is a long term treatment that needs to happen very regularly. Along with dietary changes, HD can cause physical symptoms that negatively influence life experience. Patients experienced changes in physical functioning throughout their condition. For instance, one of the common symptoms was fatigue. Particularly on dialysis days, it altered the energy level and mood, and this influenced daily activities:

> "*when I go home it's very difficult for me to do anything ...*" (3)

Due to physical symptoms such as pain and weakness, patients felt restricted. Physical functioning was closely associated with engagement in social activities. Those who had severe complaints felt isolated as they did not find strength to maintain their social life. Overall, they required dialysis sessions approximately 4 hours each, three days per week which were time-consuming and demanding for many. Hence, it limited social life to some extent. For instance, patients experienced changes in employment status, trip planning, and other social activities:

> "*3 days I come to dialysis. In between, on Thursdays or Tuesdays I have other appointments …. So my 5 days are gone*" (1)

The impact of HD was also obvious on psychological wellbeing also. Dialysis is s burdensome treatment, not surprisingly, patients commonly experienced psychological distress. For some patients, diagnosis and commencing dialysis treatment occurred suddenly.

They felt they were not prepared for such a big change. Therefore, feelings of anger and disappointment were experienced mostly at the early stages. Even after some time, patients continued to experience distress as they frequently felt helpless. Patients did not have many options that they could resort to. As they did not have the transplantation option available yet, they had no choice but continue dialysis. This led to a sense of helplessness which may be perceived as 'losing' of control over the condition. Throughout the dialysis sessions, there may be some complications and the possibility of such events also increased the distress and left some patients with feelings of worry. They were preoccupied with thoughts about what could go wrong during the sessions:

> "*it can start bleeding so you have to be very careful with that and that is another worrying thing ...*" (3)

Nevertheless, some patients developed resilience and greater psychological strength after commencing dialysis. Kidney failure with dialysis treatment itself is alone a life changing event and it may cause psychological outcomes in different forms, such as growth. Also, support received from the social environment may have contributed to development of resilience skills. Having supportive family members/carer who have resilience skills may empower patients to redefine events:

> "*my mother ... she was ...very strong minded. Because of her, I found or have lots of strength*" (1)

Patients also experienced changes in self-perception. Throughout their condition, self-perceptions kept altering. Having experienced psychological as well as physical outcomes together influenced a view of self since patients did not feel the same as before in many aspects. 'Not feeling normal anymore' after commencing dialysis treatment was prominent

among patients. For instance, inability to maintain employment, limited engagement in social activities, and physical difficulties in daily life made patients felt that they were not as 'normal' as before:

> "*… not even a half, I have become a quarter of the quarter*" (2)

Depending on the severity of their symptoms, some felt that they had lost independence, they experienced becoming dependent on others. They received support from mainly family members in household errands and during hospital visits. Patients often felt that they had become a burden on family members due to the care requirements. For some, this feeling was so dominant that they believed their absence would make others' life easier:

> "*The hereafter life is better … your family are happy, everyone is happy*" (1)

These emotional and cognitive changes also negatively influenced self-confidence. Some explicitly reported having less confidence due to limited functionality. They thought they could not make a difference with limited capabilities in their lives. They felt useless due to limited functionality that prevented them to do what 'normal' individuals could do in their life. This was mainly due to the comparison of oneself with other individuals without long-term condition:

> "*friend comes to your house who is active in work and things, we are sitting at home doing nothing*" (1)

Consistent with having negative views of oneself, patients' perception related to their identity also changed along with lived experiences. Kidney failure with dialysis treatment was like a journey, patients were reconstructing their identity at different points with the effect of the outcomes that the journey brought. Different stages of the disease contributed to shape identity. Depending on the severity of symptoms and dialysis vintage, patient experiences

varied. However, changes were observed not only between the patients also within the patients. For instance, when a patient realised that their physical functionality was not same as before, they felt like a 'renal patient'. Then, their patient identity had become more dominant than personal identity. This was supported by a comparison of past and current 'self':

"*I have changed… I am not same anymore*" (2)

Some patients identified themselves through the dialysis group they had become part of. Labelling through social environment also contributed to adopting a patient identification. For instance, individuals from social environments including colleagues at work and friends who kindly asked about health status reinforced the 'patient' identity:

"*...the kidney man. So I had this label then... the very next meeting ... he was like oh how's the kidney*" (4)

Overall, there was a struggle between personal and patient identity. Patients attempted to protect their 'own' identity in order to maintain a 'normal' status while 'being a patient' had become an important part of their identity:

"*… you shouldn't think about it… If you say that you are sick … you will end up sick*"
(2)

"*… this is an illness, but I am not ill.*" (1)

This conflict may result differently among the patients depending on their adaptation process.

5.3.3.6 Adaptation Process

This theme was generated inductively and captured how patients experienced adaptation and maintain their life on HD. This theme is different than the scope of control/cure domain which may capture coping. As this theme highlights the processes that support adaptation, it is presented separately, in addition to the illness perceptions framework. Dialysis vintage

seems to be one of the important aspects of adaptation. Patients may have had struggles to adapt to HD at first, however, with the time spent on HD, it become easier to adapt since HD become part of their life. Particularly those who had longer dialysis vintage eventually normalised receiving HD on a regular basis:

> "*It's hard at first but you get used to it … Cause I've been doing it for so long now … it's more natural…*" (3)

However, patients did not willingly make decision to commence dialysis treatment. They believed they had to adjust to HD as they did not have another option, in other words, they had 'to learn to live with it'. This 'forced adjustment' enabled patients being present physically to attend HD session in the hospital setting. However, it did not include 'psychological preparedness and adjustment' for HD. On the other hand, acceptance was another key point regarding the adaptation process, yet, it is quite different from the 'forced adjustment'. Accepting HD consciously and including it in life facilitated the adaptation process not only physically but also psychologically. Those who accepted viewing dialysis as part of their life made 'peace' with HD. This may be critical for patient experience to some extent:

> "*Whoever did not accept this disease died… there was a man …he was telling me: 'I am not like you'. He didn't want to receive dialysis, he died later*" (2)

However, those who had difficulty in accepting HD seemed to have more negative experiences. This could be explained by discrepancies between the real and ideal world. In case of refusing to accept, reality would be quite different from what an individual expected ideally. This difference was likely to cause distress which may be related to symptom experience. Moreover, adherence related behaviours represented a different aspect of adaptation. Patients generally accepted the need from regular attendance at dialysis sessions

as well as medication adherence. However, patient views and experiences differed mainly in relation to diet-adherence. Those who were adherent to dietary recommendations perceived it was their own personal responsibility to follow the recommendations. Despite it being difficult to stay away from certain food they liked, they had sufficient resources for self-efficacy so they maintained diet-adherence:

> "*Whatever I buy I read the ingredients on the pack. I read the percentages so like bananas have a high percentage of potassium, so I don't eat bananas. I like bananas*" (1)

Dietary non-adherence among some patients resulted from their own deliberate decisions. They chose not to follow dietary recommendations extensively. This was observed mainly in the form of reactance against the restrictions. They perceived the food and liquid restrictions as an attack to their freedom, and this led to non-adherence as a reaction:

> "*... most people enjoy their water and their drinks and ... you on the other hand trying to keep to the restrictions cause of the consequences ... that's not a good feeling to have these restrictions but at the end of the day it's your life so if you want to drink and don't stick to the restrictions ...*" (3)

5.4   Discussion

The aim of the review was to synthesise experiences of patients receiving HD treatment by using the illness perceptions framework of the CSM of self-regulation (Leventhal et al., 1984). Qualitative evidence on illness perceptions in HD patient groups were interpreted to understand patient experience in different settings. The review aimed to also understand the extent to which the findings from chapter 4 in the thesis are reflected of broader qualitative data in the illness experiences of patients receiving dialysis. There was a general dearth of qualitative studies on this area though far more quantitative studies have been undertaken.

Besides, this study examined whether qualitative studies that originated from a mix of regions were more inclusive of different cultural communities. Involvement of patients from different racial or ethnic backgrounds is important in health research as culture shapes illness experience (Kirmayer & Young, 1998). It is well-known that WEIRD samples are dominant in psychological research in general. However, the included studies presented cultural diversity to some extent and this allowed examination of similarities and differences in cognitions that may be influenced by culture. The overall findings indicate some experiences, beliefs and emotional reactions seem similar across different health settings however, whilst others, particularly those related to identity and control/cure components of the framework differed due to their potential link to cultural differences.

Patients commonly believed that information provided about their condition and dialysis was not sufficient. This influenced labelling symptoms and sense making. Similarly, qualitative syntheses have indicated that patients were not satisfied that they had limited knowledge regardless of treatment they received as KRT (Morton et al., 2010a; Reid et al., 2016). Emotional and behavioural responses may vary when individuals believe that their knowledge is limited about their condition (DePasquale et al., 2019). For instance, people's labelling and sense making of their symptoms (identity domain) may play a role in adherent behaviours (e.g., medication, diet etc.) (Aujla et al., 2016). Those who believed they did not have sufficient explanation have been found not to strictly follow the medical and dietary recommendations, and this may in turn, worsen their symptom experience (Sawyer et al., 2019). Cultural differences seemed to influence beliefs in relation to the identity domain, for instance, those from cultural groups were more likely to experience difficulties in accessing information about their health status. This was true for patients in non-western settings as well as minority communities in high income countries in the west. There is evidence

indicating that cultural groups tend to face more challenges when communicating with healthcare professionals (Cervantes et al., 2016; 2017). Those from different cultural backgrounds may require additional resources to feel supported as some have language barriers and in other settings, healthcare infrastructure is less developed to facilitate this.

Causality beliefs greatly differed among patients. Evidence on causal beliefs in CKD demonstrates that patients hold a variety of beliefs in relation to the development of kidney failure (Jayanti et al., 2016). Although causal beliefs can be determined by cultural influences (Kizilhan, 2012), prominent differences were not observed specifically depending on culture. The types of explanations can be broadly grouped into various risk factors that mainly attributed to other medical condition/s. These broadly reflect the findings of other studies that included patients with kidney disease (Lin et al., 2013; Wu et al., 2015). On the other hand, beliefs around control/cure of kidney failure with dialysis reflected mainly coping strategies adopted to counter treatment burden. Perceived social support has been noted as an important source (Karadag et al., 2019; Wang et al., 2020) which was received through family, dialysis groups, healthcare professionals and faith. Particularly, patients representing cultural groups perceived their condition slightly differently as their understanding was mainly shaped by faith. For some, faith even helped to accept HD. They had a positive outlook consistent with their values. They believed their condition was controlled by a higher power, at the same time, they felt responsible to adhere to treatment. Literature has demonstrated an association between perceived external locus of control and avoidant coping strategies (Arraras et al., 2002; Folkman, 1984; Gomez, 1998). There is an assumption that those who believe that they lack control over disease are more likely to engage in maladaptive coping strategies that is linked to non-adherent behaviours (Frazier et al., 1994; Matsuzawa et al., 2019). However, the current findings show that the relationship between sense of control, coping strategies and

adherence seem more complex. It should be further studied in diverse samples. Overall,

patients aimed to achieve a positive attitude however, this was obtained through different

ways, some avoided negative thinking by ignoring challenges whilst others maintained

gratitude for life. Coping strategies can vary depending on psychosocial factors among

individuals receiving HD (Wang et al., 2020). Meanwhile, considering kidney transplant as a

'cure' was common among patients as they tend to believe transplantation is the only way to

get escape dialysis and to achieve normality (Kristensen et al., 2020; Reid et al., 2016).

Conflicting beliefs related to prognosis were indicative of aspects of the timeline domain.

Symptom severity varies depending on several factors including clinical values (Ng et al.,

2020; Sak et al., 2015). Not only unclear status of the chances of kidney transplantation but

also the cyclical nature of the symptoms left patients with uncertainty related to prognosis.

Sense of uncertainty has been frequently reported in kidney failure (Chiaranai, 2016; Kim &

Kim, 2019). Due to uncertainty, patients did not have ability to predict their future and this

influenced future plans in many aspects (Pelletier-Hibbert & Sohi, 2001). Evidence indicates

that patients have experienced 'being on hold' while waiting for kidney transplantation, they

believed restrictions of HD called off life opportunities (Moran et al., 2010). The possibility

of kidney transplantation was unclear, yet patients maintained their hope in relation to kidney

transplantation, they believed it may be possible for them to have a kidney transplant in the

future. As kidney transplantation represented no more dialysis sessions, it may have been also

perceived as an end of disease. It is not uncommon to observe coexistence of uncertainty and

hope in long term health conditions (Borneman et al., 2014; Hinton & Kirk, 2017; Maikranz

et al., 2007). The struggles between uncertainty and a sense of hope have been previously

shown in patients receiving dialysis (Kristensen et al., 2020). Despite being preoccupied with

feelings of distress, patients held hope particularly about the chance of receiving a kidney

transplant. A qualitative synthesis identified hope as providing freedom, whereas it interpreted uncertainty as restricting (Schick Makaroff, 2012). The relationship between hope and uncertainty requires attention in kidney failure as there is emerging evidence demonstrating how this relationship can be associated with emotional outcomes and adherence to treatment (Maikranz et al. 2007).

In addition to physical and emotional symptoms, the change in self-perception was prominent among the patients which was interpreted as one of the aspects of consequences domain. This was a dynamic process that was maintained as illness progressed. Different stages of CKD contributed to shaping self-perception. Particularly commencing dialysis treatment affected 'independence', worsening symptoms and the long-term nature of the condition led to the perception of becoming 'dependent on HD'. Those who had more severe illness also perceived being 'dependent on others' as they required more support in daily life (Reid et al., 2016). Feeling restricted in several aspects such as, food intake, freedom, social life, and physical functionality (Beanlands et al., 2020; Cervantes et al., 2016; Morton et al., 2010b; Kristensen et al., 2020; Reid et al., 2016; Palmer et al., 2015) led to the belief that they were no longer 'normal'. In other words, comparing current and past self by looking at their own capabilities led to the belief that they were no longer 'normal'. It is known that distorted 'normality' challenges the sense of self among patients with kidney failure (Boaz & Morgan, 2014). Patients strived to achieve the 'normality' that they had before commencing dialysis (Kristensen et al., 2020). Patients receiving dialysis have been found to maintain personal identity by using different strategies such as ignoring the disease and /or hope due to being on a waiting list for kidney transplantation (Tong et al., 2013; 2015). Nevertheless, accepting the health problem has been found to facilitate identification with oneself in young patients with CKD (Bailey et al., 2018).

Qualitative data were interpreted by using the illness perceptions framework, yet the synthesis also included an inductively developed additional theme representing the adaptation process. This theme relates experiences of normalisation including challenges (e.g., force adjustment) and facilitators (e.g., acceptance). The components of this theme were found to be closely related to the several domains of the framework such as identity, control/cure, and consequences. For instance, diet- nonadherence was common among patients. As mentioned earlier, this can be related to difficulty to make sense of the changes and /or symptoms due to perceived lack of information which represents the identity domain of the framework (Demiray Kara et al., 2017). Besides, a sense of control has been associated with adherent behaviours (Howren et al., 2017). It is known that patients' perceived control can increase with patient centred care as patients are actively involved in the decision-making process (Kvåle, & Bondevik, 2008; Sladdin et al., 2018). Patients receiving HD have been shown to consider themselves as 'passive recipients of care' due to lack of communication with healthcare professionals, limited understanding and feeling of powerlessness (Reid et al., 2016). On the other hand, non-adherence can also be observed in the form of reactance when patients believe their freedom is restricted, therefore, they may engage in non-adherent behaviours (De las Cuevas et al., 2017; Lowenthal et al., 2021). The current findings showed that diet non-adherence was mostly due to patients' own rational decision. On the other hand, patients agreed that HD treatment affects their survival so they had to include HD into their life. It is possible that those who felt that they were 'forced to adjust' to the demands of HD may react as not adhering to dietary recommendations. Change in diet is another aspect of the treatment and potentially linked to physical outcomes (Tong et al., 2009). This indicates the importance of acceptance where an individual acknowledges the reality and re-establishes their perception about the health condition. It was observed that those who accepted their

condition, as well as HD treatment, seemed more adherent to dietary advice, this may indicate greater quality of life (Kamody et al., 2018). Generally, dialysis vintage helped to normalise the HD through managing the difficulties with learned experience, however, it did not change the treatment burden for the patients (Cabrera et al., 2017).

With the additional theme representing the adaptation process, the illness perceptions framework has been useful to interpret and reflect on perspectives and experiences in kidney failure. We used rigour to synthesise the qualitative evidence examining experiences of patients receiving HD treatment. Considering objectives of the synthesis and the flexibility of reflexive TA, we used combined inductive and deductive reasoning to synthesise qualitative evidence (Braun and Clarke, 2006; 2019). Characteristics of primary studies and their representation of the illness perceptions framework were reported. Nonetheless, the findings should be taken into account with few limitations. Literature searches were conducted without date restriction, yet the review was limited to studies reported in English only. Despite multiple databases being searched, manual searching was conducted, and the search was repeated at different stages, there is possibility of failing to capture unpublished materials that could be included in the synthesis. Additionally, patients recruited in the primary studies had been diagnosed with kidney failure and had received HD treatment for different periods. Some also had experience of different KRT modalities. This can potentially influence the diversity in illness perceptions. However, considering philosophical approach undertaken, the synthesis seems to have the evidence to support *analytical generalisability* (Carminati, 2018; Smith, 2018).

5.4.1 Implications for Practice and Future Research

The findings of this synthesis highlight patients experienced physical as well as psychological outcomes. As patient experience may change over time, interventions for adaptation to dialysis can be designed for those expected to start dialysis treatment. Interventions could be delivered at different time points. Domains of the illness perceptions framework along with relevant themes presented in the synthesis (e.g., conflicting beliefs related to prognosis, forced adjustment etc.) may be targeted to amend negative perceptions. Nevertheless, interventions should be culturally sensitive and inclusive. By adopting patient centred care, strategies to improve communication with healthcare professionals could be developed. Particularly those who likely to face language barrier should be supported further to enhance communication with healthcare professionals.

There is limited qualitative research using illness perceptions framework. Considering the unique contribution of qualitative research in healthcare practice (Curry et al., 2009; Gough & Deatrick, 2015), further qualitative research guided by illness perceptions framework may be useful in the context of CKD. Longitudinal qualitative evidence examining illness perceptions in kidney failure could be helpful to make sense of changes in patient experience overtime. Overall, systematic reviews are invaluable as they gather evidence to inform healthcare practice. Particularly, a rigorous qualitative systematic review (i.e., qualitative evidence synthesis) can unearth new understandings, as well as answer 'why' question that helps to build an explanation in relation to phenomena of interest (Flemming & Noyes, 2021). Different to quantitative systematic reviews (i.e., meta-analysis), qualitative systematic review can answer the questions focusing on lived experiences. Future qualitative evidence synthesis guided by illness perceptions framework will be helpful to further understand experiences of patients and to inform kidney related healthcare.

5.4.2 Conclusion

This study is the first to systematically summarise qualitative evidence on illness perceptions in HD patients. Whilst quantitative reviews exist in this context (Muscat et al., 2018; Parfeni et al., 2013), it is widely accepted that qualitative data adds depth of experience and may also be better suited to help explore cultural influences on patient experience. The review has evidenced the dearth of qualitative studies in HD that have explored illness perceptions, with most patients (75%) from minority ethnic communities either in high income countries in the west, or in countries that cover global majorities but in healthcare systems that are less well advanced in kidney care practices. The reporting of studies was generally high quality and the limited studies combined have evidenced the cross-cultural usefulness of illness perceptions to help understand how patients make sense of their situation. Qualitative findings help elucidate where culture shapes beliefs and representations, here as exemplified through faith in particular. Further to illness perceptions, the adaptation process was segregated as a theme in its own right despite relations closely with other illness perception domains. This was to capture more holistically how settling into life as a patient occurs. The findings confirm that the study (Keskindag et al., 2021) reported in chapter 4 is novel and makes a significant contribution to this field. It also evidences that supporting patients with reframing may be useful to facilitate adjustment. Overall, research in the field of illness perceptions in HD could advance the use of this method of enquiry to better time interventions to patient needs and cultural strategies that may be more meaningful in supporting adjustment.

Chapter 6: The Trajectory of Illness Perceptions in Patients with Kidney Failure Being Treated by Haemodialysis or Peritoneal Dialysis

6.1   Introduction

The aim of this chapter is to progress understanding of how illness perceptions change over time amongst patients receiving HD and PD, including from the pre-dialysis stage. This is to improve knowledge of patient adaptation and holistic care needs over time, within a specific healthcare context. The chapter presents a longitudinal study that addresses this in an attempt to consider the timeliness of patient support.

As the thesis has highlighted, chronic kidney disease (CKD) refers to progressive kidney failure. It influences 9% of the population across the globe (Bikbov et al., 2020). The prevalence of kidney failure has been shown to increase prominently over the last 20 years (Saran et al., 2019), attributed several aetiologies, mainly to diabetes and hypertension (Stanifer et al., 2016). Treatment for CKD from stage 1 to 4 includes diet based management and pharmacotherapy in order to slow down the progression of kidney failure and to decrease the chances of complications (Inker et al., 2014). CKD associated progression to kidney failure requires kidney replacement therapy (KRT) and is recognised as an important public health challenge (El Nahas & Bello, 2005). Individuals with kidney failure have reported higher level of disease burden, increased number of hospitalizations and have been found to be at greater risk for mortality (Saran et al., 2019). Worldwide, kidney failure (CKD stage 5) is most commonly treated by dialysis, of which there are two main modalities- haemodialysis (HD) and peritoneal dialysis (PD) (Schieppati & Remuzzi, 2005). HD and PD share the fact that both modalities aim to remove waste and toxins from the body, although treatment itself

may have differing impact on the quality of life of patients since HD is mainly hospital based and PD allows patients more control to dialyse at home. Yet, a significant proportion of patients continue to prefer in centre HD. Overall, individuals with kidney failure tend to experience multiple concurrent symptoms (Almutary et al., 2013). The symptom experience particularly of those receiving dialysis treatment is quite complex (Ng et al., 2020). A study examining patients' experience of physical and psychological symptoms demonstrated that HD treatment has an impact on the bidirectional relationship of the prominent symptoms and depression (Flythe et al., 2018).

Psychological distress is commonly observed in patients with CKD (Palmer et al., 2013). It has been frequently assessed by measuring self-reported depressive symptoms (Chilcot et al., 2018b; Goh et al., 2018; Hudson et al., 2016; Kim et al., 2019). Importantly, these symptoms are not related to HD or PD alone; there is evidence indicating persistent depressive symptoms over the different stages of CKD (Chilcot et al., 2013). Longitudinal studies have determined that psychological distress may vary at different stages of CKD due to burden of treatment, and psychosocial factors (Chilcot et al., 2013; Goh et al., 2018). Findings have shown that individuals with CKD not receiving KRT tend to report lower psychological distress compared to those receiving dialysis (Goh et al., 2018). It has been reported that individuals with kidney failure have been commonly hospitalised due to psychiatric diagnoses particularly for depression (Kimmel et al., 2019). Consistently, longitudinal assessments have indicated that those receiving HD and are clinically depressed are at higher risk for hospitalization, dialysis withdrawal and mortality (Hedayati et al., 2008; McDade-Montez et al., 2006).

The common-sense model (CSM) of self-regulation of health and illness (Leventhal et al., 1984) advances a useful framework to better understand various behavioural and emotional responses to long term conditions. The CSM explains that individuals develop cognitive and emotional representations regarding a health threat and make sense of their condition. These representations inform the coping strategies adopted which can contribute to illness outcomes such as mental and physical functioning (Damman et al., 2018; Pavon et al., 2019). Illness perceptions represent a patient's beliefs about illness timeline (duration of illness), cause, cure/control (treatment /personal), identity (symptoms) and consequences (impact of illness) (Leventhal et al., 2003). Illness perceptions have been shown to influence emotional and behavioural responses (Leventhal et al., 1980; 2003). A meta-analysis has suggested associations between mental well-being and perceptions of illness consequences, control/cure, and timeline among patients with different medical conditions (Hagger, & Orbell, 2003). Favorable illness perceptions (higher level perceptions of coherence and control) have been found to be related to better health outcomes, on the other hand, unfavorable illness perceptions (higher level perceptions of consequences, emotional representation, and timeline) have been found to be related to poorer health outcomes (Sawyer et al., 2019).

The CSM has been considered as a dynamic model where behavioural responses shaped by illness perceptions are continuously assessed, therefore illness perceptions can be amended (Wearden & Peters, 2008). Illness perceptions may change overtime among patients with long-term health conditions. There are studies aimed at observing the change of illness perceptions in various long-term conditions such as obesity, chronic obstructive pulmonary disease (Bonsaksen et al., 2015), coronary heart disease (Juergens et al., 2010), cancer (Kaptein et al., 2011), asthma (Tiggelman et al., 2014), myocardial infraction (Petrie et al.,

1996), diabetes (Fortenberry et al., 2014), and rheumatoid arthritis (Groarke et al., 2005). Illness outcomes may change depending on the illness beliefs. For instance, physical functioning and depressive symptoms of patients undergoing cardiac surgery have been predicted by their illness perceptions in a three-month prospective study (Juergens et al., 2010). Another longitudinal study found an association between concern about the illness and greater emotional distress in adolescents with asthma (Tiggelman et al., 2014). On the other hand, a two-year prospective study indicated that illness perceptions of women with rheumatoid arthritis explained up to 33% of the change in pain, anxiety and depressive symptoms and physical functioning (Groarke et al., 2005). Similarly, a six-year prospective longitudinal study has demonstrated relationships between illness perceptions and functional disability in patients with osteoarthritis (Kaptein et al., 2010).

As illness experiences may differ between patients with CKD, their illness perceptions may also differ. Trajectories of illness perceptions in CKD are poorly studied, however, there are limited available prospective studies conducted among patients with CKD. It is known that generally illness perceptions of patients in the pre-dialysis phase and those receiving dialysis vary due to treatment burden. Patients receiving dialysis tend to perceive greater illness consequences than those in the pre-dialysis phase (Jansen et al., 2013). In a follow-up study, perceptions of treatment control and timeline were found to increase when patients commenced dialysis (Jayanti et al., 2016). Illness perceptions may vary across the different stages of illness process. Negative illness perceptions (e.g., lower levels of personal control, illness coherence, and greater levels of illness consequences) have been even associated with faster decline in kidney function in a prospective study (Meuleman et al., 2015). Perceptions of chronic timeline and treatment control have been found to predict mortality after controlling for kidney function and comorbidity status among patients in the pre-dialysis

phase (Muscat et al., 2020). Those patients who had negative illness perceptions (e.g., greater illness consequence and emotional distress) tended to report poorer physical and mental health (Meuleman et al., 2017). However, these perceptions may change over time. A six-year prospective study has demonstrated that patients receiving HD reported stronger perceptions of illness chronicity and lower illness consequences at follow-up (Tasmoc et al., 2013). Similarly, in another study, patients receiving HD indicated better illness coherence and lesser emotional response to their illness two-years after receiving dialysis treatment (Covic et al., 2006). These findings have indicated that patients had a more optimistic view at follow-up. Overall, findings of prospective studies have shown that identifying negative illness perceptions in the early stages of the illness may help with the implementation of interventions that bolster illness outcomes. Therefore, illness perceptions should be determined in different stages of CKD including the early stage of the condition.

Additionally, research mainly based on cross-sectional designs has examined the association between illness perceptions and illness outcomes such as depression (Chilcot et al., 2011a; 2012; Griva et al., 2010). In a study which included patients with kidney failure treated with dialysis, greater perception of illness consequences and decreased perceptions of control were found to be related to depression symptoms (Griva et al., 2010). Similarly, Chilcot and colleagues found patients with kidney failure who had depression reported negative illness perceptions (i.e., lower levels of identity, control and greater levels of consequences, and timeline) compared to the patients who did not have depression. They also found patients with depression had greater illness-related distress (Chilcot et al., 2011a).

The stability of the association between illness perceptions and psychological distress has been evidenced with Turkish patients receiving HD (Kocaman Yildirim et al., 2013; Krespi

& Kuntuz, 2017). Lower personal control and higher perceptions of the cyclical timeline and emotional representations (i.e., worry, anger, and fear) have been associated with a risk of developing depression (Kocaman Yildirim et al., 2013). However, in another study, all perceptions except for chronicity and cyclical timeline were found to be related to depression (Krespi & Kuntuz, 2017). Depression has been indicated as the most frequent psychological difficulty that the Turkish patients may experience in CKD. Limitations due to dialysis, dependency on health care professionals and family may increase tendency to develop depression (Yavuz et al., 2012). However, there are no studies that have attempted to explore illness perceptions and its relation to other clinical and psychological outcome variables overtime. This acts to limit the timely targeting of interventions.

6.1.1   Rationale

Quantitative research on illness perceptions commonly has utilised cross-sectional designs. However, literature demonstrates that illness perceptions may change depending on different stages of the illness. Evidence on longitudinal assessment of illness perceptions in CKD, particularly in kidney failure is limited. Clarification of illness perceptions in both pre-dialysis and dialysis groups and determining the links to illness outcomes can contribute to better health outcomes in early stages of CKD. Understanding trajectories of illness perceptions is crucial as it can guide future psycho-educational interventions programs which can have positive outcomes on illness adjustment (Fischer et al., 2013). There are few studies examining illness perceptions of Turkish patients receiving dialysis in Turkey (Karadag et al., 2016; Yildirim et al., 2013; Krespi & Kuntuz, 2017), however, illness perceptions have not been quantitatively investigated in Turkish Cypriot patients receiving dialysis in North Cyprus. This limits the extent to which local health services can accurately draw on findings from other groups to drive attempts at supporting patients further. As a useful step, it would

be sensible to consider the measurement of illness related beliefs in patients with CKD and importantly, how, if at all, they change overtime and relate to psychological markers of living well with kidney failure.

6.1.2 Aims and Objectives

This study aimed to use prospective longitudinal design to explore illness perceptions of Turkish Cypriot dialysis populations for the first time. Results of this study are expected to represent how patient experiences may change along with illness perceptions over time. This study was designed to address following objectives:

- Explore illness perceptions of patients receiving dialysis at different time points in the patient journey.
- Identify whether illness perceptions can predict some illness experiences such as depression and dialysis-related symptoms.
- Compare whether the trajectory of illness perceptions differs between patients receiving dialysis and those in the pre-dialysis phase.

Although the main objective of this study was to understand the illness perceptions trajectory among patients with CKD, it also examined depressive symptom trajectories in patients with CKD (i.e., pre-dialysis and dialysis groups) and dialysis symptoms trajectories in patients receiving dialysis treatment (i.e., PD or HD). We focused on illness perceptions domains that have been frequently shown as predictors of illness outcomes in patients with CKD. These are *consequences, personal control, timeline,* and *emotional response*. This study aimed to answer the following research questions:

1) Are there differences in illness perception domains (i.e., perception of consequences, emotional response, personal control, timeline) depending on patient's phase of

dialysis (i.e., pre-dialysis, dialysis groups) when age, gender and comorbidity status are adjusted?

2) How do illness perception domains adapt over the course of a year (i.e., perception of consequences, emotional response, personal control, timeline)?

3) How does depressive symptomatology adapt over the course of a year?

4) Does greater perception of consequences, emotional response, timeline and lower level of personal control relate to changes in depression over the course of a year?

5) Do dialysis symptoms vary between patients on PD versus HD over one year period?

6) Does greater perception of consequences, emotional response, timeline and lower level of personal control relate to change in dialysis symptoms over the course of a year?

7) Does each illness perception domain (i.e., consequences, emotional response, timeline, personal control) and depression symptomatology differ in the pre-dialysis group when they commenced dialysis treatment (i.e., HD or PD)?

Based on past evidence (Chilcot et al., 2010; 2011a; 2013; 2018; Covic et al., 2006; Griva et al., 2009; 2010; Hudson et al., 2016; Jansen et al., 2013; Jayanti et al., 2016; Muscat et al., 2020; 2021; Meuleman et al., 2017), it was hypothesised that the following differences may be observed 1) differences in illness perceptions depending on different phase/treatment (i.e., pre-dialysis, dialysis), 2) change in illness perceptions over time (1 year), 3) change in depressive symptoms over time, 4) different levels of illness perceptions relating to change in depressive symptoms, 5) changes in dialysis symptoms over time, 6) different levels of illness perceptions relating to change in dialysis symptoms, and 7) differences in illness perceptions and depression symptomatology in pre-dialysis group when they commenced dialysis treatment.

6.2 Methods

This study obtained ethical permission from both Lefkosa Dr Burhan Nalbantoglu State Hospital, Department of Inpatient Treatment, Ministry of Health in Turkish Republic of Northern Cyprus (YTIKI1.01-629-20/E.1915) and Health, Science, Engineering and Technology Ethics Committee with Delegated Authority at the University of Hertfordshire (LMS/PGR/UH/ 04505). The main ethical issue in relation to the study was care of patients who may be experiencing significant distress. This was addressed by link to a local psychologist who worked at the state hospital at the time of study.

6.2.1 Design

This study used a quantitative prospective longitudinal design to understand patient's illness perceptions at different time points. A questionnaire pack was completed by participants at three different time points. The participants who were in the pre-dialysis phase (those who were expected to start dialysis within 6 months [Time 1]) were followed up at the commencement of dialysis [within the first month = Time 2] and at 6 months after receiving dialysis [Time 3)]). Additionally, patients already receiving dialysis completed the same questionnaire pack at three different time points (when they were first approached [Time 1]), at 6 months (Time 2) and after 1 year (Time 3). The questionnaire was implemented in their native language (Turkish). This design was useful to identify illness beliefs held at different stages of the illness. Accordingly, illness perceptions and commonly reported illness outcomes (e.g., depression) were observed through longitudinal assessment.

6.2.2   Participants

At the early stage of planning the study, there were 211 patients in total who were receiving

dialysis treatment. In the previous year, there were 58 patients who started dialysis treatment

in North Cyprus. Applying a 40% refusal rate to take part, which is based on research

experience within the supervision team, it was expected that the study would recruit

approximately 160 patients over one and half-year period. It was also anticipated that this

could be higher, as research with usually ignored HD groups, i.e. minority ethnicity, has also

shown more favourable consent to completion rates (Sharma et al., 2022).

For the pre-dialysis patient cohort, at the first phase (Time 1 = between late August and early

November 2020) 68 participants were invited to participate in the study and 57 accepted

(refusal rate 17.4%). Of those 38 patients at the second phase (Time 2 = between early

February and early May 2021) and 38 patients at the third phase (Time 3 = between August

and October 2021) were followed-up. For the dialysis cohort (those receiving HD or PD), 163

(149 HD and 14 PD) patients were invited to participate in the study. Of those, 124 patients

(113 HD and 11 PD) accepted (refusal rate 23.9%) to participate and were assessed at the

first phase (Time 1 = between July and September 2020). Of those, 92 patients (83 HD and 9

PD) at the second phase (Time 2 =between February and April 2021) and 81 patients (73 HD

and 8 PD) at the third phase (Time 3= between August and October 2021) were followed-up.

Some participants were not assessed at the Time 2 (i.e., at 6 months) and Time 3 (i.e., at 12

months [1 year]) due to several reasons including death (n = 16), and withdrawal from the

study (n = 15) (Figure 6.1). Data collection at Time 1 was completed face to face, however,

data collection at Time 2 and Time 3 were completed through the telephone because the

study co-including with the COVID-19 outbreak and government restrictions worldwide.

6.2.2.1 Inclusion and Exclusion Criteria

To obtain detailed information related to the trajectories of illness perceptions of the patients receiving dialysis the inclusion and exclusion criteria below were applied.

The inclusion criteria:

- Patients with CKD who were expected to start dialysis treatment within 6 months (were assessed when first approached [Time 1], at the commencement of dialysis [Time 2] and at 6 months after receiving dialysis treatment [Time 3])

- Regardless of dialysis vintage, patients who were already receive dialysis treatment (HD or PD) (were assessed when they were first approached [Time 1], at 6 months [Time 2] and after 1 year [Time 3]).

- Patients who were verbally fluent in Turkish. They may or may not be able to read Turkish as the researcher was able to read out questionnaire items. This was to account for literacy not being a barrier to participation.

- Aged over 18 years at the time of the study.

The exclusion criteria:

- Patients with mental health issues (under referral or treated within over a last year) were excluded. This aimed to prevent further distress in these patients. Also, those patients who were involved with mental health services may already hold different beliefs towards their illness that should be investigated separately.

- Patients with disabilities that influence capacity to consent. This was due to issues related to conditions that significantly impact language skills and cognitive function.

- Patients with life expectancy of less than one year were excluded (i.e., those who are receiving end of life care).

6.2.3 Materials

The questionnaire pack included the Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent et al., 2006), Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001), Chalder Fatigue Scale (CFS) (Chalder et al., 1993), and Dialysis Symptom Index (DSI) (Weisbord et al., 2004). These scales have been widely used in CKD populations. As a part of the questionnaire pack, a sociodemographic form included items about marital status, employment status, hospital admission, dialysis vintage and significant life events such as divorce, hospitalization etc. The Charlson Comorbidity Index (CCI) (Charlson et al., 1987) was also used to assess comorbidity status of the participants. Scales of Brief IPQ (Oflaz et al., 2014), PHQ-9 (Güleç et al., 2012), CFS (Adın, 2019) and DSI (Onsoz, & Usta Yesilbalkan, 2013) are already available in Turkish language. However, an independent researcher who is fluent in both English and Turkish checked translated versions of the scales to ensure semantic equivalence and provide therefore an extra quality assurance mechanism.

6.2.3.1 Brief Illness Perception Questionnaire (Brief IPQ)

This questionnaire was developed by Broadbent and colleagues (Broadbent et al., 2006), it involves nine items assessing the views of the patients related to their illness. The items include statements such as, "How much does your illness affect your life? ", "How concerned are you about your illness?". The answers are assessed using a 0-to- 10 response scale. Some items assess cognitive illness representations, some emotional representations and others evaluate causal beliefs and illness comprehensibility. It is convenient to replace the word 'illness' with the name of particular name of illness such as kidney disease. Higher scores represent increases in the dimension assessed. Test re-test reliability analyses indicated that items are correlated among renal patients (Broadbent et al., 2006). Broadbent and colleagues

reported findings that show support for concurrent, predictive and discriminant validity for the Brief IPQ (Broadbent et al., 2006). Oflaz and colleagues translated the questionnaire into Turkish (Oflaz et al., 2014). The translated version shows a good level of internal consistency and content validity (Karataş et al., 2017).

6.2.3.2 Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 was designed to measure depressive symptoms over the past two weeks. It includes 9 items and they are assessed by using 4-point (0-3) scale (not at all: 0 - nearly every day: 3). Scores can range between 0 and 27. Items include statements such as "Little interest or pleasure in doing things", "Feeling tired or having negative energy" and "Poor appetite or overeating". For reliability of the scale, authors measured Cronbach alpha and test-retest reliability, and they were at good levels ($\alpha = .89$ & $\alpha = .84$ respectively). Also, the findings provide support for criterion and construct validity of the scale (Kroenke et al., 2001). Güleç and colleagues translated the scale into Turkish. They reported that Turkish version of the PHQ-9 showed .76 Cronbach alpha coefficient for nonclinical sample. Their findings also indicate support for criterion and construct validity of the Turkish version of the scale (Güleç et al., 2012).

6.2.3.3 Chalder Fatigue Scale (CFS)

The CFS was designed to measure fatigue severity over last month. It consists of 11 items including statements such as "Do you have problems with tiredness?", "Do you lack energy?" and "Do you have less strength in your muscles?". Answers are assessed by using 4-point scale. Reliability analysis showed that Cronbach alpha was found .89. The original study also reported findings related to construct, face and discriminant validity (Chalder et al., 1993). Adın translated the scale into Turkish and found that internal consistency of the scale was

.89. In addition, his findings demonstrated support for the concurrent, construct and convergent validity (Adın, 2019).

6.2.3.4 Dialysis Symptom Index (DSI)

The DSI was developed to assess symptom prevalence and severity of dialysis during the previous 7 days. It consists of 30 items including various symptoms (i.e., nausea, muscle cramps etc.). Responses are evaluated by using 5-point scale (0-4). The test-retest reliability assessment of the original study demonstrated the coefficient as .80. The original study also indicated evidence on content validity (Weisbord et al., 2004). Onsoz and Usta Yesilbalkan translated the index into Turkish language. Cronbach alpha for internal consistency was reported as .84. Similarly, they indicated supportive findings of good content validity (Onsoz & Usta Yesilbalkan, 2013).

6.2.3.5 Charlson Comorbidity Index (CCI)

The CCI was originally designed to classify comorbid conditions which might alter the risk of mortality in longitudinal studies. Different scores are assigned for condition/s the patient has (Charlson et al., 1987). Studies demonstrated findings related to content and construct validity and reliability of the index (De Groot et al., 2006). The index is commonly used in Turkish samples (Çıldır et al., 2013; Naz et al., 2018, Kalaycı et al., 2019).

6.2.4   Procedure

Potential participants were approached through four renal services in four different state hospitals in North Cyprus. These included Dr Burhan Nalbantoglu State Hospital in Nicosia, Gazi Magusa State Hospital in Famagusta, Girne Akçiçek State Hospital in Kyrenia and

Cengiz Topel Hospital in Morfou. These hospitals were the only health centres that provide renal services in North Cyprus at that time. The local consultant Nephrologist who works at the Nicosia Dr Burhan Nalbantoglu State Hospital and who was also part of the research team, together with the nurses working at the Nephrology Department determined potential participants according to inclusion and exclusion criteria and made the first approach. This included consent to pass on patient details to the researcher. Patients were provided with a participant information sheet at the centre and were advised to discuss it with others if they wanted to. The participant information sheet included information about the aim of the study and procedure. It was ensured that patients fully understood the particulars of the research, especially the right to withdraw at any time, and how their data would be used and handled. Although the necessary information was provided in the participant information sheet, participants were reminded verbally that agreeing or disagreeing to participate in the study would not affect the treatment that they received. All documents provided including participant information sheet, consent form and debrief sheet were in the local language (Turkish). The local consultant nephrologist informed nurses who work at the Renal Services about the study so that they could also help patient questions if necessary. Once the participants agreed to join the study, they were asked to provide informed consent. Data collection at Time 1 point were completed face to face. At Time 2 and 3, participants were contacted to administer the questionnaire pack via telephone call. Before administering the questionnaire pack, the researcher firstly explained the aim of the study, and highlighted the confidentiality, anonymity and patient's right to withdraw from the study without any explanation. After completing the questionnaire pack, verbal as well as written debriefing was provided so that patients were clear about where they could seek further support. Only the state hospital in the capital city provides comprehensive psychological support. The service includes psychiatrists, clinical psychologists, and mental health nurses. The service

was informed about the study so that staff were ready to provide support for the participants in case needed.

Each participant was assigned a unique code to facilitate follow-up. For the pre-dialysis group, the same questionnaire pack was used at three different points (Time 1: when expected to start to dialysis within 6 months, Time 2: when commenced dialysis, Time 3: 6 months after receiving dialysis treatment). Only difference was that DSI was not included in the questionnaire pack for those who were in the pre-dialysis phase. On the other hand, for those who already receiving dialysis (HD or PD), the same questionnaire pack was used at three different time points (Time 1: when first approached, Time 2: after 6 months, Time 3: at 1 year [12 months]). The questionnaire pack took approximately 30 to minutes to complete.

Blood markers were collected to understand the degree of kidney function at each time point. For each measurement occasion (i.e., Time 1, Time 2 and Time 3), medical data from routine blood reports (i.e., creatine, albumin, and haemoglobin, dialysis adequacy [Kt/V] values) were collected during planned visits to the hospitals. As the researcher could not access the medical information, she worked with a renal nurse to extract the relevant patient information.

6.2.5   Data Analysis

Descriptive statistics and longitudinal data analyses (GAMLj module) were conducted in Jamovi version 1.6.23 (The jamovi project, 2021).

6.2.5.1 Descriptive Statistics

Socio-demographic data patterns were explored in descriptive terms such as the characteristics of the patients in terms of socioeconomic status, age, gender, clinical values, and comorbidity status. Baseline illness perceptions, depression, and dialysis symptoms were investigated in different phases (i.e., pre-dialysis, dialysis group).

6.2.5.2 Longitudinal Data Analysis

Growth curve models were used as a tool for measurement of change or trajectories. Growth curve models were deemed most appropriate to address the research questions. This is because the study used longitudinal design and so is interested in change overtime. The first question is more specific to observe differences between patients in different phases. The last question similarly aims to examine differences among patients who moved from pre-dialysis to dialysis phase. The questions from two to six are focused on observing change overtime. Longitudinal data analysis is sometimes called trajectory analysis and is essentially a form of data reduction as it seeks to examine variance over time. Both similarities and differences between patients can be explored in this type of technique because of the mean and covariance structures in the data. The analysis includes both intercept (starting point) and slope (growth or the rate of change). Longitudinal data generally aim to answer two questions 1) how the dependent variable (outcome) changes over time and 2) how this change can be predicted or explained. The first question is more specific, and it focuses on understanding the form of growth, for instance, linear or non-linear. The rate of change (growth) can increase and/or decrease, accelerate and/or decelerate. The first step would be to determine the form of growth to investigate. As the second question is broader, it aims to identify the association between the rate of change (trajectory) and independent variables that would predict the outcome (Nese & Lai, 2012; Preacher, 2019).

The form of growth can be identified within three categories, linear, polynominal, piecewise. The most parsimonious form of the growth is known as linear growth. In this form, the trajectory is expected to change at a constant rate overtime, for instance, increasing (positive slope) or decreasing (negative slope). On the other hand, polynominal growth typically consists of quadratic and cubic trajectory as well as including previous form of growth such as linear. For instance, quadratic growth models can accelerate and/or decelerate over time. By using advanced statistical tests, functional form that fits the data best can be identified. It can be determined whether the change in growth is significantly different than 0, which suggests that predictors can be added to the model that may explain the change in outcome (Nese & Lai, 2012). Although there are different forms of growth models that can be tested, this also depends on number of testing occasions which occurred. For example, linear growth models require a minimum of 3 occasions, quadratic requires a minimum of 4 and cubic models require a minimum of 5 measurement occasions. One of the advantages of using advanced statistics in longitudinal data analysis is that data can be collected on a fixed schedule suggesting that observation occurred at the same time and occasions, or on a flexible schedule, suggesting that observations occurred at different times on different occasions (Singer & Willett, 2003). Therefore, advanced statistics for longitudinal data analysis by using Structural Equation Model (SEM) and Multilevel Model (MLM) have been considered as more powerful than repeated measures ANOVA (Hox et al., 2017).

One of the important assumptions of longitudinal data analysis is that outcome (dependent variable) is continuous, must maintain the same measurement scale on every occasion and be normally distributed (for maximum likelihood technique). Another important assumption is to have an *adequate* sample size. Although growth models can be applied to small sample

sizes (e.g., n = 22), it is recommended to have at least 100 cases (Curran et al., 2010). On the other hand, missing data is problematic in longitudinal data analysis similar to other statistical models. Missing data may decrease representativeness of the sample, cause loss of power to determine meaningful effects, lead to biased results and negatively affect the validity of the study. However, there are advanced statistical methods to deal with missing data in longitudinal data analysis. For instance, the maximum likelihood estimation method is available in many statistical software. It assumes that missing data are at random. This is a robust and efficient technique that allows inclusion of all participant responses into the dataset, provided they have been observed at least on one occasion when the outcome variable was normally distributed (Hox et al., 2017).

Longitudinal data analysis (growth models) can be conducted by MLM or SEM. It is acknowledged that SEM and MLM *growth curve models* are identical in terms of analytical and empirical aspects under a general set of conditions (Curran, 2003). The difference between MLM and SEM is that MLM has a univariate approach to longitudinal data where the outcome is a single variable (long format) while SEM takes a multivariate approach (wide format). MLM and SEM share several strengths and limitations. One of the advantages of using MLM for longitudinal data analysis is that more levels can be added easily. This allows observation of varying associations at different levels and modelling this variation by cross-level interactions at higher levels (Hox et al., 2017). MLM is also known as a hierarchical linear model or general linear mixed model. The MLM framework includes both fixed effects and random effects (Hoffman, 2015). When MLM is used for longitudinal data, repeated measures (within-person change) are considered as Level 1 and between person changes are considered as Level 2 (Hox et al., 2017). Hence, growth within and between individuals can be examined. Once the form of growth is identified, time-varying variables and time-

invariant covariates (predictors) can be added to the model to see how they influence the growth. Time-varying predictors may explain within person variance on the other hand, time-invariant predictors may explain between-person variance (Hoffman, 2015). In MLM, model building strategies may vary, these may include building the model with top-down or bottom-up approach. Top-down strategies may have more disadvantages as it may lead to convergence problems. Mostly, a bottom-up approach is used as it allows a starting with a simple model and progresses by adding more parameters. More specifically, this strategy uses fixed components to start then proceeds with random parts. The intercept-only model is the starting point, then the researcher adds parameters at further steps and examines the estimates to understand which parameters are significant and makes meaningful change in outcome (Curran, 2003; Hox et al., 2017).

Visual exploration of the data showed that the dependent variables (*perceptions of consequences, timeline, emotional response, personal control, depression,* and *dialysis symptoms* (six variables in total) seemed to be normally distributed. Therefore, the maximum likelihood estimation technique was used (Hox et al., 2017). It was ensured that multicollinearity was not present. Additionally, normality of residuals was tested, and examined via Q-Q plot, and homogeneity of variance of residuals was visually examined by scatterplot. Multilevel models for repeated measurements and regression analyses were conducted to examine the association between the independent (predictors) and dependent (outcome) variables (Snijders & Bosker, 1999; Hox et al., 2017). For each dependent variable (*perceptions of consequences, timeline, emotional response, personal control, depression,* and *dialysis symptoms* (six variables in total), a separate multilevel model analysis was conducted. Firstly, independent variables, for instance, *type of treatment/phase* (i.e., pre-dialysis, dialysis) were entered. Then, demographic characteristics such as *gender,*

comorbidity status (i.e., number of comorbid conditions) and *age* were entered to the model.

As it is commonly recommended practice (Hoffman, 2015; Hox et al., 2017), the data were

centred on the grand mean to make interpretation of the results easier, where possible. This

has been suggested to produce more realistic variance estimates (Hox et al., 2017). To assess

the model fit to data, values of Akaike's information criterion (AIC) was checked at each step

during model building. AIC is similar to Bayesian Information Criterion (BIC) as both are

calculated by deviance and number of estimated parameters. Lower values of AIC and BIC

would show that the model has improved (better fit). Also, interclass coefficients (ICC)

values were checked for random effects as higher ICC values indicate better fit and show

whether there is substantial evidence on Level 2-unit variables that can explain the variance

in outcome. It can be interpreted as a measure of strength of relationship (Lorah, 2018).

6.3   Results

6.3.1   Baseline Patient Characteristics

In total 231 patients were approached according to inclusion criteria. Baseline patient

recruitment included 124 patients who were already on dialysis treatment and 57 patients

who were within the pre-dialysis phase and expected to commence dialysis within 6 months.

Figure 6.1 shows baseline patient recruitment data and retention data at 6 months and 12

months follow-up. Table 6.1 presents demographic and clinical characteristics at baseline for

both groups (i.e., dialysis and pre-dialysis). The majority of patients were male, married,

retired. Mean age was > 60 years in both groups (Table 6.1). Among reported diagnoses,

uncertain aetiology (44.1%) was the most common diagnosis which was followed by diabetic

nephropathy (28%). In the dialysis group, the majority of patients received HD treatment in a

hospital setting (91.1%).
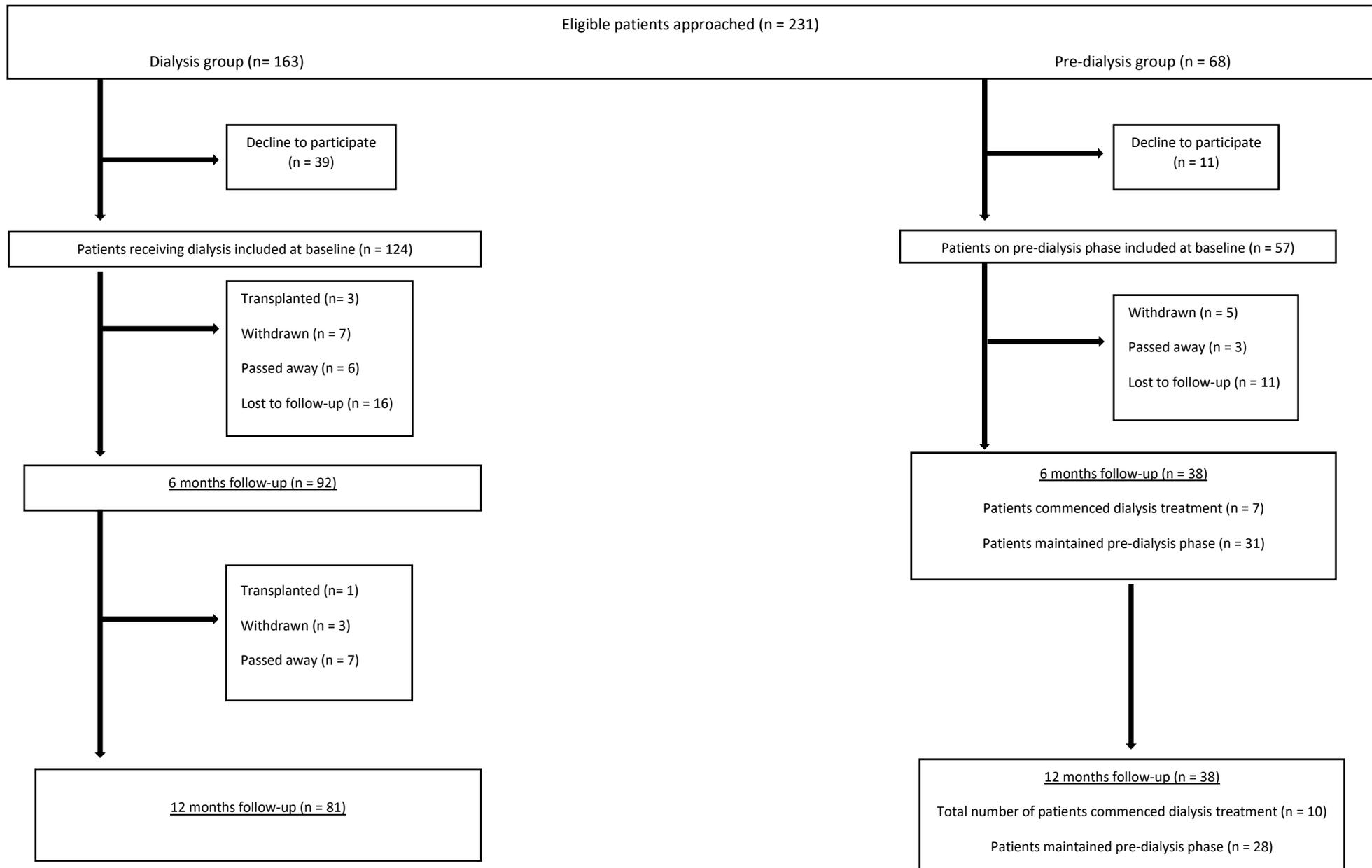
Figure 6.1. *Patient recruitment and follow-up.*

Table 6.1. *Demographic and clinical characteristics of patients at baseline.*

	Patients on pre-dialysis phase (n = 57)	Patients receiving dialysis (n = 124)
Age (mean, SD)	62.8 (13.8)	64.3 (14.9)
Gender (male n, %)	42 (73.2%)	85 (68.5%)
Marital status (n, %)		
Married	45 (78.6%)	90 (72.5%)
Singe/divorced/widowed	12 (21.1%)	33 (26.6%)
Employment (n, %)		
Retired	39 (68.4%)	80 (64.5%)
Full time/part time employee	5 (8.7%)	6 (4.8%)
Housewife	9 (15.7%)	26 (19.3%)
Unemployed	4 (7.1%)	12 (9.6%)
Dialysis vintage (in years, mean SD)	-	4.53 (4.34)
Treatment (n, %)		
Haemodialysis	-	113 (91.1%)
Peritoneal dialysis	-	11 (8.9%)
Creatinine (mg/dL, mean SD)	3.42 (1.30)	8.72 (2.43)
Albumin (g/l, mean SD)	4.13 (0.48)	3.93 (0.37)
Haemoglobin (g/dL, mean SD)	11.4 (1.82)	11 (1.86)
Dialysis efficiency (Kt/V, mean SD)	-	1.59 (0.48)
	Overall (n = 181)	
Diagnosis (n, %)		
Uncertain aetiology	41 (44.1%)	
Diabetic nephropathy	26 (28%)	
Polycystic kidney	9 (9.7%)	
Hypertension	7 (7.5%)	
Other	10 (10.9%)	

6.3.2 Differences between Pre-dialysis and Dialysis Patients

Table 6.2 indicates the mean levels of illness perceptions (i.e., consequences, timeline, personal control, treatment control, identity, concern, coherence, emotional response), depression and dialysis symptoms at baseline. The mean level of depression symptoms (7.02) demonstrated that the dialysis group have had mild depression symptoms at baseline. This is according to Kroenke et al. (2001), scores obtained from PHQ-9 may indicate level of depression severity such as minimal (1-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe (20-27) depression. Besides, 30.2% of the patients in the dialysis group

scored 10 and above on PHQ-9, which may suggest a possible clinically significant condition (Kroenke et al., 2001). Additionally, fatigue severity scores were obtained through CFS, higher scores represent greater level of fatigue (Chalder et al., 1993). Similarly higher scores on DSI indicates greater symptom severity (Weisbord et al., 2004).

Table 6.2. *Mean and standard deviation values for Brief IPQ, PHQ-9, CFS and DSI scores at baseline*.

	Patients on pre-dialysis phase (n = 57)	Patients receiving dialysis (n = 124)
	M (SD)	M (SD)
Brief IPQ		
Consequences	3.39 (3.36)	7.40 (3.35)
Timeline	6.92 (3.06)	8.10 (2.74)
Personal Control	4.81 (2.30)	2.79 (2.36)
Treatment Control	7.47 (2.57)	8.23 (2.21)
Identity	1.32 (1.99)	5.07 (3.36)
Concern	3.46 (3.69)	3.27 (3.72)
Coherence	7.34 (3.78)	7.22 (3.57)
Emotional response	3.98 (3.44)	5.26 (3.83)
PHQ-9	3.63 (3.86)	7.02 (3.86)
CFS	12.1 (4.16)	16.4 (5.03)
DSI	-	50.8 (22.9)

Brief IPQ, Brief Illness Perceptions Questionnaire; PHQ-9, Patient Health Questionnaire-9; CFS, Chalder Fatigue Scale; DSI, Dialysis Symptom Index.

By using Cronbach's alpha, the internal reliability values of the scales were measured and were interpreted according to the range values reviewed in Taber (2018). The Brief IPQ scale (1-8) had a moderate reliability score of 0.60. The PHQ-9 scale indicated a robust reliability score of 0.81. Both CFS and DSI demonstrated high reliability scores of 0.91 and 0.89 respectively.

6.3.3   Correlates of Illness Perceptions at Baseline

As mentioned in the Methods section, literature suggests that several illness perception domains (e.g., consequence, timeline, emotional response, personal control) may differ

depending on the phase of the patient journey (Chilcot et al., 2010; 2011; 2013; 2018; Covic et al., 2006; Griva et al., 2009; 2010; Hudson et al., 2016; Jansen et al., 2013; Jayanti et al., 2016; Muscat et al., 2020; 2021; Meuleman et al., 2017). Perceptions of consequences, timeline, emotional response, and personal control were selected to observe its correlates with demographic (i.e., age and dialysis vintage), clinical variables (i.e., creatinine, albumin, haemoglobin, Kt/V) and with other measurement scales in both pre-dialysis and dialysis groups, where appropriate. Given that it is closely linked to and even overlaps with depression (Pae et al., 2007; Skapinakis et al., 2003), fatigue scores were only included in the descriptive statistics to observe whether they relate to selected illness perception domains. Spearman's correlation coefficient was used due to non-normal distribution of the measures. In the pre-dialysis group, perception of emotional response was positively correlated with age ($p < 0.001$). Among clinical markers, only creatinine was positively correlated with perception of consequences ($p < 0.001$). Depression scores were positively correlated with perceptions of consequences and emotional response ($p = 0.02$, $p<0.001$ respectively) while fatigue scores were found to be only positively related to perception of consequences ($p = 0.03$) (Table 6.3).

Table 6.3. *Correlates of illness perceptions (consequences, emotional response, personal control, and timeline, respectively) at baseline in the pre-dialysis phase.*

	Patients in the pre-dialysis phase					
	Age	Creatinine (mg/dL)	Albumin (g/l)	Haemoglobin (g/dL)	PHQ-9	CFS
Consequences						
Spearman's rho	-0.07	0.46	-0.14	-0.25	0.31	0.27
p-value	0.42	<0.001	0.32	0.07	0.02	0.03
Emotional response						
Spearman's rho	0.44	0.21	0.01	0.03	0.50	0.19
p-value	<0.001	0.12	0.95	0.80	<0.001	0.14
Personal control						
Spearman's rho	-0.06	-0.09	0.01	0.03	-0.09	-0.26
p-value	0.65	0.53	0.93	0.82	0.52	0.06
Timeline						

Spearman's rho	0.24	0.12	-0.07	-0.09	0.01	-0.05
p-value	0.22	0.55	0.73	0.75	0.96	0.77

Brief IPQ, Brief Illness Perceptions Questionnaire; PHQ-9, Patient Health Questionnaire-9; CFS, Chalder Fatigue Scale.

On the other hand, in the dialysis group, age was negatively correlated with perception of consequences, emotional response and personal control ($p < 0.05$) while it was positively correlated with timeline ($p < 0.001$). Selected illness perception domains failed to significantly correlate with clinical variables and dialysis vintage in the dialysis group. Perception of consequences was significantly correlated with depression and dialysis symptoms ($p < 0.001$). Emotional response was found to be positively correlated with depression, fatigue and dialysis symptoms ($p < 0.001$) while perception of timeline was positively correlated with fatigue and dialysis symptoms ($p < 0.05$) (Table 6.4).

Table 6.4. *Correlates of illness perceptions (consequences, emotional response, personal control, and timeline, respectively) at baseline in the dialysis group.*

	Age	Creatinine (mg/dL)	Albumin (g/l)	Haemoglobin (g/dL)	Dialysis vintage	Kt/V	PHQ-9	CFS	DSI
				Patients receiving dialysis					
Consequences									
Spearman's rho	-0.21	0.10	-0.14	0.01	0.06	-0.10	0.37	0.07	0.36
p-value	0.02	0.23	0.10	0.92	0.45	0.25	<0.001	0.41	<0.001
Emotional response									
Spearman's rho	-0.21	0.07	0.08	0.17	0.05	-0.01	0.52	0.36	0.50
p-value	0.01	0.43	0.37	0.06	0.57	0.86	<0.001	<0.001	<0.001
Personal control									
Spearman's rho	-0.19	-0.03	-0.03	-0.01	0.04	-0.07	-0.12	-0.12	0.02
p-value	0.03	0.67	0.72	0.87	0.59	0.41	0.20	0.18	0.77
Timeline									
Spearman's rho	0.39	-0.17	0.01	0.05	0.17	-0.02	0.13	0.23	0.22
p-value	<0.001	0.08	0.87	0.61	0.09	0.81	0.17	0.01	0.03

Brief IPQ, Brief Illness Perceptions Questionnaire; PHQ-9, Patient Health Questionnaire-9; CFS, Chalder Fatigue Scale; DSI, Dialysis Symptom Index; Kt/V, Dialysis efficiency.

6.3.4   Predictors of Illness Perceptions

Separate General Linear Models (GLM) were run for each selected illness perception domain (perception of consequences, personal control, emotional response and timeline) to see whether there was a significant difference between groups while controlling for age, gender and number of comorbid conditions (Table 6.5). Controlling for age, gender and comorbidity status, the dialysis group was predicted to have 5.17 units of consequences perceptions greater than the pre-dialysis group. Regardless of age, gender and comorbidity status, the dialysis group was predicted to have 2.15 units higher levels of emotional response compared to pre-dialysis group. Similarly, the pre-dialysis group was predicted to have 4.28 units greater perception of personal control compared to dialysis group. On the other hand, increases only in age predicted higher levels of perception of timeline regardless of gender, comorbidity status and different phase (i.e., pre-dialysis and dialysis).

Table 6.5. *General Linear Models predicting illness perceptions (consequences, emotional response, personal control, and timeline, respectively) while controlling for gender, age and comorbidity status.*

	Estimate	SE	95% Confidence Interval Lower	Upper	β	t	p
Consequences							
(Intercept)	5.04	0.45	4.14	5.95	0.00	11.02	<.001
Female – Male	0.31	0.44	-0.56	1.19	0.08	0.69	0.48
Age	-0.02	0.01	-0.01	0.05	-0.01	-2.20	0.02
Comorbidity status	-0.04	0.19	-0.42	0.32	-0.10	-0.25	0.79
Pre-dialysis – Dialysis	-5.17	0.44	-6.06	-4.29	-1.34	-11.50	<.001
Emotional response							
(Intercept)	4.13	0.49	3.16	5.11	0.00	8.35	<.001
Female – Male	1.64	0.48	0.49	2.59	0.44	3.39	<.001
Age	-0.05	0.01	-0.07	-0.02	-0.19	-3.69	<.001
Comorbidity status	0.01	0.20	-0.39	0.41	-0.01	0.04	0.96
Pre-dialysis – Dialysis	-2.15	0.48	-3.10	-1.19	-0.58	-4.43	<.001
Personal Control							
(Intercept)	4.55	0.17	4.20	4.90	0.00	25.71	<.001
Female – Male	0.18	0.35	-0.69	1.21	0.06	0.01	0.99
Age	-0.02	0.01	-0.04	-0.01	-0.10	-2.27	0.02
Comorbidity status	-0.03	0.15	-0.33	0.26	-0.01	-0.22	0.82
Pre-dialysis – Dialysis	4.28	0.35	3.59	4.98	1.38	12.05	<.001

Timeline							
(Intercept)	8.40	0.39	7.63	9.18	0.00	21.29	<.001
Female – Male	1.08	0.41	0.26	1.90	0.43	2.60	0.01
Age	0.05	0.01	0.03	0.07	0.31	4.95	<.001
Comorbidity status	0.22	0.16	-0.09	0.54	0.08	1.39	0.16
Pre-dialysis – Dialysis	0.03	0.42	-0.79	0.86	0.01	0.08	0.93

6.3.5   Longitudinal Data Analyses

To observe the trajectory of selected illness perception domains (i.e., consequences, personal

control, emotional response, timeline), depression and dialysis symptoms, a series of linear

Latent Growth Models (LGM) were conducted. As mentioned in the Methods section,

considering the study included 3 time points, each model assumed linear growth.

6.3.5.1 Change in illness perceptions over time

Table 6.6. *Series of linear latent growth models for illness perceptions over a one year follow up.*

	Consequences	Emotional response	Personal Control	Timeline
Fixed effects (Estimate [SE])				
Intercept	5.94 (0.64)***	5.27 (0.69)***	3.48 (0.49)***	6.99 (0.60)***
Time	-0.47 (0.20)*	-0.64 (0.22)**	0.65 (0.17)***	0.69 (0.21)***
Age	-0.02 (0.02)	-0.05 (0.01)***	-0.02 (0.01)*	0.05 (0.01)***
Comorbidity status	-0.01 (0.22)	-0.01 (0.23)	-0.05 (0.15)	0.19 (0.19)
Pre-dialysis – Dialysis	-3.43 (0.83)***	-1.09 (0.92)	-0.03 (0.69)	-0.74 (0.87)
Female – Male	0.48 (0.45)	1.69 (0.47)***	-0.01 (0.31)	0.49 (0.38)
Time x Pre-dialysis – Dialysis	-0.80 (0.41)*	-0.66 (0.46)	2.30 (0.34)***	0.17 (0.43)
Random components				
Within-patients (L1) variance	6.55	8.50	4.69	3.30
Intercept (L2) variance	2.96	2.57	0.63	2.00
Slope (L2) variance	-	-	-	-
Additional information				
ICC	0.311	0.223	0.119	0.377
AIC	1663	1724	1458	1065
BIC	1697	1758	1492	1096
Likelihood Ratio Chi-square Tests				
Random intercept	20.8***	13.8***	3.7	13.5***
Random slope	-	-	-	-
(marginal) Pseudo R^2	.34	.18	.44	.16

*p<0.05 **p<0.01***p<0.001

Table 6.6 summarises LGMs for perceptions of consequences, personal control, emotional response, and timeline separately. Coefficient estimates and variance were reported for the intercept and slope in each model. There were significant variations in perceptions of consequences, emotional response, and timeline at baseline, suggesting between-patient variability. In the first model, the slope for time (average effect of time) was -0.47 which was significant, indicating that perceptions of consequences were expected to decrease 0.47 units at each measurement occasion that passes beyond the first measurement occasion (i.e., 6 months). Considering the expected perception of consequence at baseline was 5.94, the expected perception of consequences in one year would be 5 ($\beta_{average\ mean\ of\ intercepts}$ + $\beta_{fixed\ effect\ of\ time\ variable}$ (2) = 5.94 + [-0.47(2)] = 5). Perception of consequences for the dialysis group were expected to be 3.43 units higher than pre-dialysis group at baseline. The slope of interaction between time and different phases (i.e., pre-dialysis and dialysis) was significant (p = .05), indicating that the rate of change was different between those on dialysis and in the pre-dialysis phase. When effects of time on pre-dialysis and dialysis groups were evaluated, the rate of change (expected slope for time) among the dialysis group (Estimated Mean= 7.50, SE= 0.25 at baseline) was found -0.07 and was not significant. However, the rate of change (expected slope for time) among pre-dialysis group was -0.88 which was significant, suggesting that perception of consequences was expected to decrease 0.88 units among the pre-dialysis group (Estimated Mean= 2.59, SE= 0.41 at baseline) at each time point (6 months) (Figure 6.2).
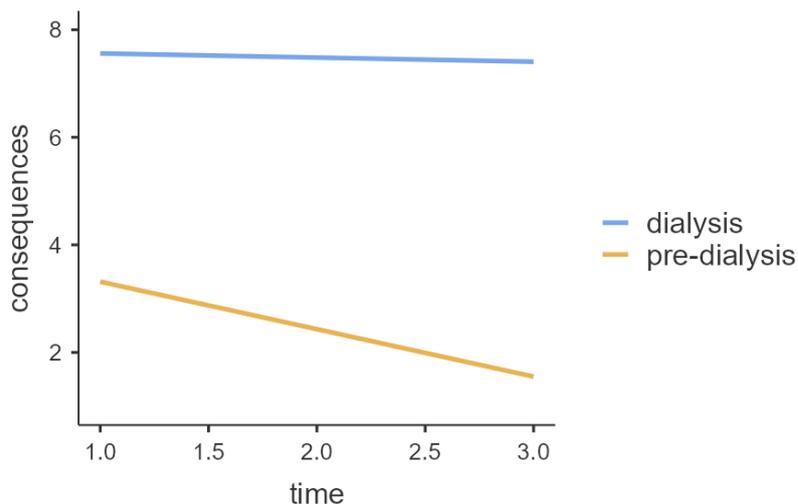
Figure 6.2. *Effects plot for perception of consequences comparing pre-dialysis and dialysis groups over 3 time points.*

In the second model, the slope for time (average effect of time) was significant, indicating that with each time point (i.e., 6 months) emotional response was predicted to decrease by 0.64 units. When average perception of emotional response at baseline was 5.27, the expected perception of emotional response in one year follow up would be 3.99 ($\beta_{average\ mean\ of\ intercepts}$ + $\beta_{fixed\ effect\ of\ time\ variable}$ (2) = 5.27 + [-0.64(2)] = 3.99). The slope of different phases (i.e., pre-dialysis and dialysis) was not significant. Similarly, the slope of interaction between time and different phases (i.e., pre-dialysis and dialysis) was not significant, however, effects of time on pre-dialysis vs dialysis groups showed that rate of change among dialysis group (Estimated Mean= 5.28, SE= 0.26 at baseline) was -0.31 and was not at a significant level. The rate of change in the pre-dialysis group, on the other hand, was -0.97 which was significant, suggesting that emotional response was expected to decrease 0.97 units among pre-dialysis group (Estimated Mean= 2.97, SE= 0.43 at baseline) at each measurement occasion (i.e., 6 months) (Figure 6.3).
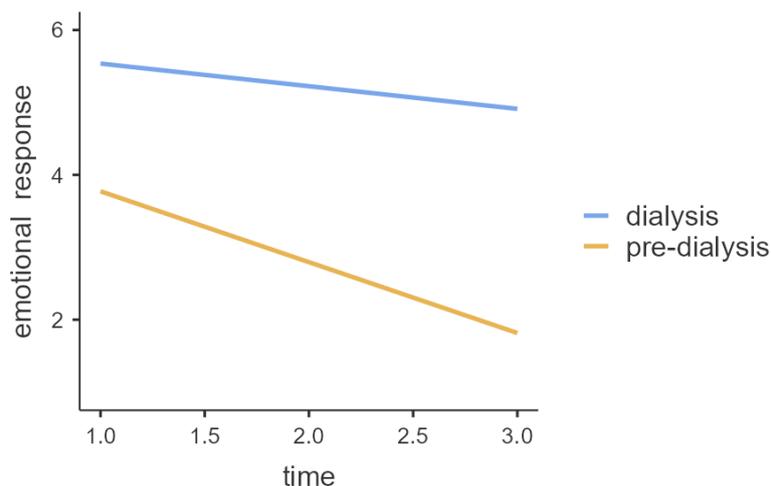
Figure 6.3. *Effects plot for emotional response comparing pre-dialysis and dialysis groups over 3 time points.*

In the third model, the slope for time was 0.65 which was significant, suggesting that with each time points (i.e., 6 months) perception of personal control was predicted to increase by 0.65 units. The expected average perception of personal control at baseline was 3.48, hence, the expected average perception of personal control in one year follow up would be 4.78 ($\beta_{average\ mean\ of\ intercepts} + \beta_{fixed\ effect\ of\ time\ variable}\ (2) = 3.48 + [0.65(2)] = 4.78$). It was observed that the rate of change in personal control was different in among pre-dialysis and dialysis groups. The expected rate of change among the dialysis group was -0.50 and was significant suggesting perception of personal control was expected to decrease 0.50 units among dialysis group (Estimated Mean= 2.47, SE= 0.17 at baseline) at each measurement occasion (i.e., 6 months). On the other hand, the rate of change among the pre-dialysis group was 1.80 which was significant, indicating perceptions of personal control was expected to increase 1.80 units among pre-dialysis group (Estimated Mean= 6.69, SE= 0.28 at baseline) at each time point (i.e., 6 months) (Figure 6.4).
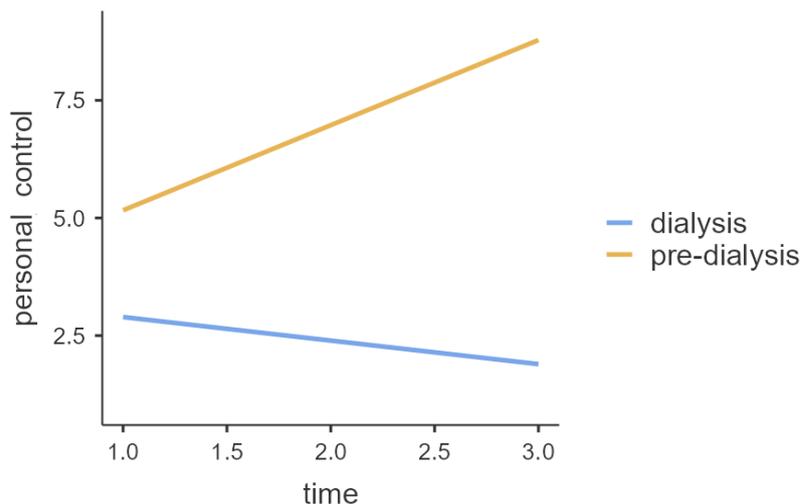
Figure 6.4. *Effects plot for perception of personal control comparing pre-dialysis and dialysis groups over 3 time points.*

In the fourth model where timeline was dependent variable, the slope for time (average effect of time) was significant. This indicated that with each measurement occasion (6 months), perception of timeline (chronicity) was predicted to increase by 0.69 units. Considering the expected perception of timeline at baseline was 6.99, the expected average perception of timeline at one year follow up would be 8.37 ($\beta_{average\ mean\ of\ intercepts} + \beta_{fixed\ effect\ of\ time\ variable} (2) = 6.99 + [0.69(2)] = 8.37$). The slope of interaction between time and different phases (i.e., pre-dialysis and dialysis) was not significant. However, the expected rate of change in the dialysis group (Estimated Mean= 8.89, SE= 0.21 at baseline) was 0.61 which was significant, indicating that perception of timeline was predicted to increase by 0.61 units in the dialysis group at each time point (i.e., 6 months). Similarly, the expected rate of change among the pre-dialysis group (Estimated Mean= 8.47, SE= 0.41 at baseline) was found to be 0.78 which was at significant level ($p = .05$), suggesting perception of timeline was expected to increase .078 units in pre-dialysis group at each measurement occasion (i.e., 6 months) (Figure 6.5).
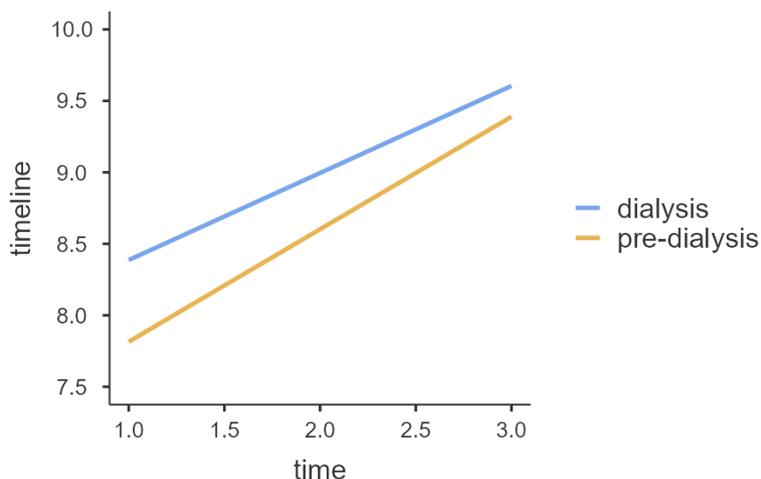
 Figure 6.5. *Effects plot for perception of timeline comparing pre-dialysis and dialysis groups over 3 time points.*

6.3.5.2 Change in depression over time

As shown in Table 6.7, five different LGMs were run to observe changes in depression scores over time. In the first model, where depression was the dependent variable, coefficients of time, age, comorbidity status, different phases (i.e., pre-dialysis and dialysis group), gender and the interaction of time and different phases were observed. The expected depression score on average was 4.53. Variance between patients' mean depression scores (intercept) was significant, suggesting that patients vary in terms of depression scores at baseline. The slope for time (average effect of time) was found to be -0.12, however it was not significant. Depression scores for the dialysis group were expected to be 3.46 units higher than pre-dialysis group at baseline. The rate of change between pre-dialysis and dialysis groups in terms of depression scores was not significant. The expected rates of change were -0.15 and -0.08 among pre-dialysis (Estimated Mean= 3.56, SE= 0.59 at baseline) and dialysis group (Estimated Mean= 7.14, SE= 0.36 at baseline) respectively, which were not at significant level.

Table 6.7. *Series of linear latent growth models for depression symptoms over a one year follow up.*

	Depression	Depression[a]	Depression[b]	Depression[c]	Depression[d]
Fixed effects (Estimate [SE])					
Intercept	4.53 (0.90)***	4.67 (0.82)***	4.17 (0.76)***	5.03 (0.89)***	5.48 (1.06)***
Time	-0.12 (0.25)	-0.003 (0.21)	0.13 (0.21)	-0.15 (0.22)	-0.33 (0.28)
Consequences[a]		0.34 (0.12)**			
Emotional response[b]			0.43 (0.12)***		
Personal Control[c]				-0.07 (0.18)	
Timeline[d]					-0.14 (0.23)
Age	-0.01 (0.02)	0.01 (0.02)	0.02 (0.02)	-0.01 (0.02)	-0.01 (0.02)
Comorbidity status	0.49 (0.32)	0.49 (0.30)	0.47 (0.28)	0.39 (0.32)	0.32 (0.37)
Pre-dialysis – Dialysis	-3.46 (1.06)***	-1.72 (0.67)*	-2.56 (0.57)***	-2.94 (0.71)***	-3.67 (0.87)***
Female – Male	2.32 (0.66)***	2.11 (0.62)***	1.49 (0.57)*	2.45 (0.66)***	2.41 (0.76)**
Time x Pre-dialysis – Dialysis	-0.06 (0.50)				
Time x Consequences[a]		0.04 (0.05)			
Time x Emotional response[b]			0.03 (0.05)		
Time x Personal Control[c]				-0.05 (0.08)	
Time x Timeline[d]					0.14 (0.13)
Random components					
Within-patients (L1) variance	9.57	8.87	8.67	9.71	10.43
Intercept (L2) variance	8.07	6.71	5.11	7.55	8.66
Slope (L2) variance	-	-	-	-	-
Additional information					
ICC	0.458	0.431	0.371	0.437	0.454
AIC	1832	1800	1771	1788	1355
BIC	1866	1837	1809	1826	1390
Likelihood Ratio Chi-square Tests					
Random intercept	50.6***	40.5***	27.0***	42.5***	27.1***
Random slope	-	-	-	-	-
(marginal) Pseudo R^2	.18	.27	.33	.21	.16

[a, b, c, d] represent separate models including only one illness perception domain as predictor (i.e., consequences, emotional response, personal control and timeline respectively).

*p<0.05 **p<0.01***p<0.001

This suggested that depression scores seem to be relatively stable in both pre-dialysis and dialysis groups at each measurement occasion (i.e., 6 months) (Figure 6.6)
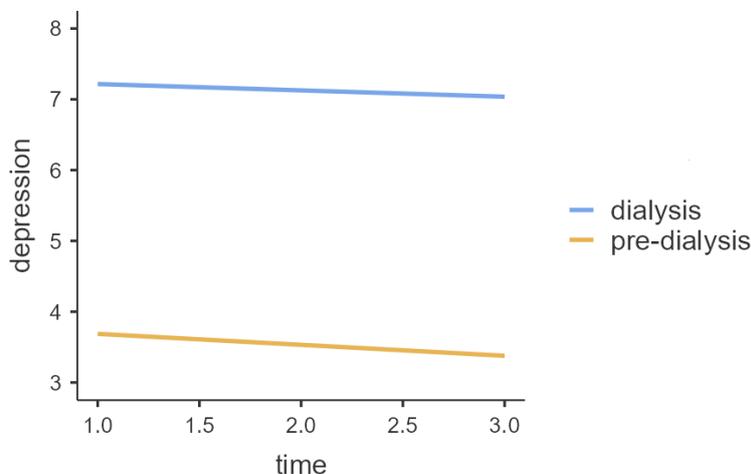
Figure 6.6. *Effects plot for depression comparing pre-dialysis and dialysis groups over 3 time points.*

Additional LGMs were conducted in which one of the selected illness perception domains (i.e., consequences, emotional response, personal control, and timeline) was entered as a predictor in addition to the established predictors from the first model (time, age, comorbidity status, different phases [i.e., pre-dialysis and dialysis groups], and gender). For each selected illness perception predictor, separate models were run. All models showed that there were significant variations between patients in terms of their depression scores at baseline (intercept) (Table 6.7). In the second model, the slope for perception of consequences was positive and significant, suggesting that depression scores were expected to increase by 0.34 unit with each increment with respect to perception of consequences. Depression scores were predicted to be 1.72 units greater in the dialysis group compared to pre-dialysis group at baseline. The slope for interaction between time and perception of consequences was not significant (Figure 6.7). According to visual data, depression scores seem to increase over

time among patients who reported greater perception of consequences than average at baseline.
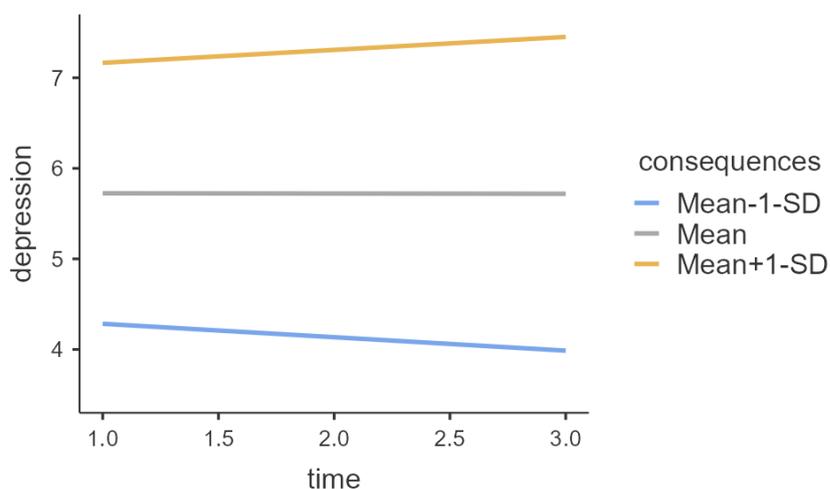
Figure 6.7. *Effect of perception of consequences level on depression over 3 time points.*

In the third model, the slope (average effect) for emotional response was positive and significant, indicating that depression scores were expected to increase by 0.43 units with each increment in emotional response. Depression scores were predicted 2.56 units greater in the dialysis group compared to the pre-dialysis group at baseline. The slope for interaction between time and perception of emotional response was not significant (Figure 6.8). However, visual evidence showed that depression scores tend to increase over time particularly among those patients with a higher level of perception of emotional response than average at baseline.
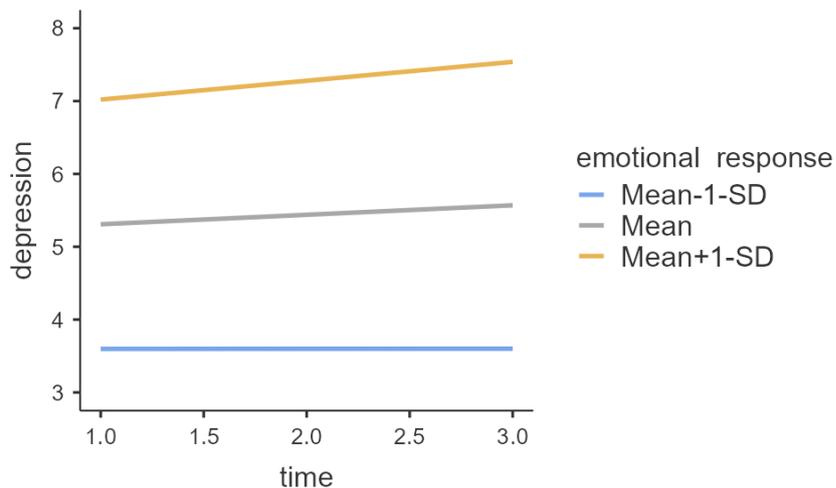
Figure 6.8. *Effect of perception of emotional response level on depression over time points.*

On the other hand, in the fourth model, slope for perception of personal control was negative but not at significant level. Depression scores were predicted 2.94 units higher in the dialysis group compared to pre-dialysis group at baseline. The slope for interaction between time and perception of personal control was not significant. As shown in Figure 6.9, depression scores tended to decrease over time, particularly in patients who reported a greater level of perception of personal control than average at baseline.
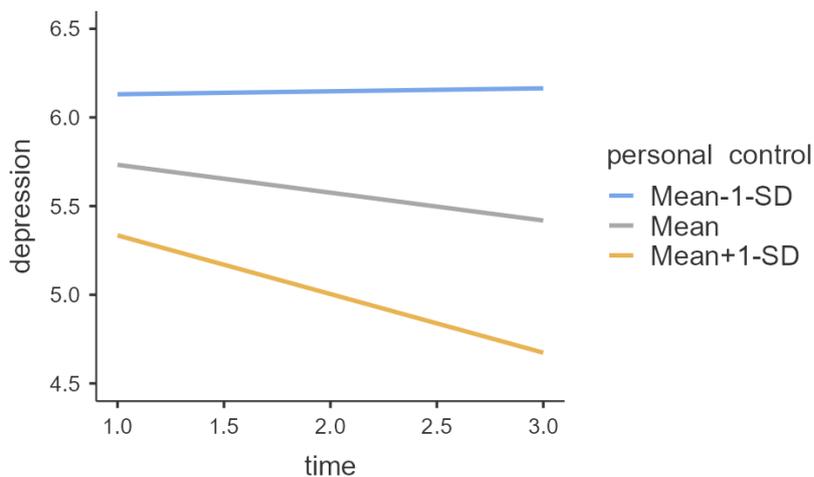
Figure 6.9. *Effect of perception of personal control level on depression over time points.*

In the fifth model, the slope for perception of timeline (chronicity) was not significant, suggesting that the average perception of timeline did not predict change in depression symptoms at baseline. Depression scores were expected to be 3.67 units higher in the dialysis group compared to the pre-dialysis group at baseline. The slope for interaction between time and perception of timeline was not significant. However, visual data indicated rate of change in depression scores over time seems to be at a higher level among those patients who reported a lower level of perception of timeline than average at baseline. In other words, depression scores seem to decrease over time, particularly in patients who reported a lower level of perception of timeline than average at baseline (Figure 6.10).
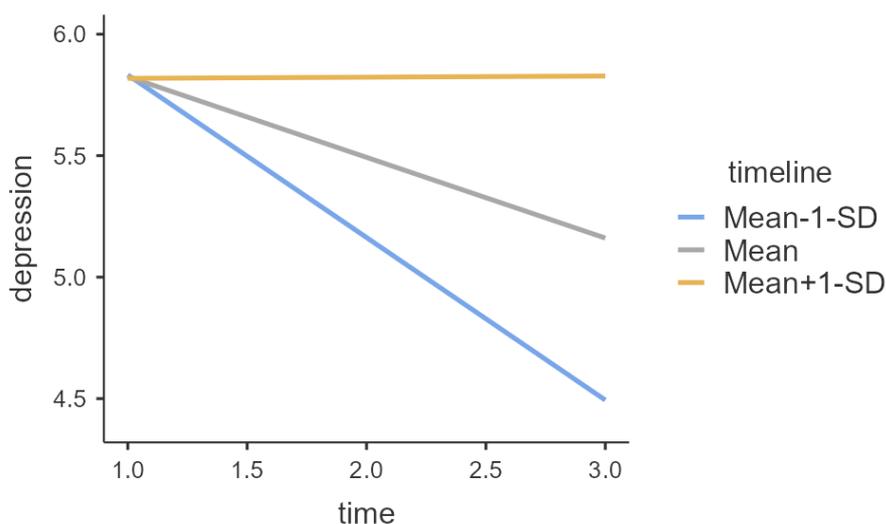
Figure 6.10. *Effect of perception of timeline level on depression over time points.*

In all models, as shown in Table 6.7, slopes for gender were significant, suggesting that depression scores were predicted to be higher among female patients at baseline. The slope for time was not significant in all models.

6.3.5.3 Change in dialysis symptoms over time

By using data on dialysis group, in total five models were run to observe change in dialysis symptoms over one year period. As shown in Table 6.8, in the first model, coefficients of time, age, comorbidity status, treatment modality (i.e., PD and HD), gender and the interaction of time and treatment modality were examined. The expected level of dialysis symptoms on average was 39.32 at baseline. Dialysis symptoms were predicted to increase 3.79 units with each increment in the number of comorbid conditions. The rate of change in dialysis symptoms were not significantly different between patients receiving PD and those receiving HD treatment. Expected rates of change were -0.29 and 2.42 among PD group (Estimated Mean= 46.1, SE= 7.07 at baseline) and HD group (Estimated Mean= 52.4, SE= 1.77 at baseline) respectively, which were not at significant level (Figure 6.11).
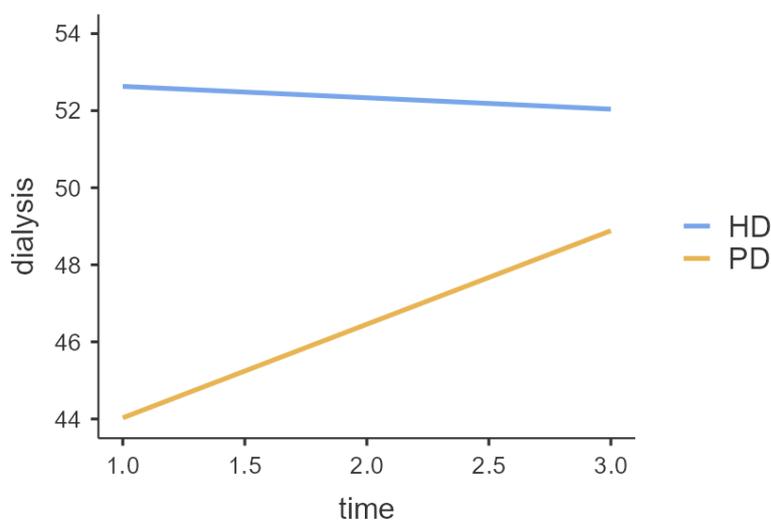
Figure 6.11. *Effects plot for dialysis symptoms comparing dialysis modalities over 3 time points.*

Table 6.8. *Series of linear growth models for dialysis symptoms over a one year follow up.*

	Dialysis Symptoms	Dialysis symptoms[a]	Dialysis symptoms[b]	Dialysis symptoms[c]	Dialysis symptoms[d]
Fixed effects (Estimate [SE])					
Intercept	39.32 (7.60)***	43.19 (4.98) ***	41.12 (4.76)***	49.16 (5.93)***	48.65 (6.39)***
Time	1.06 (2.95)	-0.16 (1.26)	0.61 (1.22)	-1.41 (1.33)	-2.15 (1.55)
Consequences[a]		1.76 (0.92)			
Emotional response[b]			2.17 (0.71)**		
Personal Control[c]				2.62 (1.28)*	
Timeline[d]					-0.01 (1.35)
Age	-0.01 (0.11)	0.06 (0.10)	0.10 (0.09)	-0.01 (0.11)	-0.04 (0.13)
Comorbidity status	3.79 (1.65)*	3.78 (1.47)*	3.82 (1.38)**	3.62 (1.64)*	2.80 (1.73)
PD – HD	-11.32 (13.99)	-2.14 (6.39)	-2.06 (6.08)	4.45 (7.65)	-4.80 (8.42)
Female – Male	6.62 (3.48)	5.17 (3.10)	2.34 (3.00)	8.39 (3.50)*	5.88 (3.63)
Time x PD – HD	2.72 (5.93)				
Time x Consequences[a]		0.32 (0.47)			
Time x Emotional response[b]			0.13 (0.34)		
Time x Personal Control[c]				-2.01 (0.65)**	
Time x Timeline[d]					0.61 (0.81)
Random components					
Within-patients (L1) variance	244	225	217.4	227	262
Intercept (L2) variance	152	103	87.8	152	128
Slope (L2) variance	-	-	-	-	-
Additional information					
ICC	0.384	0.315	0.288	0.401	0.328
AIC	2108	2074	2059	2064	1706
BIC	2140	2109	2094	2099	1738
Likelihood Ratio Chi-square Tests					
Random intercept	22.1***	13.9***	11.9***	23.4***	11.0***
Random slope	-	-	-	-	-
(marginal) Pseudo R^2	0.06	.20	.25	.10	.06

[a, b, c, d] represent separate models involving only one illness perception domain as predictor (i.e., consequences, emotional response, personal control and timeline respectively).

*p<0.05 **p<0.01***p<0.001

In the second model, perception of consequences was added to the model in addition to the predictors in the first model. The slope for perception of consequences was not significant, indicating that perception of consequences did not predict change in dialysis symptoms at baseline. The slope for comorbidity status was positive and significant, suggesting that dialysis symptoms were predicted to increase 3.78 units with each increment in the number of comorbid conditions. The slope for interaction between time and perception of consequences was not significant. Figure 6.12 shows effects of different levels of perception of consequences at baseline on dialysis symptoms over time.
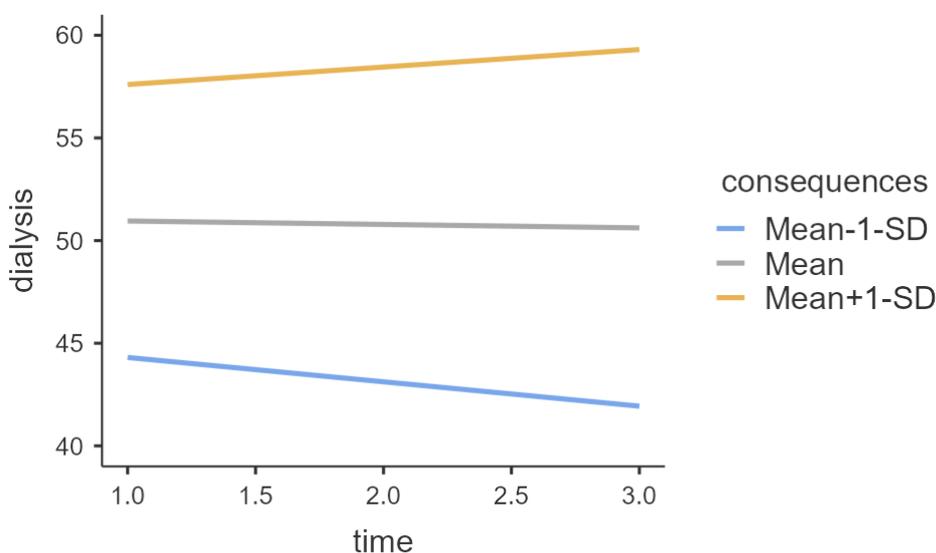
Figure 6.12. *Effect of perception of consequences level on dialysis symptoms over 3 time points.*

In the third model, the slope for emotional response was 2.17 and was significant, suggesting dialysis symptoms were expected to increase 2.17 unit with increase in emotional response scores. Similarly, dialysis symptoms were predicted to increase by 3.82 units with each increment in the number of comorbid conditions. The slope for interaction between time and perception of emotional response was not significant. According to visual data, dialysis

symptoms seemed to increase over time among patients who reported a greater level of emotional response than average at baseline (Figure 6.13).
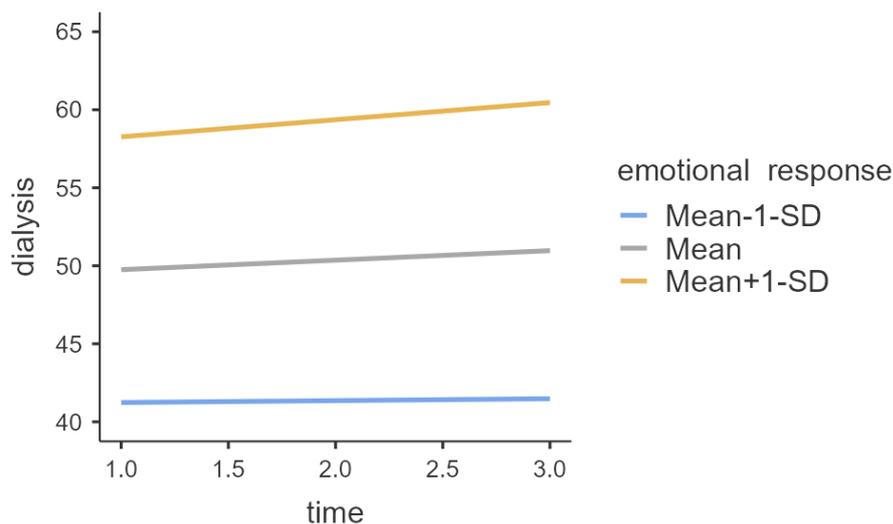
Figure 6.13. *Effect of perception of emotional response level on dialysis symptoms over 3 time points.*

In the fourth model, the slope for personal control was 2.62 and was at significant level, suggesting that dialysis symptoms were expected to increase 2.62 units with each increment in perception of personal control at baseline. Also, dialysis symptoms were predicted to increase 3.62 units with each increase in the number of comorbid conditions. The slope for interaction between time and perception of personal control was found -2.01 and was significant, suggesting that perception of personal control significantly influenced rate of change in dialysis symptoms over time. In other words, dialysis symptoms were predicted to decrease 6.12 units at each measurement occasion (i.e., 6 months) among patients who reported a higher level of perception of personal control than average (Mean +1. SD) (Figure 6.14).
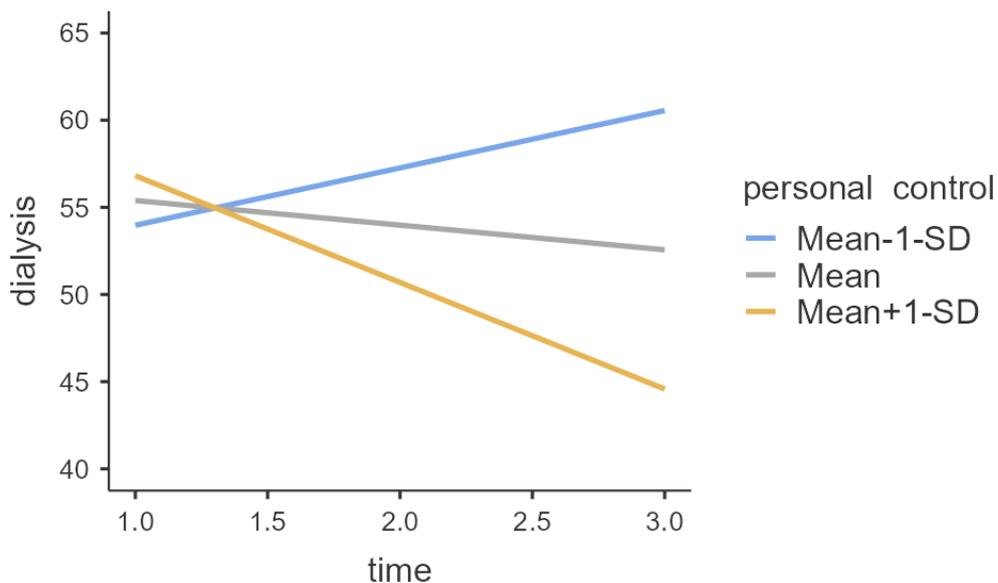
Figure 6.14. *Effect of perception of personal control level on dialysis symptoms over 3 time points.*

In the fifth model, the slope for timeline (chronicity) was -0.01 and it was not significant, indicating that perception of timeline did not predict change in dialysis symptoms at baseline. Also, the slope for interaction between time and perception of timeline was not significant. However, when data were examined visually, it was observed that dialysis symptoms tend to decrease over time, particularly among patients who indicated a lower level of perception of timeline than average at baseline (Figure 6.15).
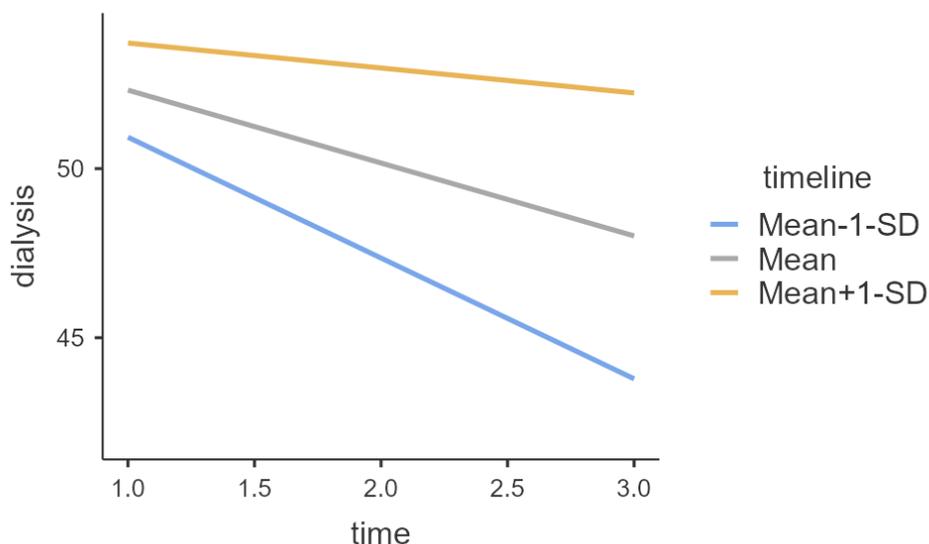
Figure 6.15. *Effect of perception of timeline level on dialysis symptoms over 3 time points.*

All models showed that variance between patients' mean level of dialysis symptoms (intercept) was significant, suggesting that dialysis symptoms varied at baseline. As shown in Table 6.8, the slope for time was non-significant in all models.

6.3.6   Findings on the Transition from Pre-dialysis to Dialysis Treatment

For patients who changed phase from pre-dialysis to dialysis, paired *t* tests were conducted to observe whether there were significant differences at different time points in terms of illness perceptions (i.e., consequence, emotional response, personal control, and timeline) and depression scores. The distribution of the data were checked visually as well as statistically. There was no violation of assumptions of parametric data therefore, paired *t* tests were conducted to observe differences at different measurement occasions.

Table 6.9. *Comparison of illness perceptions and depression scores of subgroup of pre-dialysis patients (n = 10) who moved from pre-dialysis to dialysis over the course of the study*

	Baseline		6 months		12 months		t(9)	p	Cohen's d
	M	SD	M	SD	M	SD			
Consequences									
12 months vs baseline	3.10	2.56	4.40	3.37	6.90	3.03	8.14	<.001	2.57
12 months vs 6 months							2.71	0.024	0.85
6 months vs baseline							1.49	0.169	0.47
Personal Control									
12 months vs baseline	4.89	2.52	3.70	2.52	1.70	1.95	-3.75	0.006	-1.25
12 months vs 6 months							-2.24	0.052	-0.70
6 months vs baseline							-1.09	0.308	-0.363
Timeline									
12 months vs baseline	7.33	2.52	8.20	3.03	10	0	2.65	0.077	1.32
12 months vs 6 months							1.33	0.255	0.59
6 months vs baseline							1.84	0.208	1.60
Emotional Response									
12 months vs baseline	3.80	3.58	4.60	2.95	6.60	4.03	2.94	0.016	0.93
12 months vs 6 months							2.30	0.047	0.72
6 months vs baseline							0.85	0.399	0.280
Depression Symptoms									
12 months vs baseline	11.6	4.44	11.9	6.59	13.2	6.21	1.38	0.200	0.43
12 months vs 6 months							0.92	0.380	0.29
6 months vs baseline							0.19	0.848	0.06

Table 6.9 demonstrates findings with respect to 10 patients who initiated dialysis treatment during one year follow-up. It should be noted that 7 of these patients commenced dialysis treatment at 6 months follow up and in total, there were 10 patients receiving dialysis at 12 months follow up in this patient group. Although a higher number of patients were expected to commence dialysis treatment, there may be several factors limiting follow-up particularly of pre-dialysis patients. Considering that this study was completed during Covid-19 pandemic, limited access to healthcare during this period and healthcare professionals' difficulties to monitor prognosis are some of few factors had negative impact on follow-up. Overall, there was evidence suggesting that baseline and 12 months follow-up scores were significantly different particularly in perceptions of consequences, personal control, and emotional response. In comparison with baseline, perceptions of consequences and emotional

response were significantly higher and personal control was significantly lower at 12 months follow-up. Depression symptoms and perception of timeline (chronicity) did not differ significantly at different time points.

6.4   Discussion

The primary aim of this study was to observe illness perceptions and its relation to depression and dialysis-related symptoms among patients receiving dialysis. To achieve this, illness perceptions of patients in the pre-dialysis phase were also observed to examine potential differences when commencing dialysis treatment. Examining patients in the pre-dialysis phase helped to observe variability in illness perception throughout the illness process. Generally, findings are in line with the expectation showing that patients receiving dialysis tended to have a greater level of perception of consequences, emotional response and lower level of personal control compared to patients in the pre-dialysis phase. Trajectories of illness perceptions were observed to see whether illness perceptions change over one year period. Additionally, as one of the related illness experiences, depression symptoms were examined over one year period. Some of the results seemed to be supported by findings of other studies. Depression symptoms were found to be relatively stable over a one-year period, and only baseline perceptions of consequences and emotional response were related to changes in depression symptoms. This suggested that those patients who reported higher levels of illness perceptions of consequences and emotional response at baseline may have greater depression symptoms. Similarly, dialysis symptoms were found to be stable over time among patients receiving HD or PD, nevertheless, only baseline levels of perceptions of emotional response and personal control seemed to be linked to dialysis symptoms. Those patients receiving dialysis who reported greater emotional response at baseline were more likely to report

dialysis symptoms on the other hand, dialysis symptoms were predicted to decrease overtime among those who reported a high level of personal control.

There is a growing body of research indicating that illness perceptions differ among patients in the pre-dialysis phase and those receiving dialysis treatment (Jansen et al., 2013; Griva et al., 2009). Dialysis is a burdensome treatment although it is critical for survival. It is not surprising that unfavourable (negative) illness perceptions may be observed more among patients receiving dialysis. Previous evidence determined that patients receiving dialysis tend to report greater levels of perceptions of consequences, emotional response, and timeline (chronicity) compared to patients in the pre-dialysis phase (Jansen et al., 2013; Griva et al., 2009; Muscat et al., 2021). Similarly, patients receiving dialysis in this study indicated greater perceptions of consequences, emotional response, and lower personal control. However, perception of timeline (chronicity) did not differ among dialysis and pre-dialysis groups in this study. This may be due to patients in the pre-dialysis phase identifying their condition as chronic and expecting that dialysis treatment may be required in the near future. In other words, it was assumed that the patients had realistic expectations about their illness prognosis and its likely outcome (i.e., commencing dialysis soon). Qualitative studies that included patients with CKD without requiring dialysis have suggested that patients recognised the possibility of dialysis treatment and reluctantly accepted its future role in their lives (Lin et al., 2013; Wu et al., 2015). Patients in the early stages of CKD without KRT in different studies reported significantly lower perception of timeline (chronicity) (Griva et al., 2009; Muscat et al., 2021). For instance, Griva and colleagues (2009) determined that patients receiving dialysis had greater levels of perception of timeline (chronicity), lower perceptions of control and reported greater levels of illness disruptiveness compared to patients in the pre-dialysis phase. It is important to note that patients in the current study were

recruited as they were expected to commence dialysis treatment soon (i.e., within 6 months). This may be one of the reasons that perception of timeline did not differ significantly between the pre-dialysis and dialysis group.

It is known that illness perceptions may change over time (Bonsaksen et al., 2015). Trajectories of illness perceptions have been studied in CKD (Covic et al., 2006; Jansen et al., 2013; Tasmoc et al., 2013). Similar to previous evidence, the current study observed that illness perceptions may change over time among patients with CKD. The findings showed that overall patients' perceptions of consequences and emotional response were expected to decrease over one year period. A prospective study followed patients receiving HD over two years and reported lower level of emotional response (Covic et al., 2006). Similarly, a six-year prospective study has demonstrated that patients receiving HD had stronger perceptions of illness chronicity and lower illness consequences at follow-up (Tasmoc et al., 2013). In the current study, overall patients' perceptions of personal control and timeline (chronicity) were found to increase over one year period. The reduced perceptions of consequences and emotional response may be related to time spent on treatment/phase, which may help to normalise the treatment and related difficulties. This is particularly related to patients receiving HD as was suggested in a previous qualitative study within this thesis (Chapter 4). Consistently, overall patients' perceptions of control increased along with chronic timeline beliefs over time. There is great potential that patients in different studies may have been exposed to different environmental factors that may have influenced their illness perception and experience. For instance, there is no regular psychological assessment or intervention in the local nephrology department in North Cyprus yet. It is known that such support may positively influence patient experience (Hudson et al., 2017: Seyyedrasooli et al., 2013).

Although the pre-dialysis group in this study was small, relevant analyses showed that most selected illness perceptions differed after commencing dialysis treatment. In the pre-dialysis group, perceptions of consequences and emotional response were found at a greater level and perception of personal control was found at a lower level after commencing dialysis treatment. There is limited existing research prospectively examining patients in the pre-dialysis phase. However, available research has indicated similar findings regarding the prospectively observed pre-dialysis group (Jansen et al., 2013; Jayanti et al., 2016). For instance, one of the studies showed that patients who commenced dialysis reported lower perception of personal control at four months follow-up, on the other hand, they reported less emotional response regarding their condition (Jansen et al., 2013). Similarly, another prospective study determined that patients who were in the pre-dialysis phase indicated lower perceptions of personal control, emotional response and greater perception of consequences after commencing dialysis treatment (Jayanti et al., 2016). In the current study, perception of emotional response among the prospectively observed pre-dialysis group were found at greater level after commencing dialysis. The difference in the findings may be related to the different time interval used in different studies, for instance, Jansen and colleagues (2013) repeated the measurement at four months after commencing dialysis however, patients in the current study were measured after six months commencing dialysis. The difference in measurement timing may be one of the factors related to differences in illness perceptions. It should be also noted that patients who were expected to commence dialysis only received basic patient education that aimed to provide general information on required dietary changes and functions of dialysis. Patients did not receive psychological support at the local nephrology department. Moreover, patients' depression symptoms and timeline (chronicity) beliefs did not change after commencing dialysis. Patients in the pre-dialysis phase have been shown to report distress particularly those with greater perceptions of consequences, timeline

(chronicity), emotional response and lower perception of personal control (Muscat et al., 2020). In the current study, patients in the pre-dialysis phase who commenced dialysis on the second measurement occasion already experienced moderate depression symptoms at baseline, which may be the reason that depression scores did not differ significantly after commencing dialysis.

Depression scores among the whole patient groups seemed relatively stable over one year period. In line with findings in the literature (Goh et al., 2018; Muscat et al., 2021), patients receiving dialysis were found to report greater levels of depression symptoms compared to those who were in the pre-dialysis phase. When selected illness perceptions were evaluated as predictors, only higher levels of perceptions of consequences and emotional response at baseline were associated with increase in depression symptoms. In a different sample, lower levels of perception of control have been also shown to predict depression symptoms among patients receiving dialysis (Griva et al., 2010). Depression has been associated with negative illness perceptions (i.e., lower level of control and greater levels of consequences, timeline) in patients receiving dialysis when compared with those patients without depression symptoms (Chilcot et al., 2011a). Similarly, Covic and colleagues (2006) found lower perception of consequences were related to better mental functioning over two years among patients receiving HD. In a different study (Chilcot, 2010), contrary to the current findings, it was found that a greater perception of timeline at baseline predicted an increase in depression symptoms over time among patients who received dialysis for one year. In a study including patients who commenced dialysis, different depression trajectories were examined, and findings suggested that different depression symptom trajectories were associated with baseline illness perceptions (Chilcot et al., 2013). It was observed that illness related emotional distress and greater perceptions of illness consequences were found to related to

increase in depression symptoms (Chilcot et al., 2013). Overall findings indicated that depression symptoms in this patient group may be relatively stable over time or linear growth model may not adequately represent the trajectory of depression symptoms in this sample. Nevertheless, dialysis vintage and differences between health settings in terms of providing support may play a role in differences between findings. In the current sample, patients with CKD diagnosis normally receive a patient education once before they have commenced dialysis. The patient education aims to briefly inform patients mainly about required dietary changes and functions of dialysis. There is currently no psychological service provided within the local nephrology department. This means that access to psychological counselling is limited which could be related to self-management strategies of patients (Seyyedrasooli et al., 2013). The link between depression symptoms and negative illness perceptions (i.e., perceptions of consequences and emotional response) in the current sample may be an indicator of the need for psychological counselling. It is known that in some high income countries such as the United Kingdom, the government has established policies about psychological care for patients with kidney disease by publishing a national service framework (National service framework: kidney disease, 2004). It seems that the local renal service policies do not capture psychological care for patients with CKD. Hence, it will be important to determine and include psychological care practices in the local renal service framework.

Symptom severity is not stable among patients receiving dialysis treatment. It has been shown that symptom burden may vary even at short follow-up period (Moskovitch et al., 2020). The current study examined trajectories of dialysis-related symptoms among patients receiving dialysis (i.e., HD or PD). Findings demonstrated that dialysis symptoms were relatively stable over one year period among patients receiving HD or PD treatment. It is

possible that linear growth model may not adequately represent the trajectory of dialysis symptoms in this patient group. HD treatment has been frequently associated with poorer physical functioning due to greater emotional distress, and treatment burden (Chuasuwan et al., 2020). Interestingly, the current study did not establish significant difference in terms of dialysis related symptoms between patients receiving HD and those receiving PD. This may be related to that HD and PD group may be similar in terms of age and comorbidity status (Iyasere et al., 2019). Nevertheless, a greater number of comorbid conditions at baseline was associated with increase in dialysis related symptoms over time. This is not surprising as comorbidity status have been associated several worsened patient outcomes such as illness symptoms, emotional, and physical dysfunction (Song et al., 2018). Higher level of perception of emotional response at baseline was found to be related to increase in dialysis related symptoms. It was also observed that greater perception of personal control was associated with reduction in dialysis symptoms over time. Similarly, in a two years follow-up study, patients receiving HD with greater perception of personal control and lower level of perception of emotional response at baseline reported better physical functioning scores (QoL) (Covic et al., 2006).

6.4.1   Strengths and Limitations

The findings of this study support utility of the illness perception framework in a specific cultural group and are generally consistent with results of research examined illness perceptions in patients receiving dialysis. This is the first study to quantitatively examining illness perceptions in this patient group within the socio-cultural context. Variables measured in this study were determined based on previously conducted qualitative work (Chapter 4) as this patient group has not been studied earlier. Fortunately, the availability of measurement scales in the local language (Turkish) made it practical to include the scales in the

questionnaire pack. Overall, patients who agreed to participate in this study were willing to engage throughout the research. This may be related to their willingness to share their experience including illness related difficulties and treatment burden. This was expected as there is no regular counselling service provided yet in the local units. The patient group mainly communicates with nurses in the local nephrology departments. As evidenced in chapter 7, this communication seems to be based on culturally conducive relations. Yet, it was limited due to several factors such as limited staffing and psychosocial practice skills. Therefore, patients seemed content to be asked about their experiences and to have an opportunity to express their thoughts. This also facilitated follow-up measurements. Although data collection mode was changed on the second measurement occasion due to Covid-19 conditions, patients generally found data collection via telephone better as they could share their experiences in private, not in a hospital setting. Therefore, the change in data collection mode may have had a positive impact on data collection. Multiple data collection modes have been suggested in longitudinal designs to maintain the response rate (Bianchi et al., 2017). However, it should be mentioned that there may be potentially negative effects of the difference in mode of data collection e.g. in terms of comparability between responses at different time points. Compared with the similar studies (Chilcot et al., 2013; Jansen et al., 2013; Tasmoc et al., 2013), baseline response rate was better (78%) despite the sample was research naïve group. The majority of the participants were familiar with the researcher who shares similar socio-cultural characteristics. She has regularly visited the local unit for data collection, and to meet with the local nephrologist from time to time between 2019 and 2021. Throughout this period, the researcher somehow has established a relationship with the participants. This may have positively influenced the rate of consent to completion the study. The majority of those whose contact details were available also did consent to complete the study at second and third time points.

This study provides longitudinal examination of illness perception of an under-represented group in research evidence receiving dialysis treatment, however there are some limitations to consider in this study. As mentioned earlier, there were three measurement occasions in this study, which limited analyses to build a linear model. It is known that illness perceptions may vary at different time points, hence, linear modelling may not have well-captured trajectories of illness perceptions and related experiences such as depression and dialysis related symptoms. Minimum four and more measurement occasions could allow observing non-linear relationship (e.g., quadratic and cubic growth models) between the variables which could provide further information about patients' experiences (Nese & Lai, 2012). On the other hand, Covid-19 conditions negatively affected follow-up. Change of data collection mode itself (from face to face to telephone) should not be considered as a limitation however, the contact details of some patients registered in local health system were not up to date, some of them were out of service. It can be said that this was the main reason for losing patients to follow-up. The majority of patients who were reached through telephone at the second time point (at 6 months) accepted to answer questions at the third time point (at 12 months). Though, particularly, Covid-19 conditions made it difficult to follow-up the pre-dialysis group who were expected to commence dialysis treatment. Within the limits due to pandemic conditions, the local nephrology department was regularly visited to record the patients' status so that they could be contacted when they have commenced dialysis. However, many patients in the pre-dialysis phase did skip their appointments and did not attend screening at the hospital setting due to Covid-19 conditions. This prevented doctors to monitor patients' health status. Hence, it made it difficult to identify patients who were expected to commence dialysis. These may be some of the reasons that the pre-dialysis sample was small in the current study.

Overall, considering the eligible number of the local patient group at the time of the study (n = 231), the negative impact of Covid-19 conditions during the data collection and the fact that the sample was a research naïve group, the consent rate at baseline (78%) was high, which was maintained at the third time point (66%) when the study was completed. This is critical in terms of representativeness of the sample as well as reflecting on study findings which have highlighted the psychological care needs of the patients.

6.4.2   Implications for Clinical Practice and Future Research

The current study observed trajectories of illness perceptions in patients with CKD. To better understand illness perceptions in patients with kidney failure receiving dialysis, the pre-dialysis group was also prospectively observed and assessed before and after commencing dialysis. The overall findings showed that illness perceptions may vary over time among patients receiving dialysis. Negative illness perceptions (i.e., greater perceptions of consequences, emotional response, and lower personal control) were associated with some illness outcomes, such as depression and dialysis-related symptoms. Therefore, it will be critical to include regular psychological assessment into healthcare provided at the local nephrology departments. This would help identifying negative illness perceptions and emotional distress at early phase. Psycho-educational interventions may be designed to modify negative illness perceptions considering socio-cultural characteristics of the patient group. Additionally, a symptom questionnaire may be utilised regularly in the hospital setting to examine dialysis-related symptoms and treatment burden, this may facilitate the identification of difficulties and suggestions to develop self-management strategies.

Future longitudinal studies are suggested to include a greater number of measurement occasions in order to observe trajectories of illness perceptions by using a non-linear model which may better explain trajectories of illness perceptions in this patient group considering variability over time. This would also help to compare patients' perceptions at different measurement occasions to understand when patients' perceptions are likely to vary most.

6.4.3   Conclusion

This study, for the first time, longitudinally examined illness perceptions of Turkish Cypriot patients receiving dialysis. General findings indicated that the dialysis group tended to have negative illness perceptions (i.e., greater perceptions of consequences, emotional response and lower personal control) compared to patients in the pre-dialysis phase. Longitudinal data analyses showed that illness perceptions changed over time. However, depression symptoms and dialysis related symptoms seemed to be relatively stable over one year period, though associated with some of the baseline illness perceptions. The findings overall seem to be consistent with findings of other studies examining illness perceptions in this patient group. However, some differences were observed which may be related to several factors including the methodology used in this study and differences between health settings. Regular psychological assessment has been suggested in local nephrology departments to screen for negative illness perceptions and emotional distress. This may help to design and deliver culturally suitable interventions to decrease emotional distress.

Chapter 7: Perspectives of Healthcare Professionals in North Cyprus on Psychosocial Care Needs of Patients receiving Dialysis

7.1   Introduction

Compared to other kidney replacement therapy (KRT) modalities, haemodialysis (HD) has been associated with poorer mental health in individuals with kidney failure. Psychological adjustment to kidney failure varies during the treatment process (Goh & Griva, 2018). While pathophysiological symptoms due to abnormal kidney function can be modified by HD (Sarafidis et al., 2021), the treatment process and being dependent on HD may cause various difficulties in patients receiving HD, as evidenced also in chapter 4 within this thesis (Keskindag et al., 2021). Patients may experience multiple problems including emotional and psychological difficulties (Basaran et al., 2016). Individuals with kidney failure have been shown to have higher risk of mental illness, hospitalisation and mortality compared to the general population (Chang et al., 2011). Emotional distress, particularly depression is prevalent in individuals with chronic kidney disease (CKD) (Liu et al., 2017; Loosman et al., 2015) which has been associated with dietary nonadherence (Khalil et al., 2011; Gebrie & Ford, 2019), poor health related quality of life (Vázquez et al., 2005; Davison & Jhangri, 2010) and greater mortality risk (Chilcot et al., 2018a; Fan et al., 2014). Apart from nonadherence, patients' behaviours may be demanding for healthcare professionals. These behaviours may be closely related to several factors such as aggression, and other emotional difficulties that patients experience (Janoseiv et al., 2019). The interplay between depression and nonadherence to HD may result in patients having to attend the emergency department due to fluid overload (Dobbles et al., 2019). It is critical for healthcare professionals, in particular for renal nurses to be able to recognise emotional and psychological difficulties and

how these can interact with patients' adjustment to dialysis treatment and illness outcomes.

The existing literature, mainly quantitative studies, have highlighted the importance of routine assessments of distress and addressing psychosocial health care needs in patients receiving KRT (Christensen & Ehlers, 2002; Hansen et al., 2022; Griva et al., 2013; Jankowska-Polańska et al., 2019; Kimmel, 2000b; Knowles et al., 2018; Vázquez et al., 2005). These suggestions have been made generally based on observation of the psychosocial challenges of patients receiving KRT, albeit mainly from evidence in healthcare systems based in higher income countries in the west (Christensen & Ehlers, 2002; Hansen et al., 2022; Knowles et al., 2018). Psychological distress has been frequently examined through depressive and anxiety symptoms in patients with kidney failure (Chilcot et al., 2018b). Psychological distress has been reported in up to 50% of patients with CKD (Hettiarachchi & Abeysena, 2018). Depression, particularly based on self-administrated scales, has been shown to influence up to 40% of the patients receiving ` KRT (Palmer et al., 2013). Although depression is a common complaint in patients receiving dialysis, specifically HD, it is poorly treated (AlAwwa et al., 2020). According to research, 29% of patients with kidney failure who require KRT were negatively affected by moderate to severe depression (AlAwwa & Jallad, 2018; Nabolsi et al., 2015). This makes it essential to consider both patient and provider side challenges in meeting care needs.

Individuals who have emotional distress do not always engage in help seeking behaviours (Blais & Renshaw, 2012; Knowles et al., 2018). They may develop different strategies to deal with the challenges (Karabulutlu et al., 2005; Sevindik & Yuruyen, 2017). Coping strategies of individuals with long term conditions have been examined to describe association between

coping style and illness outcomes (Aldwin & Park, 2004). Individuals with kidney failure

have emphasised the critical role of network support (i.e., family, friends and clinical staff)

and sense of control regarding their condition while coping with emotional distress (Sein et

al., 2020). On the other hand, a study conducted with patients receiving HD indicated

dominance of emotion-focused coping strategies among the patients (Zamanian et al., 2018).

Individuals who adopt emotion-focused coping strategies would be motivated to reduce their

unpleasant feelings regarding stressful events. This coping strategy has been considered as

less effective in the long term since it can interfere with the decision-making process to

eliminate stressors (Zamanian et al., 2018). However, coping strategies against psychological

distress can be also observed in the form of spiritual/religious attitudes, and these can be

assessed within emotion-focused coping strategies (Santos et al., 2017) which have been

shown to be positively related to quality of life among patients from different cultural groups

receiving HD (Cruz et al., 2016; Taheri et al., 2014). Individuals' responses to stressful

events may be related to cultural factors as these can shape the way individuals deal with

emotional difficulties (Hansen & Cabassa, 2012; Kim et al., 2006). In other words, the coping

approaches adopted may be culturally rooted (Keskindag et al., 2021).

It is well established that culture shapes health behaviour including help seeking for mental

health. This is driven by a range of factors such as beliefs about causal attribution, attitude

toward mental health services, subjective norm, perceived behavioural controllability,

perceived social support, perceived benefits of seeking help (Aldalaykey et al., 2019;

O'Connor et al., 2014; Ten Have et al., 2010). For instance, one study reported several

factors affecting help seeking behaviour among individuals of Chinese heritage, these factors

were causal beliefs of mental illness (e.g., somatic, supernatural explanations, societal stress),

influence of network (e.g., reliance on family instead of seeking professional help) and

knowledge about the illness (e.g., correct understanding of mental health literacy facilitating recognition of the problems) (Wong & Li, 2014). Another study conducted with minority ethnic people in the UK highlighted the need of education of communities as traditional and cultural explanations of mental illness have been dominant which linked to stigmatising attitudes and behaviours and consequently, influenced help seeking behaviours (Shefer et al., 2013). Similarly, several studies reported the presence of mental health stigma related attitudes and behaviours in Turkish communities (Heredia Montesinos et al., 2012; Ikizer et al., 2018; Von Lersner et al., 2019; Sarikoc & Oz, 2016). For instance, mental health stigma in the Turkish Cypriot community has been poorly studied, however, findings showed that Turkish Cypriot culture, as collectivistic culture, has a negative attitude toward mental illness and has been associated with high levels of stigma (Zorba, 2015). Research focusing on culture and mental illness have highlighted the lack of mind-body distinction, tendency for somatisation and affect of shame are factors that have an impact on help seeking behaviour in some collectivistic cultures. Also, these factors can explain why collectivistic cultures such as Chinese, Indian and Islamic societies may make sense of, and report mental illness differently compared to individualistic cultures in west (Kirmayer & Young, 1998). On the other hand, according to dominant view of mind-body dualism in west, psychological distress is commonly expressed in psychological terms, unlike collectivistic cultures where there is less segregation of mind and body (Kirmayer & Young, 1998; Ng, 1997).

Healthcare professionals' attitudes and perspectives are also critical as they may have an impact on patient experience. Like the general population, healthcare professionals may also hold stigmatising attitudes towards patients with clinically relevant emotional distress (Huggett et al., 2018; Lien et al., 2021) for instance negative attitudes toward psychiatric illness can result in greater neglect of patients' needs (Alsalem et al., 2020). This can cause

poor care due to lack of attention to patients' medical needs (Lien et al., 2021). Therefore, negative beliefs and attitudes related to mental illness among healthcare professionals may negatively influence patient experience (Jacobs et al., 2002). Stigmatising attitudes towards mental illness can be attributed to limited knowledge (Thornicroft et al., 2007). Apart from negative stereotypes and prejudices, behavioural reflections such as avoidance and social distancing can also be observed (Corrigan et al., 2012). Several studies reported non-psychiatric clinicians' and/or nurses' views on psychosocial care in different contexts, such as cancer (Aldaz et al., 2017; Güner et al., 2018; Regan et al., 2015; Schouten et al., 2019), physical injury rehabilitation (Middleton et al., 2014), diabetes (Carey & Burdett, 2020; Stoop et al., 2019; Stuckey et al., 2015) and kidney failure (Pedreira Robles & Aguayo-González, 2019). Healthcare professionals across different contexts have recognised the connection between physical and emotional impact of the disease and they have highlighted importance of integrated, compassionate, and sensitive care which is critical to identify patients' psychological support needs throughout treatment (Aldaz et al., 2017; Pedreira Robles & Aguayo-González, 2019). Lack of knowledge regarding mental health was also reported therefore, training for healthcare professionals, particularly nurses in psychological skills have been suggested for being able to provide integrated care (Carey & Burdett, 2020).

Still, little is known about how healthcare professionals perceive their own role in external support and/or barriers to meet psychosocial care needs of patients, particularly in nephrology services. Considering that most patients receive in-centre HD treatment and frequently attend the services for a long time, views of the healthcare professionals who are regularly in contact with the patients are important to gain insight and better understanding on psychosocial care needs of patients. Perceptions of the healthcare professionals will contribute to identifying factors closely related to the psychosocial aspect of patient experience. To enhance the

psychosocial aspect and integrate it into traditional care, it is crucial to unearth views of healthcare professionals involved in nephrology services. This is particularly important for nephrology services in Northern Cyprus as local healthcare infrastructure is limited in terms of providing psychological care. This study, for the first time, will help to understand healthcare professionals' views on psychosocial care needs of patients receiving dialysis in Northern Cyprus. Findings of this study are expected to make novel contribution to literature and to inform local healthcare practice.

7.1.1   Aims

Qualitative approaches have been useful as they allow participants to reflect on their perspectives and experiences (Orford, 1995; Patton, 1990). With this in mind, to explore healthcare professionals' views on psychosocial care for patients receiving dialysis, an interview study was undertaken. The overall aims the study sought to address included:

- Defining healthcare professionals' experiences with patients receiving dialysis
- Identify nephrology healthcare professionals' perception of psychosocial care
- Understanding healthcare professionals' perspectives on barriers and facilitators in meeting psychosocial care needs of patients receiving dialysis

7.2   Methods

This study obtained ethical permission from both Lefkosa Dr Burhan Nalbantoglu State Hospital, Department of Inpatient Treatment, Ministry of Health in Turkish Republic of Northern Cyprus (YTIKI1.01-629-21/E.2419) and Health, Science, Engineering and Technology Ethics Committee with Devolved Authority in University of Hertfordshire (LMS/PGR/UH/04589).

7.2.1 Design

A qualitative method was used to describe perspectives and perceptions of healthcare professionals. Healthcare professionals (nurses/doctors) who work at the Nephrology Departments in Northern Cyprus were invited to attend one to one interviews which were conducted in their native language (Turkish). Consistent with the approach used to analyse data, the number of healthcare professionals to be invited was arranged by information power (Malterud et al., 2016). One to one interviews are frequently conducted in health and social research (Ryan et al., 2009) and have already been shown within this thesis to provide useful insights into aspects of patient care experiences (Keskindag et al., 2021). This method provides access into interviewee's ideas and perceptions and helps the interviewer to understand perspectives and experiences of the interviewee in given context. This can help to gain in-depth knowledge about perceptions of the interviewee (Ryan et al., 2009). With permission from the interviewees, one to one interviews were audio-recorded, transcribed verbatim and forward translated into English once the analysis was completed in Turkish. The design of this study was advised by the researchers who are successfully managing both health related qualitative and quantitative projects particularly with patients receiving kidney replacement therapy (Hucker et al., 2017; 2019; Keskindag et al., 2021).

7.2.2 Participants

One to one semi-structured interviews were conducted face to face. Participants were recruited from four renal services in four different state hospitals. These are Lefkosa Dr Burhan Nalbantoglu State Hospital in Nicosia, Gazi Magusa State Hospital in Famagusta, Girne Akcicek State Hospital in Kyrenia and Cengiz Topel Hospital in Morphou. These hospitals are currently only health centres that provide renal services in Northern Cyprus. The hospital in Nicosia has the largest capacity hence, the number of healthcare professionals

participating was more in Nicosia, including two doctors (i.e., nephrologists) and seven nurses.

7.2.2.1 Inclusion Criteria

The inclusion criteria include:

- Experience in providing care for patients receiving dialysis

- Working as nurse or doctor in the Nephrology Department

- Fluent in Turkish.

There were no restrictions on time spent working with patients receiving dialysis.

7.2.3 Data Collection

An interview topic guide was developed by the research team based on previous similar studies (Chen et al., 2017; Dong et al., 2016; Güner et al., 2018; Pedreira Robles & Aguayo-González, 2019). The interview topic guide included questions such as *What factors do you think contribute to patients adjusting well to receiving dialysis? What is the meaning of 'good overall health' to you in relation to the care of dialysis patients?* and *What has been your experience of the psychological impact of receiving dialysis on patients?* Prompts were used to help participants elaborate on their responses (Table 7.1).

Table 7.1. *Interview topic guide*

1. What is your role in caring for patients with advanced kidney disease?
2. How accessible are kidney health services locally?
3. What are the key strengths of the kidney health services locally?
4. Is there anything that frustrates you or that you would change about kidney health care provision?
5. From your previous experiences, what factors do you think contribute to patients adjusting well to receiving dialysis?
6. From your previous experiences, what factors do you think hinder patients from adjusting well to receiving dialysis?
7. What is meaning of 'good overall health' to you in relation to the care of dialysis patients?
8. What factors, such as individual, environmental, family, social, health system do you think contribute to patients having good overall health outcomes when receiving dialysis?
9. What in your experience matters most to patients in terms of the symptoms that bother them when receiving dialysis?
10. What has been your experience of the psychological impact of receiving dialysis on patients?

By using purposive sampling strategy, the local consultant nephrologist who is a member of the research team determined potential participants according to inclusion criteria. Although there is no specific way to justify data set size in reflexive thematic analysis (TA), the number of healthcare professionals to be invited was arranged by information power (Malterud et al., 2016). According to this approach, sufficient sample size is dependent on several factors including study aim, sample specificity, quality of dialogue, and analysis strategy. Hence, it is the reflection of researcher/s on "information richness" of the data set and whether this is suitable with factors mentioned above (Braun & Clarke, 2021). In total, 19 participants were invited to participate in the study, 16 of these accepted to participate. Those who decline to participate (16%) indicated that they did not have time for an interview.

Healthcare professionals were informed about the study at the renal services of the hospitals. A participant information sheet was used to inform healthcare professionals about the aim of the interview and what was expected from the participants. Before they were asked whether they would like to participate in a one to one interview, staff had sufficient time to review the

information about the study and discuss it with others. The consultant nephrologist did

approach potential participants on their next shift to determine whether they wish to

participate in the study. Accordingly, informed consent was obtained. The researcher

contacted participants via telephone and arranged an interview date and time convenient for

both the researcher and the participant. Interviews were conducted at a suitable office in the

Nephrology Department. Participants were provided with a copy of the consent form before

conducting the interview. With permission of the participants, the interviews were recorded

by using a digital device to assist data analysis. The participants' socio-demographic

information is shown in Table 7.2. Three males and 13 female healthcare professionals took

part in the study. Data group included two doctors (nephrologists) and 14 nurses who work in

the Nephrology department in Northern Cyprus.

Table 7.2. *Demographic characteristics of healthcare professionals.*

Participant	Gender	Age	Job role	Experience (in years)
1	M	36	D	5
2	F	42	N	6
3	F	43	N	17
4	F	33	D	2
5	F	34	N	7
6	F	52	N	16
7	F	46	N	10
8	F	42	N	8
9	F	46	N	22
10	F	43	N	3
11	F	38	N	1.5
12	M	32	N	2.5
13	F	41	N	15
14	F	52	N	21
15	M	35	N	11
16	F	46	N	8

Note: M: Male; F: Female; D: Doctor; N: Nurse.

Most participants knew the researcher due to previous (Keskindag et al., 2021) and ongoing research projects with patients in the Nephrology Department. This may have helped participants to feel comfortable and express their opinions without censor. As she established relationships with participants earlier, she also expected that participants would be keen to share their views on patient experience. Interviews took between 35 to 55 mins. The researcher firstly explained the aim of the study, confidentiality, anonymity and participant's right to withdraw. The interviews were completed in Turkish, they were in a form of casual conversation to allow participants to contribute to the extent they wish to. At the end of the interview, participants were informed of how to request support from the hospital in case they wish to. During the interviews, the researcher took some notes about emphasised views and feelings of the participants such as frustration and excitement. She also noted her own understanding and reflection of interviewing experience at the end of each interview. Field notes are important as they can shape analysis by deeper engagement with data (Braun & Clarke, 2021; Trainor & Bundon, 2020).

7.2.4   Data Analysis

All interviews were audio recorded and transcribed verbatim. The adopted philosophical standpoint (i.e., critical realist perspective) and the nature of the research topic of this study (i.e., views of healthcare professionals) were suitable to use reflexive TA which allows describing patterned meaning across the data set (Braun & Clarke, 2013). The researcher used reflexive TA to make sense of participants' views by generating themes (Braun & Clarke, 2019b). Thematic analysis can be used in health and well-being research extensively (Braun & Clarke, 2014). Inductively developed themes are appropriate for sense-making for the fields/topics where the knowledge is very limited (Braun & Clarke, 2006). Although the researcher is familiar with the patient experience as indicated in chapter 4, she used *more*

inductive approach to code the data without pre-existing analytic conceptions. This helped her to focus on the perspectives of the healthcare professionals and identify barriers and facilitators related to psychosocial care for patients receiving dialysis within socio-cultural context. The researcher is familiar with qualitative health research and has postgraduate level experience collecting and analysing qualitative data. She is a local whose native language is Turkish with a Cypriot accent and shares socio-cultural values with the participant group. She followed the guidelines of Braun and Clarke (Braun & Clarke, 2006; 2019b) to be able to complete quality reflexive TA. During the analysis and report writing, a 15-point checklist of criteria for good TA was used (Braun & Clarke, 2013).

The researcher read the entire dataset multiple times to become familiar with it. She took initial notes for potential codes. She first completed coding manually, then merged the codes with a similar phrase. Some codes were discarded as they were not closely related to the research topic. Similar codes were then clustered to construct a meaningful theme. The researcher went through all transcripts to check codes against quotes. When codes seemed distinctive, she re-coded transcripts on NVivo software. This process facilitated examining refined codes along with data extracts. She re-checked the codes and data extracts, and these were put together to generate themes. Initially generated themes were checked against supporting codes and data extracts to make sure they represent participants' voices. Initially generated themes did not seem to have interpretative depth, hence, the researcher revised and renamed the themes to add interpretation so that theme alone could provide some information to the reader as well as to show a relation to both the research topic and other themes. The researcher concluded the analysis in NVivo software in the original language (Turkish). The reason that the analysis was completed in the original language (Turkish) is related to issues on meaning loss. It has been frequently discussed whether translated transcripts still have the

same meaning in the original language (Regmi et al., 2010). To minimise such potential issues, literature suggests staying in the original language during the analysis in case required sources are present such as local researchers who have qualitative skills (Temple & Young, 2004; van Nes et al., 2010).

The analysis in the original language (Turkish) was shared with a local supervisor of the study who checked the representativeness of the analysis. The local supervisor checked 20% of the analysis in Turkish along with transcripts. The final version of the analysis was then translated into English. The local supervisor also compared 20% of the translated analysis with the analysis conducted in Turkish to ensure semantic equivalence so that translation was accurate in terms of the content. Translated analysis was then discussed with the principal supervisor of the study who has expertise in qualitative health research and works with both patients and healthcare professionals particularly in kidney disease. The research team agreed that the analysis was meaningful and interpretative to meet the study aims. Unlike TA using coding reliability (Boyatzis, 1998), the supervisors of the study did not intend to "reach agreement on coding" but to ensure that the analysis was strong, represented participants' voice and was able to provide a meaningful story that exceeds obvious (Braun & Clarke, 2021).

7.3 Analysis

The final version of the analysis consisted of three themes: Theme 1- *Adjustment to dialysis,* represents the way that healthcare professionals intrinsically linked patient well-being to adjustment to life on dialysis and finding a new sense of balance with the associated routine. Theme 2- *Multi-faceted nature of well-being*, focuses on the range of individual, family, economic, hospital and system level factors that impact patients' overall mental health.

Theme 3- *Compassionate care*, brought into stark focus the need for empathy with patient situations but recognising the limits within which staff needed to operate due to knowledge, skills and system resources. Figure 7.1 illustrates the relationships between themes and supporting subthemes in order. The themes are sequentially presented along with relevant data extracts.
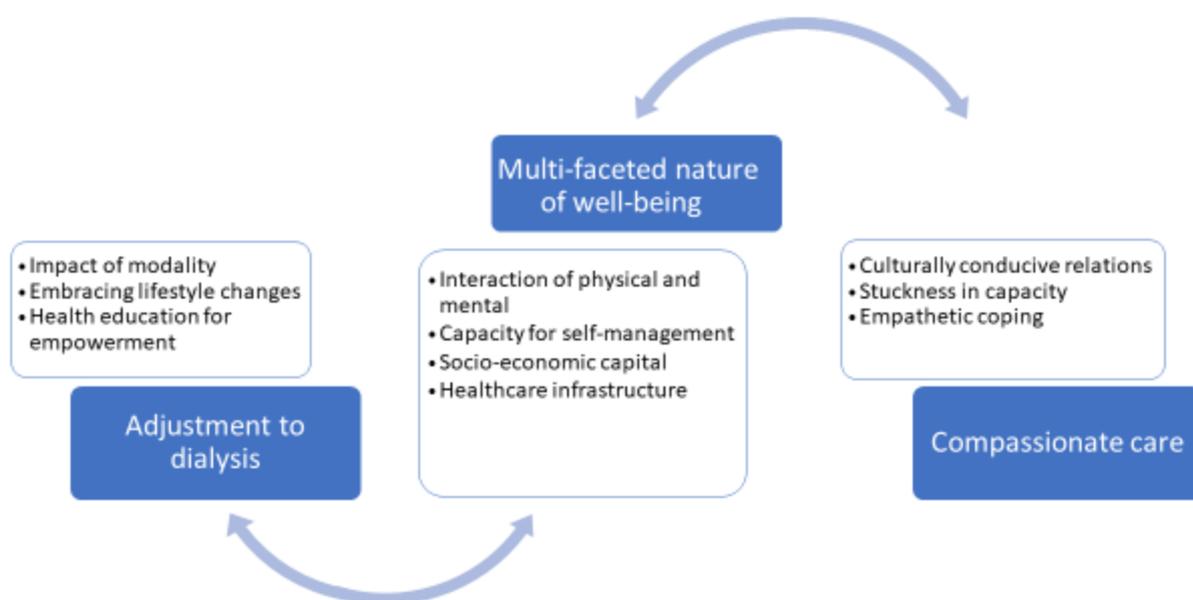
Figure 7.1. *Thematic map of the analysis*

7.3.1   Adjustment to Dialysis

The first theme encompassed several expectations and suggestions of healthcare professionals which were perceived as required steps for patients receiving dialysis to be able to maintain their 'normal' lives. By stating 'normal' life, participants referred to the routine that patients had before commencing dialysis treatment.

7.3.1.1 Impact of modality

Dialysis modalities were discussed as one of the aspects that relates to patient experience. Although modality itself cannot be a predictor for patient outcomes alone, experiences of patients have been suggested to differ with respect to dialysis modality to some extent. Although HD and PD are different forms of dialysis modalities, the way they help regulate body functioning is different. These differences bring different types of challenges specific to each modality. For instance, patients receiving in-centre HD are required to visit hospital normally three times, each session ranging from 3 to 5 hours, whereas patients receiving PD can complete dialysis at house-setting, but more frequently (i.e., everyday). Most participants, mainly nurses, found PD easier compared to HD since it is completed at house - setting and patients receiving PD were perceived as having more freedom in terms of food and liquid intake:

> Bence periton alanlar daha avantajlı. Onlar çünkü çok kopuk olmuyor kendi evlerinde. Kendi aileleriyle [I think PD is more advantageous… no displacement is needed, they (patients receiving PD) are at their home, with their family] (Participant 16, nurse, female)

On the other hand, the participants, mainly nurses, shared the view on challenges of HD and how these challenges may even make it more difficult to adapt to dialysis. Considering the burden of HD, patients were perceived as reacting to HD with diet-nonadherence. Some nurses made sense of this as a defence mechanism against the necessity and challenges of HD:

> Ama yüzde sekseni aksi şeylere girişirler, yani söylemeni yapmazlar. Mesela suyu kısıtlı iç yada muzu yeme, bir sürü muz yiyip gelir. Bence HD e karşı savunma

mekanizması geliştiriyorlar [80% of them (patients receiving HD) attempt to do things they should not have done. That is, they do not follow advice, for example, 'drink water within the limits' or 'do not eat banana', they many bananas and they come to HD session, I think this is a defence mechanism against HD] (Participant 9, nurse, female)

7.3.1.2 Embracing lifestyle changes

Participants expected patients to adhere to their treatment in order to be able to continue their routine as treatment adherence is critical for health status in kidney failure. The participants highlighted the important role of treatment adherence to increase quality of life. They discussed how those who adhere to treatment tend to have better quality of life which is necessary to maintain well-being. More specifically, diet and medication adherence were dominant elements that were frequently associated with better quality of life:

Uyumlu olacak. Diyetine uyum sağlayacak. Getirdiği kiloya dikkat edecek. Beslenmesine dikkat edecek. Kilo almayacak. [They (patients) will show adherence to the diet. They should be careful of the weight they bring to the session. They should be mindful about diet, they should not gain kilos] (Participant 1, nephrologist, male)

Ilaçlarını düzenli kullanması gerekiyor. Bunları yapan yapan hastalarımız da var [They (patients) should take their medicines regularly, we have patients who do that] (Participant 16, nurse, female)

Additionally, participants explicitly expressed that rearrangement of the lifestyle was required to facilitate adjustment to dialysis. This was necessary not only for patients receiving HD but also for those receiving PD treatment. Patients receiving in centre-HD normally

require approximately 3 sessions per week and those receiving PD are required to complete sessions more frequently (e.g., different times of the day or at every night) at home-setting. Overall, patients receiving dialysis were expected to rearrange lifestyle in terms of scheduling dialysis days, or times and planning daily activities accordingly. Regardless of dialysis modality, patients were expected to integrate dialysis into their lives:

> Seanslarını ona göre ayarlamak durumunda. Periton hastası için de öyle. değişim saatlerini ona göre uydurmak durumunda olur [They (patients) have to adjust their sessions. Same for the peritoneal patient. They will have to adapt to changing schedule accordingly] (Participant 4, nephrologist, female)

7.3.1.3 Health education for empowerment

The participants acknowledged that commencing dialysis meant dramatic changes for many patients, therefore they suggested several strategies to facilitate the adjustment to dialysis which, in turn, would help patients to some extent to maintain their routine as before (commencing dialysis). One of the suggestions was empowering the patient, particularly at an early stage of dialysis. This was explained with attribution to perceived limited capabilities of patients. Although dialysis becomes a huge part of life and mostly has a negative impact on social life, patients tend to realise their better health status eventually as dialysis helps to regulate bodily functions. It was noted that patients should be reminded of the benefits of dialysis and the fact that they can maintain their social life along with the requirements of their condition:

> Ama diyalize başladıktan sonra aslında daha iyi olduklarını fark ediyorlar. Yeniden bir şeyleri deneyebileceklerine inandırmak lazım [After starting dialysis, they (patients) realize that they are actually getting better. It is necessary to make them

understand and believe that they can try and do things as before] (Participant 1, nephrologist, male)

In local nephrology service, traditionally only patients have been prepared for dialysis where they receive information on kidney function, dialysis and required dietary changes. Most participants agreed that families should be encouraged to get involved in the illness management. Apart from providing support such as caring and driving patient to the hospital (for HD sessions), playing an active role in illness management through shared responsibility may help to facilitate the adjustment to dialysis:

Aileyi de işin içine çekmeye çalışıyoruz. Daha fazla farkındalık yaratmak için [We're trying to get the family involved, too. To create more awareness] (Participant 12, nurse, male)

Mesela haftada iki gün gelen bir hastamız vardı. Değerleri istediğimiz gibi olmadığı için haftada üç gelmesini söyledik. Baktık hasta kabullenmedi. Sonra aileye güzelce anlattık ve aile onu evde ikna etti. Belkide ilkten biz aile ile konuşmuş olsaydık daha erken olurdu. Biz hemen hemen altı ay bekledik hasta ikna olsun diye. Hastaya detaylı bilgi verdik ama belki hasta kavrayamadı. Aileyi de bilinçlendirmek lazım [For instance, we had a patient who came twice a week. We told him to come three times a week because his values were not what we expected. The patient did not accept to come 3 times a week. Then we explained his family carefully and the family convinced him. Maybe it would have been sooner if we had talked to the family first. We waited almost six months for the patient to be convinced. We gave detailed

information to the patient, but maybe the patient could not understand earlier.

Families should also be informed] (Participant 16, nurse, female)

7.3.2 Multi-faceted Nature of Well-being

It was acknowledged that there were multiple factors affecting patients' well-being. This theme discusses aspects that have been suggested to influence patient wellbeing. In other words, there are more than one dimensions affecting patients' well-being and illness adjustment, which relate to psychosocial needs of patients receiving dialysis treatment.

7.3.2.1 Interaction of physical and mental

One of the factors discussed was the view of the interaction of physical complaints and psychological difficulties. This was quite evident in the dataset. Most participants realised that patients had physical complaints during and after dialysis sessions, particularly HD sessions. However, they were also aware that patients experienced physical complaints along with psychological/emotional difficulties. Nevertheless, healthcare professionals mostly were consulted due to physical complaints such as, fatigue:

> Baş dönmeleri krampları, tansiyon düşmesi. diyaliz. dışında başka şikayetleri baska
> problemleri çıktığında o da etkiliyor [Dizziness cramps, low blood pressure. Apart
> from the dialysis complaints, it (dialysis) also affects when other (physical health)
> problems arise] (Participant 12, nurse, male)

However, they were able to recognise those patients who also had psychological distress. Some of the patients even shared their emotional distress with participants:

Burada hasta zaten kendini kötü hisseder. Daha fazla yük olduğunu hisseder.Mesela bir hastamız kendini yük hissettiğinden dolayı intihar etmeyi düşündüğünü bana söyledi [Patient already feels bad. They feel that they are more of a burden. For example, one of our patients told me that considering committing suicide because they felt as burden (for other)] (Participant 13, nurse, female).

Most nurses considered dialysis as burdensome treatment and most found that psychological distress among patients was an expected outcome. Nurses also recognised the difference in health status of the patients when they experienced emotional distress. For instance, some indicated that patients tend to experience distress, but this may increase and decrease in different periods and eventually may affect treatment adherence. As a result, change in adherence is likely to interfere with well-being:

Psikolojik olarak kendini iyi hissetmediklerinde daha fazla sıvı getirdikleri olur. Mesela her zaman dikkat eden bir hasta vardı. Fakat eşi öldükten sonra çok sever getirmeye başladı. Dönem dönem kötü olurlar, sana düzelirler [When they (patients) do not feel psychologically well, they tend to bring more kilos to HD sessions (diet-nonadherence), for instance, there was one patient started to bring more kilos to sessions after her husband passed away. This happens to all patients periodically, later they rearrange their diet/liquid intake] (Participant 10, nurse, female)

Despite such feelings, patients tended to avoid expressing their emotional difficulties. It was reported that only few patients with severe distress attempted to engage in help seeking behaviours by sharing their experience with a nurse. Reactions of patients were further discussed in relation to advice on visiting the psychiatric state hospital for psychological

support. It was perceived that patients have a negative attitude towards mental health difficulties and therefore they avoided asking for psychological support from the psychiatric hospital. The participants discussed potential reasons that patients were not willing to seek support. These included the psychiatric hospital being physically far from the unit, and the fact that it is normally an inpatient service aiming to provide treatment for a variety of disorders such as schizophrenia, severe mood disorders etc. It seems that socio-cultural factors and limited resources together may help to explain why patients did preferred not to visit the psychiatric service for psychological support although they experience distress:

> Hasta zaten burdan yorgun çıkıyor diyaliz sonrası. Üç gün dört gün hastaneye gelen bir insan, iki gün de psikologa git başka bir bölümde. Uygun olmaz. Zaten.rahatlamak için gittiği bir yer değil, tedavi için gittiği bir yer olarak gördüğü için mental külfet olarak da sayıyor olabilir [Patient already comes out tired after dialysis. It would not be suitable to refer the patient who comes to hospital 3/4 days in a week to psychiatric service. They already consider it (psychiatric hospital) as a treatment not a place to relax at, they may even consider it (going to psychiatric hospital for psychological support) as mental burden] (Participant 1, nephrologist, male)

7.3.2.2 Capacity for self-management

Perceptions at the individual level seemed an important aspect of patient well-being as it was associated with behavioural responses to illness outcomes. Patients' understanding about their own health status was considered an important factor that influenced adherence to treatment. For instance, some patients were perceived as having difficulty adhering to restrictions related to food and fluid intake due to limited understanding about their own condition. This patient group was considered as experiencing severe illness outcomes:

Algılamada güçlük çeken hastalar vardır. Onlar mesela zorlanırlar [There are patients who have difficulties in comprehending their condition, they experience difficulties] (Participant 11, nurse, female)

Patients' difficulty in understanding their health condition seemed to be partly related to patients' (health) literacy status. Some indicated that this may be linked to adjustment to dialysis and overall well-being. However, most participants considered that health literacy is not always a stable predictor for adjustment to dialysis:

Tabiki okuryazarlık seviyesinde bunlara bir etkisi var. Ama bazen eğitim seviyesi çok yüksekte olan bir insan düşük seviyede olan bir insana göre çok daha uyumsuz olabilir. O yüzden okuryazarlığı çok belirleyici bir kısas olarak değerlendirmemek lazım [Of course, it (health literacy) has an impact on adjustment to illness. But sometimes a person with a high level of education can be much more maladaptive than a person with a low level. Therefore, literacy should not be considered as a critical factor for adjustment] (Participant 1, nephrologist, male)

With commencement of dialysis treatment, patients experience restrictions in their freedom such as restrictions related to social life and involvement in social activities due to required attendance in dialysis sessions. This is a dramatic change for most patients although many normally are aware that they will start dialysis treatment. Patients start even experiencing restrictions before commencing dialysis and not only in social aspects but also in terms of physical capabilities and complaints such as, breathlessness, great level of exhaustion. These experiences may also trigger emotional distress. Therefore, it is important to understand how these restrictions are perceived among patients even before commencing dialysis:

Çünkü zaten diyalize gelene kadar özgürlükleri hastalıklarından dolayı bayağı kısıtlanıyor hastaların. Hele evre 4, evre 5 e girdiklerinde Ciddi bir kısıtlama ile karşı karşıyalar… Diyalizin yaklaştığını bilmek onları biraz çökkünlüğe itiyor [Patients' freedom becomes very limited due to their diseases, particularly just before commencing dialysis. Especially when they reach stage 4, stage 5, they are faced with serious restrictions… Knowing that dialysis is approaching makes them a little depressed] (Participant 1, nephrologist, male)

Along with sense-making, patients also learnt through their experiences and eventually engaged in more adaptive behaviours. The participants observed that even though patients may resist adjusting to required changes related to their treatment, some of them later change their behaviour because of learning from bad consequences:

Mesela bir hastam var. Birkaç fistül ameliyatına girdim. Çok korktuğu için gözü gibi bakar. Ama bir şeyler yaşadıktan sonra böyle oldu. Aslında bir yerde sonucunu görmeleri lazım ki davranışlar düzelsin [For instance, I have a patient, I was present for her fistula surgery. She is really afraid, so she is taking care of it. But she had some unfortunate experiences before. Indeed, they (patients) should see consequences in order to change their behaviour] (Participant 12, nurse, male)

7.3.2.3 Socio-economic capital

The importance of social support and economic status on patient wellbeing was evident in the dataset. The participants defined social support in different aspects, one of these aspects was family support. However, family support discussed here represented how family members cared for the patient and provided help, for instance, driving the patient to the hospital for HD session and/or helping with personal care and household work. Therefore, the presence or

absence of family support is different from the importance of family involvement in illness management which was interpreted earlier to highlight how shared responsibility may facilitate the adjustment to illness. Family support was identified as a critical factor since presence of such support tends to make a positive difference in patient experience. The nurses shared observations on those patients who seemed lacking in family support and the fact that this influenced patients not only psychological but physical health:

> Ama köyden gelmiştir. Kimsesi yoktur, okuma yazması yoktur, bakımsızdır. Yalnız başına yaşıyordu, onun durumu daha zor. Çünkü aile desteği önemli. böyle hastalarımız oluyor. Biz burada dört saatini gözlüyoruz ama eve gidince ne durumda bilemiyoruz [He (patient) comes from a village, does not have anybody, is illiterate, not being able to take care of himself… He may live alone, his case is worse than others…because family support is important. We have these types of patients, they are cared at the hospital but we cannot know his situation when he is at home]
> (Participant 16, nurse, female)

On the other hand, participation in social life and leisure activities was mentioned as another factor that may play a role in wellbeing. As patients struggle with the burden and challenges of the dialysis session, the participants agreed that it is crucial to maintain involvement in social life and leisure activity within the physical capacity. The participants were able to identify how involvement and/or maintaining social life has a positive effect on patients' well-being by comparing patients' experiences based on their observations:

> …kendine güzel uğraşlar bul... Yani kafasını dinlemesi için becerilerini artırması için. Keyif aldığın şeyleri yapıyorsun yani. Çünkü boş boş oturan insan.... depresyona giriyor. Sağlıklı düşünmeden. uzaklaşıyor. Bir şeylerle uğraşan insan mesela bahçecilikle …Ama yorulmayacaksın. Bu işi keyif almak için yapacaksın diyoruz

["Find a leisure activity for yourself" … to be mindful.... They (patients) should do things they enjoy. Because if a person is … not doing anything… they can be easily depressed. They are not able to think coherently. A person who has a leisure activity for example gardening… but they should not be tired. They should engage in such activities for enjoyment] (Participant 2, nurse, female)

Mesela bir hastamız var. 20 yıllık. Bilinçli bir insan, eşi halen yanında. Sosyal açıdan da çok aktifler. O yüzden aile desteği çok önemli [For example, we have a patient for 20 years. She is a very conscious and mindful person, her husband is supporting her. They are also very active socially. That's why family support is so important] (Participant 3, nurse, female)

Sources of support also included communication between patients. The participants perceived patients tended to rely on experiences of other patients, therefore participants reported that information shared by others (patients) was important to them. However, the participants highlighted the problem that arises with this tendency. The information exchanged between the patients was not always accurate and sometimes even completely wrong so that it should not have been relied on. One of the nurses explained this issue:

Mesela dışarıda bekleme salonumuz var. hastalar seans beklerken. kendi aralarında konuşuyorlar bazen. "Ben içmedim.Ama hiçbir şey olmadı." .... Bu sefer ona gidip O yanlışı düzeltmeye çalışıyoruz. Ne doğru ne yanlış… Ama hastalar, onlara (diğer hastalara) daha çok inanıyorlar [For example, we have a waiting room outside. The patients are waiting for the session. Sometimes they talk among themselves. "I did not take it (a medicine), nothing happened" … Then we try to fix this misunderstanding

and clarify what is right and what is wrong. But patients believe in them (other patients) more] (Participant 16, nurse, female)

One of the aspects reported to have an impact on overall patient experience was economic status. It was viewed that the economic status of patients may affect the wellbeing to some extent. For instance, some nurses shared that some patients have difficult experiences because of the requirement of transportation for HD sessions. Those patients who seemed to have better economic status were considered as less likely to experience challenges as they have their own cars, even if they cannot drive, they have sufficient resources for transportation. On the other hand, depending on the region where patients live, some municipalities provide service for those receiving HD. Unfortunately, not every patient was provided this opportunity:

Bazen ulaşımda sorun yaşıyorlar. Kimisinin ailesi taşıyor kimisini çalıştığı için belediyeye taşıyor... [Sometimes they (patients) have problems with transportation… For some, their family drives…for some, the municipality provides transportation…] (Participant 16, nurse, female)

Opportunity inequality seemed to play a role in patient experience as some nurses perceived it as one of the determinants of dialysis modality:

Herkese periton yaparmısın diye önermiyorlar sanırım. Bir de çok masraflıymış [I think they (doctors) do not offer PD modality for everyone, I think it is expensive] (Participant 8, nurse, female)

7.3.2.4 Healthcare infrastructure

Although local nephrology services have now been enhanced compared to the past, the service still needs to develop to fully meet the needs of the patients. For instance, it was clearly expressed that the nephrology service was quite limited in the past due to lack of nephrologists. Participants agreed that patients currently do not have difficulty accessing nephrology service and receiving medical treatment. This was considered as a great positive improvement for the service:

> Erişilebiliyor, tabiki de merkezler genişletildi şimdi. Şimdi daha kolay bence.Eskiden bir tek burasıydı (Lefkoşa). Bir de Mağusa vardı. Girne ve Güzelyurt'ta (diyaliz servisi) açılınca (orada yaşayan) hastalar için daha kolay oldu [It (service) is accessible, of course, the centres have been expanded now. I think it's easier now. It used to be the only this place (in Nicosia). There was also one centre in Famagusta. When (dialysis services) in Kyrenia and Morfou have been opened, it became easier for those living these regions] (Participant 8, nurse, female)

The local healthcare system determines and provides sources for each service in state hospitals. Despite medical care provided within the unit having improved and now providing better service than before, nurses shared their perception that their work was negatively influenced mostly due to limited staff (nurses) in the department. This was particularly mentioned in the main dialysis centre in the capital city as it tends to be busier compared to supporting centres in other cities. This was perceived as something that potentially could influence patients' well-being:

> Periton hastaları için bir kural vardır, ev ziyareti. Yılda bir ya da iki …Biz daha önce yapıyorduk. Özellikle peritona yeni başlayan hastanın ev ortamını görüyorduk. …

Görmek zorundaydık. Personel eksikliği…Bizi geri plana itti [There is a rule for PD patients, home visit. Once or twice a year …We were doing this before. We were seeing the home environment of the patient who had just started PD … We had to see it. Lack of staff… it negatively affected our work schedule (Participant 2, nurse, female)

Due to limited time and work burden, some nurses felt they did not have sufficient time to provide better social support for patients:

Teknik servisin olması gerektiğini düşünüyorum. İş yükümüz çok fazla bu sıkıntı bizde. Mesela Türkiye'de hep teknik elemanlar yardımcı olur. Mesela makina hazırlamak yerine, hastayla diyaloğa odaklanabilirisin. Hastayı daha fazla gözlemleyebiliyorsun. Aceleye getirmeden gözlemlersin. İş yoğun olduğunda bazen önemli birşey gözden kaçabiliyor. Çünkü bir yandan iş yetiştirmeye çalışıyorsun bir yandan aslında sorularına cevap vermeye çalışıyorsun. Bir yandan da işi çok iyi yapmaya çalışıyorsun. Kısıtlı süre var. Ama bir teknik eleman yardımcımız olsaydı daha verimli olurdu diye düşünüyorum [I think there should be technical service. Our workload is too much, and this is a problem. For example, technical staff always help nurses in Turkey. For instance, instead of preparing a (HD) machine, you can focus on the dialogue with the patient. You can better observe the patient. You could observe without rush. When work is busy, sometimes something important can be overlooked. Because on the one hand, you are trying to do your job, on the other hand, you are trying to answer patient's questions. On the other hand, you are trying to do the job very well. There is limited time. But I think it would be more efficient if we had a technical assistant. (Participant 7, nurse, female)

Hemşire sadece hastayi diyalize bağlayıp çıkarıyor, hiçbir kelime konuşmuyor. Hiçbir iletişime girmiyor, sadece işine odaklanıyor, işini yetiştirebilmek için. Bu sefer hastanın bir problem varsa onu kaçırıyor. Her yönden hastayla iletişime geçip onlarla konuşmak gerekiyor. Çünkü doktorla hasta arasındaki kanal hemşiredir. Çok büyük bir görevi var. Sadece makineye bağlayıp çıkarmak gibi bir görevi yok [Nurses just put the patient on dialysis and does not speak any word with the patient. They do not have any communication, they just focus on their work, in order to manage things in time. In such cases, if the patient has a problem, they (nurses) miss it. It is necessary to communicate with the patient. Because the bridge between the doctor and the patient is the nurse. They have a huge task. It does not include only putting the patient on dialysis machine (HD) (Participant 9, nurse, female)

On the other hand, nurses from one of the supporting dialysis centres explained that the dialysis centres other than the main state hospital do not regularly have a nephrologist and other qualified doctors in relevant fields for urgent cases. This created frustration and distress for some nurses as they felt they were not really able to help patients who have some difficulties:

Lefkoşa'daki verilen hizmetin daha iyi olduğunu düşünüyorum. Çünkü doktorlar orda. Biz sadece gerektiğinde telefon ile ulaşabiliyoruz. Doktorun olmaması burası için dezavantaj. Burada sorumlu hekim var, pratisyen hekim. Ona ulaşmaya çalışıyoruz, onu ulaşamadığımız da Lefkoşa'daki doktorlara (nefrologlara) ulaşmaya çalışıyoruz [I think the service provided in Nicosia (capital city) is better. Because there are doctors (nephrologists) in Nicosia. We can only reach them by phone when necessary. The

lack of a doctor is a disadvantage for here. There is a responsible physician here, the

general practitioner. We are trying to reach him, and when we can't reach him, we try

to reach the doctors (nephrologists) in Nicosia (Participant 13, nurse, female)

Lefkoşa Devlet Hastanesi'ndeki gibi her branştan bir on-call doktor olsa daha iyi

olurdu [It would be better if there were an on-call doctors from every branch like in

Nicosia State Hospital] (Participant 15, nurse, male)

Although nephrologists regularly visit other dialysis centres at specific time intervals in

different cities, some nurses who work at one of the supporting centres felt they did not have

access to the immediate professional support that was required. It seemed the experiences and

perspectives of nurses who work at dialysis centres in cities other than the main state hospital

were different in this aspect.

In order to prepare patients and maintain wellbeing after commencing dialysis treatment,

patients normally receive brief education on dialysis which is provided by a training nurse in

the nephrology department in the main state hospital. This patient education is delivered in

different forms depending on dialysis modality. The patient education normally provides

information to patients on the aspects of functions of the kidney, how dialysis works, and

information on dietary changes (food consumption and fluid restrictions). Patient education is

delivered only once to patients who are expected to commence dialysis. These patients have

already been diagnosed with CKD. The participants agreed that providing patient education

once is not sufficient as patients may forget critical information and/or may just pretend to

understand treatment requirements. Therefore, they thought that the patient education should be updated and delivered frequently at different times throughout the treatment:

> Tabiki bir kere olmaz. Bunu zaman zaman hatırlatmak lazım… Yeni eğitimler düzenlemek gerekir. Belki broşürler dağıtmak... Belli aralıklarla toplantılar yapıp bilinçlendirmek… [Of course, once (training) is not sufficient. It should be reminded from time to time… It is necessary to organize new training sessions. Maybe handing out brochures... Raising awareness by holding meetings regularly…] (Participant 7, nurse, female)

The participants also recognised the difference between patients who received patient education at the early stage and those who could not receive the education due to several reasons such as urgent need to start dialysis. It has been explained that there may be some patients who urgently need to start dialysis, therefore they may not have a chance to obtain detailed information as expected. In such cases, nurses mainly tried to provide necessary information after commencing dialysis at each session. However, this may not be sufficient as it is supposed to be. Some nurses perceived that this case may be disadvantageous for those patients who urgently commence dialysis (i.e., HD modality) as they would not have enough time to prepare psychologically to the idea of receiving dialysis treatment. For instance, it was shared that experiencing fistula surgery and waiting for the fistula to mature physically tend to help patients to get used to the idea of dialysis. This has been recognised as critical since it provides a chance to become familiar with the required treatment. Compared to urgent cases who commence dialysis without training, patients who experience this 'preparation period' were perceived as more likely to have easier process when commencing dialysis:

Hasta son evrede değil de fistülü açılarak o süreyi bekleyerek diyalize alınması çok daha kolay. Daha konforlu… daha da kaliteli yaşar. Çünkü katater ile (diyalizi) almakla fistül ile almakla arasında çok fark var. Çünkü hasta gerçekten ajite olur. Fistüllü hastanın psikolojik olarak hazırlanma şansı var [It is much easier for the patient to be taken to dialysis by fistula and waiting for that period, not in the last stage. It is more comfortable… even better quality of life. Because there is a big difference between receiving it (dialysis) with a catheter and receiving it by the fistula. Because the patient with catheter becomes really agitated. The patient with fistula has a chance to prepare themselves psychologically for the dialysis] (Participant 9, nurse, female)

Bazıları akut gelişmiştir. Tahliller sonucunda. Bazıları kronik, uzun takipler sonucunda diyaliz alınmasına karar verilir. Kronik olanların kabullenmesi biraz daha kolay oluyor. Tabiki akut gelişen durumlarda hastanın kabul etmesi daha zor oluyor [Some patients develop acute conditions. Some patients are advised to commence on dialysis as a result of chronic condition. Those with chronic condition are taking a little easier to accept. Of course, it is more difficult to accept for patients who acutely developed the disease] (Participant 7, nurse, female)

One of the nurses who provides patient education for those who are expected to commence dialysis treatment added:

Bir grup hasta var, ben onlara hiç görmem. Bir anda diyalize başlarlar. Çünkü başlamak zorunda kalırlar. Yani mesela böbrek bozulur o gece diyalize alınır. Bu hastalar bana sonra olan eğitime gönderilmez. Çünkü normalde hastaları eğitimle hazırlarız ve sonra diyalize hazır girerler [There is a group of patients, I never see

them. They immediately start dialysis. Because they have to start. So, for example, if the kidney suddenly deteriorates, they start to receive dialysis on the same day. These patients are not referred to me for the training later. Because normally we prepare patients with training and then they commence dialysis] (Participant 3, nurse, female)

Although the participants discussed and highlighted psychosocial support needs of patients, most felt they did not have sufficient education on providing psychosocial support for patients. Particularly, nurses who tend to spend greater time with patients (those receiving HD particularly) mostly felt they approach patients according to what they learnt from their experience. Most shared that a training for nurses on how to approach patients would be beneficial for nurses themselves as well as patients to facilitate communication to enhance illness adjustment:

Psikososyal destek bir şekilde veriyoruz ama uzman değiliz. Belki de doğru bilip yanlış şekilde aktarıyor olabiliriz. Belki de yanlış yaklaştığımız zamanlar da olmuştur [We provide psychosocial support somehow. We are not experts. Maybe we know ``correct" things to do but convey it in the wrong way. There may have been times that we approached (patients) in the wrong way] (Participant 7, nurse, female)

On the other hand, one of the nurses explicitly indicated that patients' emotional distress is not on the level that may require professionals' attention. He perceived patients' psychological difficulties as cyclical hence, he thought these challenges were not permanent complaints requiring attention. He felt he would not be interested in such training to enhance communication skills as he already felt burn out due to workload:

Öyle bir eğitim alsak da ben öyle şeylere inanmıyorum. Alsak da çok uygulayabileceğimiz zannetmiyorum. Çünkü bizde de var tükenmişlik. Zaten

kendinden veriyorsun, yoğun çalışarak. Çoğu hasta zaten XXX (psikiyatrik ilaç) alıyor. Destek ilaçları var… Kendine dikkat eden bilinçli hastaların desteğe ihtiyacı olmuyor. Hastaların çoğu umursamaz zaten. Ne yaparsan yap. Kendi bildiklerini okuyorlar [I do not believe in such things, even though we receive such training, I don't think we can practice much. Because we also experience burnout. You are already giving of yourself, by working hard. Most patients are already taking XXX (psychiatric medication). They have supporting drugs… Conscious patients who take care of themselves do not need support. Most patients don't care anyway. Whatever you do, it does not make any difference for them] (Participant 12, nurse, male)

It is clear that apart from limited knowledge related to psychosocial care, this case may be also related to the lack of staff and busy schedule within the unit. Within the limited conditions, nurses attempted to do basic required work in the aspect of medical care.

7.3.3   Compassionate Care

This theme focuses on psychosocial reflections of healthcare professionals which mostly represent nurses' responses and experiences towards challenges that patients experience.

7.3.3.1 Culturally conducive relations

Considering that nurses tend to spend greater time with patients particularly with those receiving HD in the hospital setting, most expressed that the relationship with patients has shifted from nurse-patients relationship to family-like relationship. Although these close relationships with patients were established, the nurses felt that communication with patients was not straightforward, it included ups and downs. For instance, there were times that they experience discussions about requirements related to diet-adherence, also there were times

that they have very close positive relationships to the extent that patients ask about the nurses when they do not see them regularly:

> Çünkü hep bizi görüyorlar. Zaten birinci derece akrabam gibi oldular. Aile gibi oluyoruz [Because they (patients) always see us. They are like my first-degree relatives. We become like a family] (Participant 5, nurse, female)

Particularly, patients receiving HD tend to see nurses three times a week approximately. Dialysis is a long-term treatment that patients' lives depend on unless they receive kidney transplantation. As the nature of the relationship changes, the way nurses address patients also changes. This may become problematic when nurses advise on, for instance, diet adherence. Most nurses tend to address patients as one of the family relatives (e.g., uncle, aunt etc.) thinking patients would listen to recommendations so it would facilitate adjustment to treatment, however, this exceeds the professional relationship between nurses and patients which may link to patient experience. This case may also be related to socio-cultural characteristics of Turkish Cypriot culture which is collectivistic and also allows building close relationships with others easily:

> Bizim hastalarla olan bağımız diğer servislerden farklı. Baş.hemşerimiz bizi bazen uyarır, hastalara amca, teyze demeyeceksiniz, hanım, bey diyeceksiniz diye. Ama bazen diyoruz işte [patient's name] dayı, [patient's name] abla. Yani bunun bazen uyarısını alıyoruz ama. Yaşlılara da yaştan dolayı… Geçirdiğimiz vakitten dolayı… Bu şekilde oluyor [Our bond with patients is different from other services. Our chief nurse warns us sometimes on this issue: "you will not call the patients uncle or aunt, you will say Mr./Mrs" But sometimes we call them uncle, sister. Because of age towards elderly… Because of the time we spend with them. It happens this way] (Participant 6, nurse, female)

As patients experience challenges, some patients were perceived as demanding. However, positive outcomes experienced by patients were recognised as rewarding by some nurses as they become happy for the patients:

> Ne zaman ki hasta rahat bir şekilde çıkıp evine gittiğini görürsün diyorsun ki tamam önemli değil. Mutlu oluyorsun [When you see that the patient leaves comfortably and goes home, you say it's okay, it doesn't matter whatever the problems is. you become happy for them] (Participant 16, nurse, female)

7.3.3.2 Stuckness in capacity

The participants, mainly nurses, had difficulties in terms of responding to patients' needs. They clearly stated their role in providing necessary medical care to patients, however, patients tended to experience psychological as well as physical difficulties. This situation created challenges for most nurses as they acknowledged that they were not able to fully help patients all the time. They felt that they were confident in their ability to meet physical care needs but experienced a sense of helplessness or stuckness when meeting mental health needs. This was expressed in the form of psychological as well as physical aspects. Stuckness experience caused nurses to feel sad, helpless, not feeling sufficient, and feeling tied up to the extent that they felt they could not provide further help and support for patients to overcome difficulties:

> Hastaya yetmediğini düşünüyorsun. Hemodiyaliz hemşiresi olarak yapabildiğimi yapıyorum.Ama diğer taraftan. Yetmediğini düşünüyorum. Çünkü artık beni aşıyor olay. Mesela hasta daha önce kaybettiğimiz bir hasta, hemodiyaliz sırasında iğnelerini makineden ayırıp kanları yerde bırakıp 400ml, neredeyse yarım litre kanı orada

bırakıp, çeker giderdi. kendi başına. Biz hastaya hiçbir şey yapamazdık [You think you are not being sufficient for the patient. I do what I can as a haemodialysis nurse. But on the other hand. I think it's not enough. Because it's beyond me (my capabilities). For example, we had a patient who passed away. During haemodialysis, he removed his needles from the machine and left the blood on the floor, leaving 400ml of almost half a litre of blood there. And he just left. We couldn't do anything] (Participant 13, nurse, female)

The participants discussed how they felt helpless due to critical conditions where patient rejects adjusting to treatment:

Bazen hastaya söylüyorsunuz, 'su içme fazla kilo getirme'… Diyalize alıyorsunuz, ertesi gün yine getiriyor. Öbür gün yine getiriyor…Yapmaması gerektiğini söylüyorsunuz. Hasta tamam diyor. Ama eve gidince yine bir mazareti oluyor. O zaman ben bunu nasıl çözerim? sorusunu yaşıyorsunuz [Sometimes you tell the patient 'don't drink water and don't bring extra weight (to HD sessions) … You take them to dialysis. The next day, they do the same, bringing extra weight. He brings it again also on the following day... We say that he shouldn't do it. The patient says okay. But when he goes home, he has a new excuse. Then you start having questions by yourself 'How do I solve this problem?'] (Participant 1, nephrologist, male)

Bir hasta diyalize gelmeme kararı aldığında oturup sadece beklemek durumundaydık, çaresizdik [When a patient decided not to come to dialysis, we had to sit and just wait, we were helpless] (Participant 11, nurse, female)

Nurses particularly stated that they often felt exhausted because of difficult circumstances where they were not able to do anything, but they sometimes stayed next to patients during dialysis (HD) sessions as the patients needed to feel their presence and support:

> Diyaliz süresince hastanın yanında kaldığım zamanlar oldu. Makinenin başından ayrılamadığım, zamanlar oldu [There were times when I stayed with the patient throughout the HD session. There were times when I couldn't leave the patient bedside] (Participant 5, nurse, female)

As patients were struggling not only from physical difficulties but also due to emotional distress, mainly nurses, were exposed to aggressive attitudes such as anger and temper tantrums. They tried to tolerate these as they were expected to. Some recognised that these negative attitudes were nothing to do with nurses themselves, and related to patients' unresolved conflicts that they experienced:

> O kızgınlık anında bizi suçluyorlar çünkü birini suçlama eğiliminde olur. Ama kişisel algılamam bunu çünkü bana yapılmış bir şey olarak saymam [In that moment of anger, they blame us, because they tend to blame someone. But I don't take it personally because I don't consider it as something against me] (Participant 10, nurse, female)

However, these negative attitudes and aggressiveness of the patients were not easily tolerated by some of the nurses who experienced feelings of sadness and frustration in response:

> Bazıları saygısız ve daha fevri. Çok Ajite... Bu sefer bütün ajitasyonunu geldiğinde sürekli gördüğü kişilere, yani bize (sözlü) saldırarak gösterirler [Some are disrespectful and more impulsive. Very Agitated... in such cases, these patients reflect

all their agitation by (verbally) attacking the people they see regularly, in other words

to us (nurses)] (Participant 15, nurse, male)

7.3.3.3 Empathetic coping

Participants used several strategies to deal with non-adherent behaviours as well as patient

distress. As most patients in particular those receiving HD were perceived as demanding,

most nurses continuously attempted to communicate with patients and give advice on, for

instance, regulating food/fluid intake. Even though advice went repeatedly unheeded, they

continued to provide explanations and tried to help patients to change non-adherent

behaviours:

> Sabırla tekrar tekrar anlatmayı deniyorum [I patiently try to explain it again and
>
> again] (Participant 11, nurse, female)

Some nurses mentioned empathy as one of the ways to deal with emotional difficulties of

patients. According to them, interpersonal skills and empathetic skills are critical to be able to

maintain work in the nephrology department. One of the nurses also highlighted differences

between nurses in terms of interpersonal skills which was perceived as critical factor for

patients' as well as for nurses' well-being:

> Empati...yani karşımdaki biri yatakta yatıyor ama o yatakta ben de olabilirim
>
> tutumunda olduğunda insan...Bu çok önemli. Bu şekilde yaklaşırsan zaten bütün
>
> problem çözülür [Empathy...patient is lying in bed (during HD session), but I could
>
> also be lying in that bed (and receiving HD) … This is really important. If you
>
> approach it this way, the whole problem will be solved anyway] (Participant 6, nurse,
>
> female)

On the other hand, most nurses did not know how to help patients regarding their emotional difficulties, particularly when patients experienced frustration during HD sessions. Therefore, one of the nurses suggested patients try to ignore their 'patient identity', assuming that ignoring and/or denying illness would help patients to get rid of their 'psychology of patient' and enhance their well-being:

> Ben hastayım diye düşünmemelerini ben her zaman söylüyorum. Hasta olarak kendini kabullenirsen hiçbir şey aşamazsın. bizi böyle görmeye geldiğini farzedelim diyorum ama, eğer ben hastayım diye tutum alırsa üzerine daha fazla çekecek. Onun dışında böyle sanki gezmeye gider gibi gelirse daha iyi olur ama 'ben hastayım, sürekli hastayım' derseler daha kötü olur [I always tell them not to think that they are sick. If you accept yourself as a patient, you cannot overcome anything. I tell them "Let's pretend you came here (hospital) to visit us (nurses)". If they consider themselves sick (patient), it becomes worse… It is better to perceive it (HD session) as visiting/going for a trip. If they repeatedly remind themselves that they are sick, it will be worse] (Participant 6, nurse, female)

Ignoring may not be an effective strategy to deal with difficulties in the long term. This approach seems to reflect the nurse's preferred way to cope with challenges. This suggestion may result in greater difficulties in illness adjustment as it deviates from reality.

7.4   Discussion

This study aimed to understand perspectives of healthcare professionals on psychosocial care needs of patients receiving dialysis. The analysis highlights criticalness of adjustment and adherence to the treatment. Like research in different health settings (Griva et al., 2013; Tong

et al., 2009; Sein et al., 2020), it has been reported that multiple factors contribute to health status and affect the capacity to adjust. For instance, transition to the dialysis process is important, therefore cyclical patient education has been suggested. It was recognised that the patients may experience emotional difficulties. However, opportunities to support patients were limited due to the way mental health services are resourced and operated in the local healthcare system. Another important key finding was how patient experiences were reflected on healthcare professionals, mainly nurses. This was discussed particularly indicating challenges nurses face in terms of meeting the psychosocial care needs of the patients. Nurses seemed to play a key role in supporting patients with a compassionate care approach, yet they also experienced stress as part of this effort. This study, for the first time, provides insight on healthcare professionals' perspectives on patients' experiences of receiving dialysis in Northern Cyprus. This study has potential to inform local healthcare policy to enhance psychosocial care of patients receiving dialysis.

Most healthcare professionals in this study recognised that patients' physical difficulties were likely to interact with emotional distress. Although patients tended to share their physical complaints, it was obvious that some also experienced emotional difficulties. Regarding this issue, they discussed the limited local sources and opportunities which were believed to decrease the chances to access psychological support. Unfortunately, there is no psychological service provided within the local nephrology department. There is only one general psychiatric state hospital in the capital city in Northern Cyprus. Staff consist of psychiatrists, clinical psychologists, and mental health nurses. This hospital is mostly suitable for individuals with severe mental health issues (e.g., psychotic conditions). It rarely provides support for those with moderate emotional distress. Healthcare professionals normally advise patients to visit this psychiatric hospital when necessary or patients may choose to access

psychological support in private. In other words, there is no regular psychological assessment and/or support provided within the unit. According to the (informal) protocol, when nurses recognise the patients' requirement of psychological support, they are expected to inform the doctors in the unit, and the doctors communicate with the patients and advise them to ask for psychological support from the general psychiatric hospital and/or patients are prescribed suitable medication in collaboration with the psychiatry service. Considering there is currently no regular psychological assessment within the unit, and the fact that psychological support can be accessed through only state psychiatric hospital, these were highlighted as critical barriers for patients. On the other hand, mental health stigma seems to play a role as patients were perceived as avoiding visiting the psychiatric hospital for psychological support. Although mental health stigma is poorly studied in Northern Cyprus, the limited research that there is indicates that Turkish Cypriot culture is associated with negative attitudes toward mental health problems (Zorba, 2015) and self-stigma are associated with negative attitudes toward help seeking behaviours (Mertan et al., 2014). Nevertheless, a meta-analysis including population-based studies have shown that lay individuals preferred psychologists /psychotherapists over psychiatrists and psychotherapy over medication. It also seems to be the case that there is preference for initial management of depression by psychologists/psychotherapists in Europe and America (Angermeyer et al., 2017). Given the evidence, it is not surprising that the patients with emotional distress were perceived to not relate to psychiatric care.

Patient education that is normally delivered before commencing dialysis treatment was perceived as critical for patients as it aimed to prepare them for dialysis and provide information on required changes related to diet. However, patient education was not found to be sufficient therefore it was recommended to repeat patient education at different time

points. This could also include a counselling service for patients. It is known that patients

receiving dialysis may face challenges due to uncertain prognosis (Tong et al., 2009). This

tends to contribute to emotional distress (Kim & Kim, 2019). Therefore, patients may benefit

from regular counselling service which may help to increase adherence to treatment and

enhance patient wellbeing (Van Camp et al., 2012). It is known that some cultural groups

may be less likely to engage in help seeking behaviour in relation to mental health due to

concern related to stigmatisation (Chung, 2010). Considering Turkish Cypriot culture has

been associated with mental health stigma (Zorba, 2015), interventions in different forms

such as, in a group setting may facilitate help seeking behaviour among patients (Price &

Dalgleish, 2013).

Patients receiving dialysis, particularly HD, have been associated with non-adherence to

treatment (Gebrie, & Ford, 2019). Treatment adherence has an impact on health status in

kidney failure (Alikari et al., 2019; Beerendrakumar et al., 2018). Healthcare professionals in

this study discussed how patients on different dialysis modalities may have different types of

challenges therefore their adjustment to kidney failure may differ. It is known that patients

receiving HD treatment may have greater challenges (Gebrie, & Ford, 2019) therefore the

adjustment process may be different than those receiving PD treatment (Jung et al., 2019).

For instance, healthcare professionals agreed that patients receiving HD are more likely to

report emotional distress and more likely to engage in non-adherent behaviours such as

exceeding limits of liquid intake. Family involvement in illness management was discussed

as it may facilitate the adjustment and adherence to treatment through shared responsibility

(Whitehead et al., 2018). Research has suggested family involvement in patient education is

critical as it may play an important role in adherence to treatment (Lee & Molassiotis, 2002).

This may facilitate rearranging lifestyle and integration of the dialysis into patients' lives.

Actively being involved in the illness management may be achieved with educating families also. It is known that interventions targeting family caregivers of patients receiving dialysis can decrease distress and burden among family caregivers (Belasco et al., 2006).

Patients receiving HD treatment frequently interact with nurses in nephrology department. Nurses in this study, who work at the unit mentioned that the relationship between patient-nurse changed into family-like relationship leading to addressing patients frequently as *uncle* or *aunt*. This may be partly influenced by the Turkish Cypriot culture which represents a small society. It is known that communication style may affect patient experience (Lang, 2012). Cultural knowledge has been shown to shape nurse-patient relationship which was suggested to increase understanding of and communication with patient (Larsen et al., 2021). Nevertheless, nurses sometimes shared that they did not know how to help patients to overcome emotional difficulties and enhance the adaptation process. They developed various strategies to cope with distress and non-adherence of patients, for instance, some suggested ignoring the patient identity to reduce emotional difficulties patients experience, however, this may emphasise the gap between ideal self-concept and real self-concept. It is known that the difference between expected and real experience may result as greater emotional distress (Marcussen, 2006). Denial may not be an efficient way to cope with difficulties in the long term (Whitmarsh et al., 2003). This strategy may reflect the nurse's approach to cope with challenges. However, this suggestion may reinforce avoidance among patients which may cause greater difficulties in illness adjustment (Spendelow et al., 2018). In the meantime, mainly nurses in this study acknowledged that they did not feel that they fully met psychosocial care needs of patients. It was obvious that healthcare professionals' understanding of psychosocial care was different. This may be due to lack of training on this aspect and the traditional approach adopted in local healthcare. They thought they could

benefit from training aiming to help them to know proper ways to approach patients. This may also help nurses to deal with 'stuckness experience'. Feeling stuck or experience of heartsink have been evident in health research where professionals experience challenges in response to demanding patient experience (Alexander et al., 2021; Wilkinson, 2019). Observing stuckness experience in this study was not surprising as nurses did not seem very familiar with psychosocial care practices particularly in terms of dealing with emotional distress of patients. Mostly they used their own strategies attempting to comfort the patients, however, not all of these strategies seemed efficient.

7.4.1   Strengths and Limitations

This study for the first time provided insight on the perspectives of healthcare professionals on psychosocial care needs of patients receiving dialysis in Northern Cyprus. The current research findings have potential to be generalised. More specifically, the analysis may be generalised by *naturalistic generalisability* which suggests that research findings can resonate with readers' personal experiences (Smith, 2018). Healthcare professionals who work at the nephrology department may find the findings similar to their experiences. For instance, nurses elsewhere have reported the importance of patient-centred care which highlights patients' needs and preferences. In the same study, adequate staffing was also discussed (Kieft et al., 2014). Similarly, in the current study, nurses might be less likely to experience 'stuckness' if they could refer patients to psychologist/counsellor for emotional distress. On the other hand, nephrology nurses' beliefs and practices have been considered unique in comparison with nursing practices in different contexts (Morehouse et al., 2011). One of the factors influencing this view was the nature of the relationship between nurse and patient (Morehouse et al., 2011), which was also discussed in the current study.

On the other hand, there were a few limitations with this study. For instance, data were collected in September 2021. The local healthcare system has been negatively affected by COVID conditions since 2020. Healthcare professionals who work at local nephrology department, particularly nurses were busier, working longer hours than usual. Due to pandemic conditions, available nurses were more limited due to quarantine requirements in case of contact with COVID-positive case. Available nurses were invited to take part in the study. The reason that some nurses did not agree to participate in the study was related to busy schedule they had. Although nephrologists and nurses mainly shared similar perspectives, the experiences of the nurses were dominant in the dataset. This is due to the limited number of nephrologists in Northern Cyprus (n= 3 in 2021).

7.4.2   Conclusion

Overall, the findings of this study provide insight on views of healthcare professionals on patient experience and psychosocial care needs of the patients' receiving dialysis. The findings are useful as they may be used to improve patient well-being in local healthcare. The analysis highlights the importance of an holistic approach to healthcare which may help to enhance traditional care provided in local healthcare. Including psychological services in kidney care would be important for patient experience. Considering local sources, making some changes within the unit may positively influence patient experience. For instance, providing counselling services for patients as well as family caregivers would facilitate adjustment to illness and may help both patients and family caregivers to adopt efficient coping strategies to deal with treatment burden and emotional distress. In designing such interventions, it should be considered that local patients may hold negative attitudes toward mental health difficulties. Additionally, as adjustment to treatment is critical, repeating patient education at different time points would remind patients for instance required diet-

related changes to maintain diet adherence. Finally, informing healthcare professionals about psychosocial care practices would be helpful for both staff and patient experience at the local nephrology department.

Chapter 8: General Discussion

8.1 Overview

The aim of this programme of research was to understand illness experiences of Turkish Cypriot patients diagnosed with chronic kidney disease (CKD) and receiving dialysis, particularly haemodialysis (HD) including how this is shaped by illness perceptions. A programme of studies was designed to examine illness perceptions and related health behaviours of this patient group within the socio-cultural context. The objectives of the research programme were addressed by using mixed methods, which included a systematic review, longitudinal quantitative data analysis and qualitative data analyses that represented views of both patients and healthcare professionals working in kidney care. By using the Common Sense Model (CSM) of self-regulation (Leventhal et al., 2003), patients' illness perceptions and related experiences were studied. The findings make a unique contribution to enhancing local clinical practice and informing future research. A summary of the key conclusions from each study is included below. Together, the main conclusions drawn include that:

1. Mixed-methods research is advantageous, particularly in healthcare contexts and focusing on patient groups where research is generally lacking

2. There is a need to advance qualitative research particularly on illness perceptions in patients receiving HD, given the dearth of studies that draw on this method specifically

3. The illness perceptions framework itself is useful cross culturally to help explore patient adjustment to CKD and associated intervention through HD

4. Cultural influences on how patients construct illness beliefs may be adaptive for aspects such as coping but may also contribute to the process of sense making and cognitive re-framing.

5. There is a need to advance psychological care of patients in healthcare infrastructures where workforce is lacking and pathways to care may be stigmatised due to association with severe mental health

6. Including regular psychological assessment into care within local nephrology department would be helpful to screen negative illness perceptions and emotional distress as they may vary over time.

Further, there are overarching themes from the research that highlight the importance of:

1. Methodological considerations in the measurement of illness perceptions

2. Illness perceptions as a cross-cultural framework

3. Illness perceptions as a tool for understanding health behaviours

8.2   Summary of Findings

Qualitative enquiry with patients demonstrates the stability of illness perceptions cross-culturally as a framework from which to identify illness experiences, and importantly indicates culture-related mechanisms that shape responses to treatment burden and maintaining life on HD. A systematic review of qualitative studies highlights that patients may experience similar challenges that influence life experience however, cultural differences may play a role in different cognitions and experiences which confirms findings of qualitative enquiry with patients. The prospective longitudinal study determined that patients receiving dialysis tended to have negative illness perceptions (i.e., greater perceptions of consequences, emotional response and lower personal control) compared to patients in the pre-dialysis phase. Illness perceptions may change over time and they may be associated with emotional distress. On the other hand, qualitative interviews conducted with healthcare professionals in Northern Cyprus highlight the importance of self-management in

the context of psychological adjustment to CKD, with recognition of a stuckness in their capacity to extend further care.

8.2.1 Methodological Considerations

Mixed-methods research has much potential to be utilised in social and health sciences research (Curry et al., 2009; Doyle et al., 2016). Healthcare researchers particularly can benefit from using a dynamic approach to enrich their conceptualisation of complex phenomena (Östlund et al., 2011) by including 'the patient's voice' into the analysis also (Morse, 2015). For instance, a qualitative study initially conducted may help to form a hypothesis or to inform a follow-up questionnaire for a quantitative study. Although standardized measurement scales are helpful in interpreting scores and in providing an overview about issues examined, they are not as useful in establishing the needs and experiences of the patients in depth. They allow for mapping patterns in the main. Therefore, it would be valuable to incorporate both quantitative and qualitative approaches to get better insight about life experiences of the patients and their response to the treatment (Curry et al., 2009). This thesis was successfully able to apply a range of measures in studying illness perceptions, importantly in what may be generally considered an under-researched patient group in the local cultural context.

Using different methods to collect and analyse data was considered suitable to provide in-depth understanding of the illness perceptions of the patient group within this programme of research. The studies were designed by using mixed method approach, particularly exploratory sequential mixed method design with longitudinal methodology. Conducting studies in the original language was critical which made it possible to access illness beliefs and make sense of patient experience. This is believed to promote the success of the mixed

methods approach. Besides, the language of origin allowed this approach to be more inclusive. Initially a qualitative study provided insight into patient experience. Findings of the first qualitative study informed variables to measure by prospective quantitative study, where data were collected at three measurement occasions. In parallel to a quantitative study, a systematic review of qualitative studies (i.e., qualitative evidence synthesis) was completed, which provided an overview of experiences of patients receiving dialysis. The review study included data from different health settings in various countries. This was helpful to observe similarities and differences between patients receiving dialysis by comparing with findings of the first qualitative study. This evidences that experiences of the patients from a range of cultural backgrounds may be similar due to their sense-making processes. Prospective longitudinal study provided data on the change of illness perceptions over time. A longitudinal design is more complicated than cross-sectional survey designs to administer because it is challenging to motivate participants to commit to study at specific time intervals to maintain retention rate high, otherwise, these can be considered methodological limitations (Lynn et al., 2019). However, the relationship between researcher and patients was established earlier, which is believed to play a role in patients' commitment to research. Finally, qualitative study conducted with healthcare professionals highlighted not only how healthcare professionals perceive patients' experiences but also how they perceive support needs of patients considering barriers and facilitators of the local healthcare system. Using different sources for data collection facilitated to understand patient experience within the socio-cultural context.

8.2.2   Illness Perceptions as a Cross-cultural Framework

Individuals' illness perceptions may differ even if they have the same health condition, therefore they may respond differently to their illness (Petrie & Weinman, 2006). It is known

that cultural factors are likely to shape the sense making process of illness (Baumann, 2003). Quantitative illness perceptions measures have been translated into many languages. For instance, the Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent et al., 2006) was translated into 25 languages, these include but are not limited to Turkish, Greek, Polish, Japanese, Italian, and Persian (Broadbent et al., 2015). This facilitated quantitatively measuring illness perceptions in different socio-cultural contexts. Translation and adaptation processes may differ, and as a result, there may be confusing wording in some translated versions (Broadbent et al., 2015), however, illness perceptions framework seem to apply in different cultural groups. Nevertheless, patients' beliefs and sense-making process may be different depending on cultural differences. As it has been indicated earlier that culture may shape how individuals perceive and make sense of health and illness (Kaptein et al., 2015). While quantitative measures have been dominant in illness perception research, it has been suggested to qualitatively examine illness perceptions particularly in cultural groups, even may be as part of the translation process (Brzoska et al., 2012). Although illness perceptions domains seem to be universal, the significance of understanding illness perceptions in cultural groups qualitatively has been shown in the first qualitative study of the research programme (Chapter 4). Illness representations and experiences of patients receiving HD treatment were identified through developed themes, corresponding different illness perception domains. For instance, one of the themes was related to how patients managed the burden of kidney failure as well as HD treatment. This theme represented control/cure related beliefs. The strategies used mainly reflected cultural values, highlighting cultural impact on this domain. Overall, the findings supported the illness perceptions domains. Although the patients' experiences were similar to dialysis groups from mainly white heritage backgrounds, the findings also demonstrated culture playing a role in illness beliefs as well as experiences of the patients. Despite translated version was available in Turkish, it is

recommended to conduct a qualitative study in order to better understand illness related beliefs of patients. For instance, in response to question regarding timeline (duration of health condition), patients hesitated to provide response. This may be related to the nature of CKD and its' treatment, for instance, patients on HD may receive kidney transplant if eligible. This creates unclear expectations and feelings related to future (Rees et al., 2018). However, considering socio-cultural values of the sample, patients were unclear about future expectations not only due to unclear expectations regarding modality of kidney replacement therapy but also due to religious/spiritual attitudes. This was also evident in the quantitative measure of illness perceptions in response to timeline related question (Chapter 6). Some patients had difficulty identifying to what extent they believed their condition will last. When asked about the duration of illness quantitatively, they replied: "I cannot know/ I do not know", "God knows", "nobody can know about the future" and thought about chronicity related question about the illness perception scale. Cultural influence in illness perception domains was obvious also with the findings of the systematic review study (Chapter 5) where illness perceptions were qualitatively examined among patients in different health settings. The review study aimed to look into whether illness beliefs of Turkish Cypriot patients receiving HD suggested by first qualitative study (Chapter 4) are parallel with evidence describing beliefs of patients from diverse populations within the illness perception framework. Consistently, the synthesis indicated that cultural values and/or belief system shaped the coping strategies adopted. Overall, domains of illness perception framework were supported in this patient group, however, illness related beliefs seemed to vary with the potential influence of culture.

8.2.3 Illness Perceptions and Health Behaviours

Regardless of illness type, illness perceptions of primary care patients and those who are impacted by longer term health conditions have been widely examined (Petrie et al., 2007; Richardson et al., 2016). Negative illness perceptions (emotional distress, consequences, concerns, identity) have been associated with severe somatic symptoms (Zhang et al., 2014), and psychological distress (Wu et al., 2014). When examined prospectively, negative illness perceptions (timeline, greater consequences, and emotional representations) have been shown to predict poorer physical and mental health outcomes (Frostholm et al., 2007).

Illness perceptions have been closely associated with psychological outcomes (Foxwell et al., 2013; Hudson et al., 2014; Petrie et al., 2007; Richardson et al., 2016), which may play a role in treatment engagement and overall health. Patients with CKD frequently have psychological as well as physical complaints. Research has looked to identify illness perceptions of patients with CKD and how their perceptions may be associated with psychological outcomes. Negative illness perceptions (e.g., timeline, identity, coherence, consequences) have been found to be related to depression in patients receiving HD (Chilcot et al., 2011a). A prospective research study has noted that negative perceptions of treatment control, consequences and cyclical timeline were associated with higher depression symptoms among patients receiving dialysis (Chilcot et al., 2013). Emotional distress in this patient group was evident in the first qualitative study (Chapter 4) as well as in the qualitative study conducted with healthcare professionals (Chapter 7). The healthcare professionals who work with patients receiving dialysis reported many patients struggled with emotional distress at least once throughout their illness. This may even be cyclical such that it can be experienced at different stages. Illness perceptions and depression were examined in the prospective quantitative study (Chapter 6). The findings showed that illness perceptions

tended to change over time (1 year) in this patient group. Although depression symptoms seemed to be relatively stable over one year, baseline greater perceptions of illness consequences and emotional response were associated with the change in depressive symptoms. Moreover, it was observed that patients receiving dialysis had greater depression symptomatology compared to those in the pre-dialysis phase. This indicated that illness perceptions and related health outcomes may vary depending on the treatment/phase of the illness.

The associations between illness perceptions and physical outcomes have been examined in CKD. It is known that patients with CKD, specifically those receiving dialysis treatment tend to report severe physical symptoms (Cha, 2018; Delmas et al., 2018). In the prospective quantitative study (Chapter 6), dialysis related symptoms were also investigated along with illness perceptions among patients receiving dialysis. Dialysis related symptoms were found to be stable over time (1 year). Baseline greater emotional response was associated with change in dialysis related symptoms. Furthermore, greater perception of personal control was found significantly influencing rate of change, causing decrease in dialysis related symptoms over time (1 year). Interestingly, dialysis related symptoms did not vary depending on dialysis modality. This could be related to patients receiving different modality of dialysis having similar clinical characteristics such as comorbidity status (Iyasere et al., 2019).

8.3   Implications

Consistent with the literature, this thesis highlights that illness perceptions are not stable and may change with illness progression. This change may also affect illness experience. Therefore, it is important to assess illness perceptions regularly in the patient group. This may inform strategies that can assist illness management, which likely to influence patient

experience (Sararoudi et al., 2016; Seyyedrasooli et al., 2013). Regular assessment of illness perceptions would require cultural sensitivity and understanding that cultural values may be reflected with responses. Studies of the research programme have shown that culture may shape illness perceptions and how patients respond to their illness.

Although the Brief IPQ includes an item regarding emotional response, it is recommended to regularly assess emotional distress considering patients receiving dialysis reported (mild) depressive symptoms. It has been shown that Turkish Cypriot culture has been associated with negative attitude towards mental health difficulties (Zorba, 2015). Socio-cultural characteristics and attitudes toward mental health seeking behaviours of Turkish Cypriot society should be considered when planning how to psychologically support the patient group. Moreover, considering that the current local healthcare infrastructure is limited and it mainly provides psychological care for severe mental health difficulties, this may have a potential effect such as stigmatisation. Although healthcare professionals adopted a compassionate care approach in the local nephrology unit, it was evident that their capacity to help patients regarding emotional distress was limited which was reflected as stuckness experience on the part of healthcare professionals. Suitable psychological care pathways should be designed to meet the support needs of the local patient group.

This thesis highlights the utility of illness perceptions framework in a cultural group. Beliefs and experiences corresponding to each illness perception domain were observed. Cultural impacts on illness beliefs were also identified, which were linked to overall patient experience. It shows the applicability of the framework in understanding illness perceptions and related experiences in an under-researched group. This may inform future culturally adapted interventions targeting negative illness perceptions in the patient group. The

importance of mixed-method approach has been indicated with the research programme considering the strengths of both qualitative and quantitative methods. Even though the patients can be considered as research naïve group, it has been shown that it is possible to use a complex, prospective (exploratory sequential) mixed method design, which has provided in-depth understanding about the patient experience. Future studies aiming to understand illness perceptions, particularly in an underrepresented group are encouraged to use qualitative method first even if a suitable translation of quantitative illness perception measure is available. This could help better making sense of illness related beliefs that patients hold.

Further research should examine illness perceptions in this patient group qualitatively. Quantitative data alone may not allow access to patient beliefs in-depth. Illness perceptions should be further studied by using qualitative methods in the patient group. Considering that illness perceptions may change over time, qualitative studies may also utilise longitudinal design. Prospective qualitative research would help to understand how sense making of illness beliefs may change over time. This would provide insight into how illness perceptions vary over time in this patient group. It has been suggested that conducting interviews in the context of the CSM of self- regulation along with the illness perceptions measures is most advantageous to truly reflect an in-depth understanding regarding illness beliefs across patient populations (French & Weinman, 2008). Questionnaire completion alone may not meaningfully capture patient beliefs about their condition, especially, when the patient group is under-researched with cultural context.

8.4   Strengths and Limitations

The research programme includes several studies aiming to understand illness perceptions of Turkish Cypriot patients receiving dialysis, for the first time. To achieve this, a mixed-method design was utilised, which is one of the key strengths of this research programme. It allowed us to gain in-depth understanding of illness perceptions of the patient group while considering the socio-cultural context. The research programme was designed by the multidisciplinary team, local professionals were also involved in this team. This was critical in terms of planning the studies effectively. One of qualitative studies was conducted with healthcare professionals to understand how they viewed patient experience. Including perspectives of the healthcare professionals was helpful to identify patients' psychosocial care needs. The findings of the programme therefore draw on a range of methods to holistically summarise the role of illness perceptions in this setting aiming to understand patient experience in a culturally meaningful way as well as informing service support development needs. The thesis does not only provide findings on illness perceptions of an under-represented group, but it also highlights methodological considerations and informs clinical practice with recommendations.

Despite strengths of the research programme, there are some limitations that should be noted. One of the limitations is related to prospective quantitative measurement of illness perceptions. The sample of the prospective quantitative study included both dialysis groups and pre-dialysis groups. Although overall the dataset met the assumptions of the General Linear Model, when the baseline scores of the pre-dialysis group were examined separately, the distribution of scores seemed to be heterogeneous in this group. This may indicate that patients in the pre-dialysis group vary in terms of illness perceptions and depression symptoms. This could be attributed to different health status and differences in recognition of

the possibility of commencing dialysis treatment soon. The pre-dialysis group included patients who were expected to commence dialysis treatment within 6 months, in other words, they were expected to initiate dialysis in a planned fashion. Therefore, findings regarding the transition from pre-dialysis phase to dialysis treatment do not represent experiences of patients who "crash" onto dialysis as emergent-start hence may have different illness-related experiences. Additionally, follow-up of the patients was difficult particularly for the pre-dialysis group. Covid pandemic conditions negatively affected follow-up. Therefore, the patient group who moved from the pre-dialysis phase to dialysis was smaller than expected, though sufficient for planned analyses. Due to pandemic conditions, data collection mode was changed from face to face to telephone. Although it is suggested to use mixed modes of data collection in longitudinal studies (Bianchi et al., 2017) and most patients seemed to feel more comfortable answering questions via telephone, it is possible that we failed to follow those patients who did not use telephone or those who changed their contact details.

It is known that illness perceptions may vary depending on disease progression. Three measurement points were used in the prospective longitudinal study which allowed utilising linear modelling. Although the findings are generally supported by previous evidence (Chilcot et al., 2013; Covic et al., 2006; Jansen et al., 2013; Goh et al., 2018), it is recommended to include more measurement points into future prospective studies as trajectories of illness perceptions and related health outcomes may be better represented with non-linear models in this patient group (Chilcot et al., 2013). This may help to better identify when illness perceptions are likely to change.

It should be noted that data collection for prospective quantitative study was completed during Covid pandemic. It is not clear how challenges in relation to Covid pandemic may

have an effect on illness perceptions and related experiences in the patient group. Particularly patients receiving HD are clinically vulnerable, yet they were required to attend HD sessions in the hospital setting regularly. It is possible that illness perceptions may have been affected by anxiety related to waves of pandemic during baseline and follow up measures. Overall, the objectives of this research programme were successfully addressed despite challenges experienced related to Covid pandemic conditions and limited local healthcare infrastructure and the fact that the target group was the research naïve group. Nevertheless, being able to approach all eligible patients, particularly in the prospective longitudinal study with a high response rate can be considered an achievement which indicates the representativeness of the sample and highlights the importance of the findings. Similarly, the richness of qualitative data collected in the original language gave the researcher opportunities to be able to interpret and contextualise the patient experience in-depth.

8.5   Future directions

The findings of the research programme highlight that Turkish Cypriot patients receiving dialysis tend to report negative illness perceptions and emotional distress. Regular assessment of illness perceptions and emotional distress may be included into care provided in the local nephrology department. This would help identifying negative illness perceptions and emotional distress at different stages. Psycho-educational interventions targeting negative illness and emotional distress could be planned according to the regular assessments. With these interventions, patients may benefit from strategies to enhance self-management. The local healthcare system does not yet provide psychological support for secondary care services specifically. There is only one governmental setting comprehensively providing mental health service once applied for. This thesis highlights that the patient group can benefit from psychological support. However, it is important to plan culturally appropriate

psychological support as Turkish Cypriot culture has been associated with mental health stigma (Zorba, 2015). For instance, psychological support may be delivered as part of patient education in the form of psycho-educational program. This may be repeated at different time points. According to the qualitative work, experiences of other patients seemed to be important, therefore peer support groups may be arranged from time to time. Experienced patients for instance, may share useful information on self-management with those patients newly commenced on dialysis treatment. Peer support has been positively perceived by patients with CKD as it offers empathy, confirmation and practical information based on lived experience. It may also increase a sense of empowerment (Hughes et al., 2009). Culturally adapted peer support interventions have been successfully delivered among patients receiving dialysis (Perry et al., 2005). Given the evidence elsewhere, local patient groups may facilitate adjustment to kidney failure through learning from experienced peers.

Clinical practice guidelines for psychosocial care have been increasingly used in many high-income countries like United States, United Kingdom, Canada, and Australia (Turner et al., 2005). These guidelines target healthcare professionals including those without psychology/ psychiatry backgrounds to inform clinical decision-making, to improve quality of healthcare and the effect of treatment for patients with a medical illness. Clinical guidelines are critical to manage psychosocial distress of patients with long-term health condition (Steginga et al., 2006). However, a clinical guideline for psychosocial care has not been yet developed and used within the local healthcare system in North Cyprus. The need for such clinical guideline was clear in the qualitative study conducted with healthcare professionals (Chapter 7). Many healthcare professionals shared that they did not know how to respond particularly when they observed patients greatly influenced by emotional distress. It would be critical for local healthcare system to have a quick reference guide which may be designed by mental health

professionals in the future. For instance, the renal service delivery framework in the United Kingdom highlights the importance of psychological support for patients with kidney disease at all stages of the care pathway, this includes a referral from primary care, the pre-dialysis phase, and the period after commencing kidney replacement therapy (National service framework: kidney disease, 2004). Nevertheless, healthcare professionals who work in the local nephrology department may benefit from short training about psychosocial care and how to respond patients' emotional difficulties. Trainings for the healthcare professionals particularly nurses as they spent most time with patients could be arranged at different time intervals, depending on the resources of the local healthcare system.

8.6   Conclusion

Despite research and healthcare infrastructure being limited locally, this research programme successfully used a mixed method approach to understand illness experiences of an under-represented cultural group in kidney research. This thesis provides insight on experiences of Turkish Cypriot patients who receive dialysis. Findings are believed to make a significant contribution to the kidney literature. The findings of the research programme have implications for the development of care pathways that take a more integrated approach considering both physical and mental well-being in local kidney healthcare. Development of self-management strategies for patients in the local nephrology units is suggested. Psychosocial practice policy is required to meet psychological support needs of patients receiving dialysis in Northern Cyprus. It is recognised that changing a healthcare system will take time, yet this thesis at least is a first step in evidencing support needs of the patient group in Northern Cyprus. Nevertheless, suitable actions could be considered within the local nephrology department, for instance, local patient groups may be considered to be included in

the future care plan to improve self-management strategies among patients in the local kidney

healthcare.

References

Abdel-Kader, K., Unruh, M. L., & Weisbord, S. D. (2009). Symptom burden, depression, and quality of life in chronic and end-stage kidney disease. *Clinical Journal of the American Society of Nephrology*, *4*(6), 1057–1064. http://doi.org/10.2215/CJN.00430109

Abdulkader, R. C., Burdmann, E. A., Lebrao, M. L., Duarte, Y. A., & Zanetta, D. M. (2017). Aging and decreased glomerular filtration rate: An elderly population-based study. *PloS one*, *12*(12), e0189935. https://doi.org/10.1371/journal.pone.0189935

Adın, R.M. (2019). *Chalder Yorgunluk Ölçeği'nin Türkçe'ye uyarlanması ve genç yetişkin bireylerde psikometrik özelliklerinin incelenmesi* (Unpublished doctoral dissertation). Hacettepe University, Ankara, Turkey.

Aflakseir, A. (2012). Role of illness and medication perceptions on adherence to medication in a group of Iranian patients with type 2 diabetes. *Journal of Diabetes*, *4*(3), 243–247. https://doi.org/10.1111/j.1753-0407.2012.00183.x

Ajzen, I. (1991) 'The theory of planned behavior,' *Organizational Behavior and Human Decision Processes 50*, 179–211. https://doi.org/10.1016/0749-5978(91)90020-t

Ajzen, I. & Fishbein, M. (1980) Understanding Attitudes and Predicting Social Behavior, Englewood Cliffs, Prentice-Hall.

Akturk, U., & Gul, E. (2019). Investigation of Fatigue in Hemodialysis Patients, Severity and Influencing Factors. *Turkish Journal of Nephrology*, *28*(3), 197–201. https://doi.org/10.5152/turkjnephrol.2019.3433

Aldalaykeh, M., Al-Hammouri, M. M., & Rababah, J. (2019). Predictors of mental health services help-seeking behavior among university students. *Cogent Psychology*, *6*(1), 1660520. https://doi.org/10.1080/23311908.2019.1660520

Aldaz, B. E., Treharne, G. J., Knight, R. G., Conner, T. S., & Perez, D. (2017). Oncology healthcare professionals' perspectives on the psychosocial support needs of cancer patients during oncology treatment. *Journal of Health Psychology, 22*(10), 1332–1344. https://doi.org/10.1177/1359105315626999

Aldwin, C. M., & Park, C. L. (2004). Coping and physical health outcomes: An overview. *Psychology & Health*, *19*(3), 277-281. https://doi.org/10.1080/0887044042000193514

Alharbi, A. A., Alraddadi, R. M., Alharbi, A. A., & Alharbi, Y. A. (2017). Comparison of Saudi Arabian hemodialysis and peritoneal dialysis patients' illness perceptions. *Renal Failure*, *39*(1), 187-192.

Alikari, V., Tsironi, M., Matziou, V., Tzavella, F., Stathoulis, J., Babatsikou, F., ... & Zyga, S. (2019). The impact of education on knowledge, adherence and quality of life among patients on haemodialysis. *Quality of Life Research*, *28*(1), 73-83. https://doi.org/10.1007/s11136-018-1989-y

Almutary, H., Bonner, A., & Douglas, C. (2013). Symptom burden in chronic kidney disease: a review of recent literature. *Journal of Renal care*, *39*(3), 140-150.

Almutary, H., Douglas, C., & Bonner, A. (2017). Towards a symptom cluster model in chronic kidney disease: A structural equation approach. *Journal of Advanced Nursing*, *73*(10), 2450-2461. https://doi.org/10.1111/jan.13303

Alsalem, M., Alamri, R., & Hejazi, S. (2020). Nonpsychiatric healthcare professionals' attitudes toward patients with mental illnesses in Makkah city, Saudi Arabia: A cross-sectional study. *Neuropsychiatric Disease and Treatment, 16*, 341–348. https://doi.org/10.2147/NDT.S236148

Al-Smadi, A. M., Tawalbeh, L. I., Ashour, A., Hweidi, I. M., Gharaibeh, B., Slater, P., & Fitzsimons, D. (2017). The influence of treatment modality on illness perception and

secondary prevention outcomes among patients with acute myocardial infarction. *International Journal of Nursing Sciences*, *4*(3), 271-277. https://doi.org/10.1016/j.ijnss.2017.06.007

Alzubaidi, H., Mc Narmara, K., Kilmartin, G. M., Kilmartin, J. F., & Marriott, J. (2015). The relationships between illness and treatment perceptions with adherence to diabetes self-care: A comparison between Arabic-speaking migrants and Caucasian English-speaking patients. *Diabetes Research and Clinical Practice*, *110*(2), 208–217. https://doi.org/10.1016/j.diabres.2015.08.006

American Association of Kidney Patients (AAKP) (2022). *What is Hemodialysis and How Does it Work?* https://aakp.org/what-is-hemodialysis-and-how-does-it-work/

American Psychological Association (2019). *Journal Reporting Standards – Qualitative Research*. Retrieved from https://apastyle.apa.org/jars/qualitative

Andersen-Hollekim, T., Landstad, B. J., Solbjør, M., Kvangarsnes, M., & Hole, T. (2021). Nephrologists' experiences with patient participation when long-term dialysis is required. *BMC Nephrology*, *22*(1), 1–10. https://doi.org/10.1186/s12882-021-02261-w

Angel, R. & Williams, K. (2000). Cultural Models of Health and Illness (F.A. Paniagua & A. M. Yamada (Eds.).*Handbook of Multicultural Mental Health: Assessment and Treatment of Diverse Populations.* Academic Press. https://doi.org/10.1016/b978-012199370-2/50003-1

Angermeyer, M. C., Van Der Auwera, S., Carta, M. G., & Schomerus, G. (2017). Public attitudes towards psychiatry and psychiatric treatment at the beginning of the 21st century: a systematic review and meta-analysis of population surveys. *World Psychiatry*, *16*(1), 50-61. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5269489/

Anees, M., Hameed, F., Mumtaz, A., Ibrahim, M., & Khan, M. N. S. (2011). Dialysis-Related Factors Affecting Quality of Life in Patients on Hemodialysis. *Iranian Journal of Kidney Diseases*, *5*(1), 9–14.

Armay, Z., Özkan, M., Kocaman, N., & Özkan, S. (2007). Hastalık Algısı Ölçeği ' nin Kanser Hastalarında Türkçe Geçerlik ve Güvenirlik Çalışması. *Klinik Psikiyatri*, *10*, 192–200.

Arraras, J. I., Wright, S. J., Jusue, G., Tejedor, M., & Calvo, J. I. (2002). Coping style, locus of control, psychological distress and pain-related behaviours in cancer and other diseases. *Psychology, Health & Medicine*, *7*(2), 181-187.

Aromataris, E., & Pearson, A. (2014). The systematic review: an overview. *AJN The American Journal of Nursing*, *114*(3), 53-58.

Arbuckle, J. R. (2008). *The cultural contexts of Turkish Cypriot ethnic identity in contemporary north Cyprus* (Master dissertation, Purdue University). https://www.proquest.com/dissertations-theses/cultural-contexts-turkish-cypriot-ethnic-identity/docview/304501028/se-2?accountid=206344

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A. & Volmink, J (2008). Conducting a meta- ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology,* *8*(21). doi.org/10.1186/1471-2288-8-21

Aujla, N., Walker, M., Sprigg, N., Abrams, K., Massey, A., & Vedhara, K. (2016). Can illness beliefs, from the common-sense model, prospectively predict adherence to self-management behaviours? A systematic review and meta-analysis. *Psychology & Health*, *31*(8), 931-958. https://doi.org/10.1080/08870446.2016.1153640

Awwa, A., Ahmad, I., & Jallad, S. G. (2018). Prevalence of depression in Jordanian hemodialysis patients. *Iranian Journal of Psychiatry and Behavioral Sciences*, *12*(2). https://doi.org/10.5812/ijpbs.11286

Ayodele, O. E., & Alebiosu, C. O. (2010). Burden of chronic kidney disease: an international perspective. *Advances in Chronic Kidney Disease*, *17*(3), 215-224.

Axelrod, D. A., Schnitzler, M. A., Xiao, H., Irish, W., Tuttle-Newhall, E., Chang, S. H., ... & Lentine, K. L. (2018). An economic assessment of contemporary kidney transplant practice. *American Journal of Transplantation*, *18*(5), 1168-1176. https://doi.org/10.1111/ajt.14702

Bach, K. E., Kelly, J. T., Palmer, S. C., Khalesi, S., Strippoli, G. F., & Campbell, K. L. (2019). Healthy dietary patterns and incidence of CKD: a meta-analysis of cohort studies. *Clinical Journal of the American Society of Nephrology*, *14*(10), 1441-1449. https://doi.org/10.2215/CJN.00530119

Bailey, G., & Peoples, J. (1998). *Introduction to Cultural Anthropology*. Wadsworth Publishing

Bailey, P. K., Hamilton, A. J., Clissold, R. L., Inward, C. D., Caskey, F. J., Ben-Shlomo, Y., & Owen-Smith, A. (2018). Young adults' perspectives on living with kidney failure: A systematic review and thematic synthesis of qualitative studies. *BMJ Open*, *8*(1). https://doi.org/10.1136/bmjopen-2017-019926

Bakewell, A. B., Higgins, R. M., & Edmunds, M. E. (2002). Quality of life in peritoneal dialysis patients: Decline over time and association with clinical outcomes. *Kidney International*, *61*(1), 239–248. http://doi.org/10.1046/j.1523-1755.2002.00096.x

Bame, S. I., Petersen, N., & Wray, N. P. (1993). Variation in hemodialysis patient compliance according to demographic characteristics. *Social Science & Medicine*, *37*(8), 1035-1043.

Barrett, B. J., Vavasour, H. M., Major, A., & Parfrey, P. S. (1990). Clinical and psychological correlates of somatic symptoms in patients on dialysis. *Nephron*, *55*(1), 10-15.

Barnett-Page, E., & Thomas, J. (2009). Qualitative synthesis methods. *BMC Medical Research Methodology*, *9*(1), 1–26. https://doi.org/10.1186/1471-2288-9-59

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, *380*(9836), 37-43.

Basaran, D., Sahin Altun, Ö., Kaban, F., & Ecder, T. (2016). Hemodiyaliz Hastalarının Umutsuzluk Düzeylerinin Değerlendirilmesi. *Nefroloji Hemsireligi Dergisi*, *1*, 9–16.

Baumann, L.C. (2003). Culture and illness representation. In L. Cameron and H. Leventhal (eds). In the *Self-Regulation of Health and Illness Behaviour*. Taylor & Francis https://doi.org/10.4324/9780203553220

Barroso, J., Gollop, C. J., Sandelowski, M., Meynell, J., Pearce, P. F., & Collins, L. J. (2003). The challenges of searching for and retrieving qualitative studies. *Western Journal of Nursing Research, 25*(2), 153-178.

Bates, M. S., Rankin-Hill, L., & Sanchez-Ayendez, M. (1997). The effects of the cultural context of health care on treatment of and response to chronic pain and illness. *Social Science & Medicine*, *45*(9), 1433-1447. doi: 10.1016/S0277-9536(97)00068-3

Bean, D., Cundy, T., & Petrie, K. J. (2007). Ethnic differences in illness perceptions, self-efficacy and diabetes self-care. *Psychology and Health*, *22*(7), 787–811. https://doi.org/10.1080/14768320600976240

Becker, M. H. (1974). The health belief model and sick role behavior. *Health Education Monographs*, *2*(4), 409-419. https://doi.org/10.1177/109019817400200407

Beerendrakumar, N., Ramamoorthy, L., & Haridasan, S. (2018). Dietary and fluid regime adherence in chronic kidney disease patients. *Journal of Caring Sciences, 7*(1), 17. https://doi.org/10.15171/jcs.2018.003

Beiser, M., & Fleming, J. A. (1986). Measuring psychiatric disorder among Southeast Asian refugees. *Psychological Medicine*, *16*(3), 627-639. https://doi.org/10.1017/s0033291700010382

Belasco, A., Barbosa, D., Bettencourt, A. R., Diccini, S., & Sesso, R. (2006). Quality of life

of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *American Journal of Kidney Diseases*, *48*(6), 955-963. https://doi.org/10.1053/j.ajkd.2006.08.017

Bentley, R. A., & O'brien, M. J. (2011). The selectivity of social learning and the tempo of cultural evolution. *Journal of Evolutionary Psychology, 9*(2), 125-141.

Bethesda, M. (2007). US Renal Data System: USRDS 2007 Annual Data Report. *Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases*.

Bianchi, A., Biffignandi, S., & Lynn, P. (2017). Web-face-to-face mixed-mode design in a longitudinal survey: effects on participation rates, sample composition, and costs. *Journal of Official Statistics*, *33*(2), 385-408. https://doi.org/10.1515/jos-2017-0019

Bikbov, B., Purcell, C. A., Levey, A. S., Smith, M., Abdoli, A., Abebe, M., ... & Owolabi, M. O. (2020). Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, *395*(10225), 709-733.

Bishop, G. D. (1991). Understanding the understanding of illness: Lay disease representations. In *Mental Representation in Health and Illness* (pp. 32-59). Springer. https://doi.org/10.1007/978-1-4613-9074-9_3

Birukou, A., Blanzieri, E., Giorgini, P., & Giunchiglia, F. (2013). A formal definition of culture. In *Models for intercultural collaboration and negotiation* (pp. 1-26). Springer, Dordrecht.

Blais, R. K., & Renshaw, K. D. (2012). The association of biological and psychological attributions for depression with social support seeking intentions in individuals with depressive symptoms. *Behavioural and Cognitive Psychotherapy, 40*(5), 605–617. https://doi.org/10.1017/S1352465812000355

Brady, B. A., Tucker, C. M., Alfino, P. A., Tarrant, D. G., & Finlayson, G. C. (1997). An investigation of factors associated with fluid adherence among hemodialysis patients: a self-efficacy theory based approach. *Annals of Behavioral Medicine*, *19*(4), 339-343.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V. & Clarke, V. (2012) Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds), *APA handbook of research methods in psychology, Vol. 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57-71). Washington, DC: American Psychological Association.

Braun, V., & Clarke, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*(2).

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, *9*, 9–10. https://doi.org/10.3402/qhw.v9.26152

Braun, V., & Clarke, V. (2019a). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201-216. DOI: 10.1080/2159676X.2019.1704846

Braun, V., & Clarke, V. (2019b). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597.

Braun, V., & Clarke, V. (2020). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37-47. DOI: 10.1002/capr.12360

Braun, V., & Clarke, V. (2021). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*. http://dx.doi.org/10.1037/qup0000196

Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, *60*(6), 631–637. https://doi.org/10.1016/j.jpsychores.2005.10.020

Broadbent, E., Kaptein, A. A., & Petrie, K. J. (2011). Double Dutch: The 'think-aloud' Brief IPQ study uses a Dutch translation with confusing wording and the wrong instructions. *British Journal of Health Psychology, 16*, 246–249.

Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. *Psychology and Health*, *30*(11), 1361–1385. https://doi.org/10.1080/08870446.2015.1070851

Broadbent, E., Schoones, J. W., Tiemensma, J., & Kaptein, A. A. (2018). A systematic review of patients' drawing of illness: implications for research using the Common Sense Model. *Health Psychology Review*, *7199*. https://doi.org/10.1080/17437199.2018.1558088

Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology, *Psychology and Health, 21*:1, 87-108, DOI: 10.1080/14768320500230185

Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 34-52.

Brown, M., Gilbert, E., Calderwood, L., Taylor, K. and Morgan, H. (2019) Collecting biomedical and social data in a longitudinal survey: A comparison of two approaches, *Longitudinal and Life Course Studies, 10*(4): 453–69. doi: 10.1332/175795919X15 694156772013

Brownlee, S., Leventhal, H., & Leventhal, E.A. (2000). Regulation, self-regulation, and construction of the self in the maintenance of physical health. In M. Boekaerts, P.R. Pintrich, & M. Zeidner (Eds.), *Handbook of Self-Regulation*. Academic Press

Brophy, D. F., & Mueller, B. A. (1997). Automated peritoneal dialysis: new implications for pharmacists. *Annals of Pharmacotherapy*, *31*(6), 756-764.

Bronas, U. G., Puzantian, H., & Hannan, M. (2017). Cognitive impairment in chronic kidney disease: Vascular milieu and the potential therapeutic role of exercise. *BioMed Research International*, *2017*(Mci). http://doi.org/10.1155/2017/2726369

Bruck, K., Stel, V. S., Gambaro, G., Hallan, S., Volzke, H., Arnlo v, J., … Stojceva-Taneva, O. (2016). CKD Prevalence Varies across the European General Population. *Journal of the American Society of Nephrology*, *27*(7), 2135–2147. http://doi.org/10.1681/ASN.2015050542

Brzoska, P., Yilmaz-Aslan, Y., Sultanoglu, E., Sultanoglu, B., & Razum, O. (2012). The factor structure of the Turkish version of the Revised Illness Perception Questionnaire (IPQ-R) in patients with diabetes and cardiovascular disease. *BMC Public Health*, *12*(1). https://doi.org/10.1186/1471-2458-12-852

Bonsaksen, T., Lerdal, A., & Fagermoen, M.S. (2015). Trajectories of illness perceptions in persons with chronic illness: An explorative longitudinal study. *Journal of Health Psychology*, *20*(7), 942-953.

Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: a structured methodological review. *Systematic Reviews, 5*(1), 74. doi.org/10.1186/s13643-016-0249-x

Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., van der Wilt, G. J., Mozygemba, K., Refolo, P., Sacchini, D., Tummers, M., & Rehfuess, E. (2018). Structured methodology review identified seven (RETREAT) criteria for selecting

qualitative evidence synthesis approaches. *Journal of Clinical Epidemiology, 99*, 41-52. https://doi.org/10.1016/j.jclinepi.2018.03.003

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and Code Development*. SAGE

Boyd, R., & Richerson, P. J. (2005). *The Origin and Evolution of Cultures*. Oxford University Press.

Böger, C. A., Gorski, M., Li, M., Hoffmann, M. M., Huang, C., Yang, Q., ... & Wichmann, H. E. (2011). Association of eGFR-related loci identified by GWAS with incident CKD and ESRD. *PLoS genetics*, *7*(9), e1002292.

Buemi, M., Bruno, A., Cordova, F., Currò, V., Di Mauro, E., Santoro, D., ... & Zoccali, R. A. (2018). Negative emotions in end-stage renal disease: are anxiety symptoms related to levels of circulating catecholamines?. *Current Psychology*, 1-7. https://doi.org/10.1007/s12144-018-9796-8.

Bujang, M. A., Musa, R., Liu, W. J., Chew, T. F., Lim, C. T. S., & Morad, Z. (2015). Depression, anxiety and stress among patients with dialysis and the association with quality of life. *Asian Journal of Psychiatry*, *18*, 49–52. http://doi.org/10.1016/j.ajp.2015.10.004

Cabrera, V. J., Hansson, J., Kliger, A. S., & Finkelstein, F. O. (2017). Symptom management of the patient with CKD: the role of dialysis. *Clinical Journal of the American Society of Nephrology*, *12*(4), 687-693.

Cameron, L., Leventhal, E. A., & Leventhal, H. (1993). Symptom representations and affect as determinants of care seeking in a community-dwelling, adult sample population. *Health Psychology*, *12*(3), 171. https://doi.org/10.1037/0278-6133.12.3.171

Cameron L. & Leventhal, H. (2003). Self-regulation, health, and illness. In L. Cameron and H. Leventhal (eds). In the *Self-Regulation of Health and Illness Behaviour*. Taylor & Francis https://doi.org/10.4324/9780203553220

Campbell, K. L., Johnson, D. W., Bauer, J. D., Hawley, C. M., Isbel, N. M., Stowasser, M., … McMahon, E. (2014). A randomized trial of sodium-restriction on kidney function, fluid volume and adipokines in CKD patients. *BMC Nephrology*, *15*(1), 1–6. http://doi.org/10.1186/1471-2369-15-57

Carey, M., & Burdett, T. (2020). Exploring healthcare professionals' perspectives on the integration of diabetes and mental healthcare: A systematic literature review. *Journal of Diabetes Nursing, 24*(6), 1–6.

Cha, J. (2018). The impact of physical, psychological, social factors on illness burden of long-term hemodialysis patients in South Korea. *Journal of Health Informatics and Statistics, 43*(3), 159-166.

Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., &Wallace, E. (1993). Development of a fatigue scale. *Journal of Psychosomatic Research, 37*, 147–153. https://doi. org/10.1016/0022-3999(93)90081-P

Chang, C.K., Hayes, R.D., Perera, G., Broadbent, M.T., Fernandes, A.C., Lee, W.E., Hotopf, M. & Stewart, R. (2011) Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care register in London. *Public Library of Science One, 6*(5), e19590. https://doi.org/10.1371/journal.prone.0019590

Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases*, *40*(5), 373-383.

Calvin, D. J., Grumbach, G., Dancy, L. B., Bettina Tahsin, R. D., Fogelfeld, L., Mehrotra, R., & Mehrotra, N. (2019). Illness Perceptions of African-Americans with Chronic Kidney Disease. *Interventions*, *30*(1).

Carminati, L. (2018). Generalizability in qualitative research: A tale of two traditions. *Qualitative Health Research*, *28*(13), 2094-2101. https://doi.org/10.1177/1049732318788379

Caruana, E.J., Roman, M., Hernández- Sánchez, J., & Solli, P. (2015). Longitudinal studies. *Journal of Thoracic Disease, 7*(11):E537-E540. doi: 10.3978/j.issn.2072-1439.2015.10.63

Cavanaugh, C., & Perazella, M. A. (2019). Urine sediment examination in the diagnosis and management of kidney disease: core curriculum 2019. *American Journal of Kidney Diseases*, *73*(2), 258-272. https://doi.org/10.1053/j.ajkd.2018.07.012

Critical Appraisal Skills Programme (CASP) (2018). CASP (Qualitative) Checklist. [online] Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf

Centers for Medicare and Medicaid Services (2007). Annual Report, End Stage Renal Disease Clinical Performance Measures Project. Baltimore, MD: Department of Health and Human Services, Centers for Medicare & Medicaid Services, *Office of Clinical Standards of Quality.*

Cervantes, L., Fischer, S., Berlinger, N., Zabalaga, M., Camacho, C., Linas, S., & Ortega, D. (2017). The Illness Experience of Undocumented Immigrants With End-stage Renal Disease. *JAMA Internal Medicine*, *177*(4), 529–535. https://doi.org/10.1001/jamainternmed.2016.8865

Cervantes, L., Zoucha, J., Jones, J., & Fischer, S. (2016). Experiences and Values of Latinos with End Stage Renal Disease: A Systematic Review of Qualitative Studies. *Nephrology Nursing Journal*, *43*(6), 479–495.

Chan, M. R., Dall, A. T., Fletcher, K. E., Lu, N., & Trivedi, H. (2007). Outcomes in patients with chronic kidney disease referred late to nephrologists: a meta-analysis. *The American Journal of Medicine*, *120*(12), 1063-1070.

Chan, R., Brooks, R., Erlich, J., Chow, J., & Suranyi, M. (2009). The effects of kidney-disease-related loss on long-term dialysis patients' depression and quality of life: positive affect as a mediator. *Clinical Journal of the American Society of Nephrology*, *4*(1), 160-167.

Chang, V. T., Hwang, S. S., Feuerman, M., & Kasimis, B. S. (2000). Symptom and quality of life survey of medical oncology patients at a veterans affairs medical center: a role for symptom assessment. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *88*(5), 1175-1183.

Chen, C.-K., Tsai, Y.-C., Hsu, H.-J., Wu, I.-W., Sun, C.-Y., Chou, C.-C., … Wang, L.-J. (2010). Depression and Suicide Risk in Hemodialysis Patients With Chronic Renal Failure. *Psychosomatics*, *51*(6), 528–528.e6. http://doi.org/10.1016/S0033-3182(10)70747-7

Chen, S. L., Tsai, J. C., & Lee, W. L. (2008). Psychometric validation of the Chinese version of the Illness Perception Questionnaire-Revised for patients with hypertension. *Journal of Advanced Nursing*, *64*(5), 524–534. https://doi.org/10.1111/j.1365-2648.2008.04808.x

Chen, C. S., Chan, S. W. C., Chan, M. F., Yap, S. F., Wang, W., & Kowitlawakul, Y. (2017). Nurses' perceptions of psychosocial care and barriers to its provision: A Qualitative Study. *Journal of Nursing Research, 25*(6), 411–418. https://doi.org/10.1097/JNR.0000000000000185

Chiaranai, C. (2016). The Lived Experience of Patients Receiving Hemodialysis Treatment for End-Stage Renal Disease: A Qualitative Study. *Journal of Nursing Research*, *24*(2), 101–108. https://doi.org/10.1097/jnr.0000000000000100

Chilcot, J., Wellsted, D., Vilar, E., & Farrington, K. (2009). An association between residual

renal function and depression symptoms in haemodialysis patients. *Nephron Clinical Practice*, *113*(2), c117-c124.

Chilcot, J.J. (2010). *Studies of depression and illness representations in end-stage renal disease* (doctorate thesis). University of Hertfordshire, Hertfordshire, England.

Chilcot, J., Wellsted, D., Davenport, A., & Farrington, K. (2011a). Illness representations and concurrent depression symptoms in haemodialysis patients. *Journal of Health Psychology*, *16*(7), 1127–1137. https://doi.org/10.1177/1359105311401672

Chilcot, J., Wellsted, D., & Farrington, K. (2011b). Illness perceptions predict survival in haemodialysis patients. *American Journal of Nephrology*, *33*(4), 358–363. https://doi.org/10.1159/000326752

Chilcot, J. (2012). The importance of illness perception in end-stage renal disease: Associations with psychosocial and clinical outcomes. *Seminars in Dialysis*, *25*(1), 59–64. https://doi.org/10.1111/j.1525-139X.2011.00987.x

Chilcot, J., Norton, S., Wellsted, D., Davenport, A., Firth, J., & Farrington, K. (2013). Distinct depression symptom trajectories over the first year of dialysis: Associations with illness perceptions. *Annals of Behavioral Medicine*, *45*(1), 78–88. https://doi.org/10.1007/s12160-012-9410-5

Chilcot, J., Moss-Morris, R., Artom, M., Harden, L., Picariello, F., Hughes, H., … Macdougall, I. C. (2017). Correction to: Psychosocial and Clinical Correlates of Fatigue in Haemodialysis Patients: the Importance of Patients' Illness Cognitions and Behaviours (International Journal of Behavioural Medicine, 23, 3, (271-281), 10.1007/s12529-015-9525-8). *International Journal of Behavioral Medicine*, *24*(6), 958. https://doi.org/10.1007/s12529-017-9692-x

Chilcot, J., Guirguis, A., Friedli, K., Almond, M., Day, C., Silva-Gane, M. Da, … Farrington, K. (2018a). Depression symptoms in haemodialysis patients predict all-cause mortality but not kidney transplantation: A cause-specific outcome analysis. *Annals of Behavioral Medicine, 52*(1), 1–8. https://doi.org/10.1007/s12160-017-9918-9

Chilcot, J., Hudson, J. L., Moss-Morris, R., Carroll, A., Game, D., Simpson, A., & Hotopf, M. (2018b). Screening for psychological distress using the Patient Health Questionnaire Anxiety and Depression Scale (PHQ-ADS): Initial validation of structural validity in dialysis patients. *General Hospital Psychiatry*, *50*(September 2017), 15–19. http://doi.org/10.1016/j.genhosppsych.2017.09.007

Christensen, A. J., & Smith, T. W. (1995). Personality and patient adherence: correlates of the five-factor model in renal dialysis. *Journal of Behavioral Medicine*, *18*(3), 305-313.

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*(3), 712–724. https://doi.org/10.1037/0022-006X.70.3.712

Chronic Kidney Disease Prognosis Consortium. (2010). Association of estimated glomerular filtration rate and albuminuria with all-cause and cardiovascular mortality in general population cohorts: a collaborative meta-analysis. *The Lancet*, *375*(9731), 2073-2081.

Chuasuwan, A., Pooripussarakul, S., Thakkinstian, A., Ingsathit, A., & Pattanaprateep, O. (2020). Comparisons of quality of life between patients underwent peritoneal dialysis and hemodialysis: a systematic review and meta-analysis. *Health and Quality of Life Outcomes*, *18*(1), 1-11. https://doi.org/10.1186/s12955-020-01449-2

Chung, I. (2010). Changes in the sociocultural reality of Chinese immigrants: Challenges and opportunities in help-seeking behaviour. *International Journal of Social Psychiatry*, *56*(4), 436-447. https://doi.org/10.1177/0020764009105647

Clarke, A. L., Yates, T., Smith, A. C., & Chilcot, J. (2016). Patient's perceptions of chronic kidney disease and their association with psychosocial and clinical outcomes: A

narrative review. *Clinical Kidney Journal*, *9*(3), 494–502.
https://doi.org/10.1093/ckj/sfw014

Cohen, S. D., Cukor, D., & Kimmel, P. L. (2016). Anxiety in patients treated with hemodialysis. *Clinical Journal of the American Society of Nephrology*, *11*(12), 2250-2255. Retrieved from http://europepmc.org/ articles/pmc5142059.

Collins, A. J., Li, S., Gilbertson, D. T., Liu, J., Chen, S. C., & Herzog, C. A. (2003). Chronic kidney disease and cardiovascular disease in the Medicare population: Management of comorbidities in kidney disease in the 21st century: Anemia and bone disease. *Kidney International*, *64*, S24-S31.

Connor, T. M. F., Oygar, D. D., Gale, D. P., Steenkamp, R., Nitsch, D., Neild, G. H., & Maxwell, P. H. (2013). Incidence of End-Stage Renal Disease in the Turkish-Cypriot Population of Northern Cyprus: A Population Based Study. *PLoS ONE*, *8*(1), 1–7. http://doi.org/10.1371/journal.pone.0054394

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435–1443. https://doi.org/10.1177/1049732312452938

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rusch, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric Services (Washington, D.C.), 63*(10), 963–973. https://doi.org/10.1176/appi.ps.201100529

Couper, M. P. and Ofstedal, M. B. (2006). Keeping in contact with mobile sample members. Paper presented at the Methodology of Longitudinal Survey. http://iser.essex.ac.uk/ulsc/mols2006/programme/details.php

Cosio, F. G., Alamir, A., Yim, S., Pesavento, T. E., Falkenhain, M. E., Henry, M. L., ... & Ferguson, R. M. (1998). Patient survival after renal transplantation: I. The impact of dialysis pre-transplant. *Kidney International*, *53*(3), 767-772.

Covic, A., Seica, A., Gusbeth-Tatomir, P., Gavrilovici, O., & Goldsmith, D. J. A. (2004). Illness representations and quality of life scores in haemodialysis patients. *Nephrology Dialysis Transplantation*, *19*(8), 2078–2083. https://doi.org/10.1093/ndt/gfh254

Covic, A., Seica, A., Mardare, N., & Gusbeth-Tatomir, P. (2006). A longitudinal study on changes in quality of life and illness representations in long-term hemodialysis patients with low comorbidity. *Medica–A Journal of Clinical Medicine*, *1*(4), 12-19.

Cox, K. J., Parshall, M. B., Hernandez, S. H. A., Parvez, S. Z., & Unruh, M. L. (2017). Symptoms among patients receiving in-center hemodial- ysis: A qualitative study. Hemodialysis International, 21(4), 524–533. https://doi.org/10.1111/hdi.12521

Creswell, J. W. (2015). *A Concise Introduction to Mixed Methods Research.* Sage publications.

Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and Conducting Mixed Methods Research*. Sage publications.

Cruz, J. P., Colet, P. C., Qubeilat, H., Al-Otaibi, J., Coronel, E. I., & Suminta, R. C. (2016). Religiosity and health-related quality of life: a cross-sectional study on Filipino Christian hemodialysis patients. *Journal of Religion and Health*, *55*(3), 895-908. https://doi.org/10.1007/s10943-015-0103-9

Cueto-Manzano, A. M., Martinez-Ramirez, H. R., & Cortés-Sanabria, L. (2010). Management of chronic kidney disease: primary health-care setting, self-care and multidisciplinary approach. *Clinical Nephrology*, *74*, S99-104.

Cukor, D., Peterson, R. A., Cohen, S. D., & Kimmel, P. L. (2006). Depression in end-stage renal disease hemodialysis patients. *Nature Clinical Practice Nephrology*, *2*(12), 678-687.

Cukor, D., Coplan, J., Brown, C., Peterson, R. A., & Kimmel, P. L. (2008). Course of

depression and anxiety diagnosis in patients treated with hemodialysis: a 16-month follow-up. *Clinical Journal of the American Society of Nephrology*, *3*(6), 1752-1758.

Curran, P. J. (2003). Have Multilevel Models Been Structural Equation Models All Along ? *Multivariate Behavioral Research*, *38*(4), 529–569. https://doi.org/10.1207/s15327906mbr3804

Curran, P. J., Obeidat, K., & Losardo, D. (2010). Twelve Frequently Asked Questions About Growth Curve Modeling. *Journal of Cognitive Development*, *11*(2), 121–136. https://doi.org/10.1080/15248371003699969.Twelve

Curry, L. A., Nembhard, I. M., & Bradley, E. H. (2009). Qualitative and mixed methods provide unique contributions to outcomes research. *Circulation*, *119*(10), 1442–1452. https://doi.org/10.1161/CIRCULATIONAHA.107.742775

Cupisti, A., Brunori, G., Di Iorio, B. R., D'Alessandro, C., Pasticci, F., Cosola, C., ... & Gesualdo, L. (2018). Nutritional treatment of advanced CKD: twenty consensus statements. *Journal of Nephrology*, *31*(4), 457-473. https://doi.org/10.1007/s40620-018-0497-z

Curtin, R. B., Bultman, D. C., Thomas-Hawkins, C., Walters, B. A., & Schatell, D. (2002). Hemodialysis patients' symptom experiences: effects on physical and mental functioning. *Nephrology Nursing Journal*, *29*(6), 562-574.

Curtis, J.J. (1992). Hypertension and kidney transplantation. *Current Opinion in Nephrology and Hypertension, 1,* 100–105.

Çıldır, E., Bulut, M., Akalın, H., Kocabaş, E., Ocakoğlu, G., & Aydın, Ş. A. (2013). Evaluation of the modified MEDS, MEWS score and Charlson comorbidity index in patients with community acquired sepsis in the emergency department. *Internal and Emergency Medicine*, *8*(3), 255-260.

Daly, J., Willis, K., Small, R., Green, J., Welch, N., Kealy, M., & Hughes, E. (2007). A hierarchy of evidence for assessing qualitative health research. *Journal of Clinical Epidemiology*, *60*(1), 43-49.

Damman, W., Liu, R., Kaptein, A. A., Evers, A. W., van Middendorp, H., Rosendaal, F. R., & Kloppenburg, M. (2018). Illness perceptions and their association with 2 year functional status and change in patients with hand osteoarthritis. *Rheumatology*, *57*(12), 2190-2199.

Das, S., Mia, M. N., Hanifi, S. M. A., Hoque, S., & Bhuiya, A. (2017). Health literacy in a community with low levels of education: findings from Chakaria, a rural area of Bangladesh. *BMC Public Health*, *17*(1), 1-10. https://doi.org/10.1186/s12889-017-4097-y

Davison, S. N., & Jhangri, G. S. (2005). The impact of chronic pain on depression, sleep, and the desire to withdraw from dialysis in hemodialysis patients. *Journal of Pain and Symptom Management*, *30*(5), 465-473.

Davison, S. N., & Jhangri, G. S. (2010). Impact of Pain and Symptom Burden on the Health-Related Quality of Life of Hemodialysis Patients. *Journal of Pain and Symptom Management*, *39*(3), 477–485. https://doi.org/10.1016/j.jpainsymman.2009.08.008

De Groot, V., Beckerman, H., Lankhorst, G. J., & Bouter, L. M. (2003). How to measure comorbidity: a critical review of available methods. *Journal of Clinical Epidemiology*, *56*(3), 221-229.

De Goeij, M. C. M., Ocak, G., Rotmans, J. I., Eijgenraam, J. W., Dekker, F. W., & Halbesma, N. (2014). Course of symptoms and health-related quality of life during specialized pre-dialysis care. *PLoS ONE*, *9*(4). http://doi.org/10.1371/journal.pone.0093069

De las Cuevas, C., de Leon, J., Peñate, W., & Betancort, M. (2017). Factors influencing adherence to psychopharmacological medications in psychiatric patients: a structural equation modeling approach. *Patient Preference and Adherence*, *11*, 681.

Delmas, P., Cohen, C., Loiselle, M. C., Antonini, M., Pasquier, J., & Burnier, M. (2018). Symptoms and quality of life from patients undergoing hemodialysis in Switzerland. *Clinical nursing studies, 6(*2), 63-72.

Demiray Kara, D., Mert, E., Uysal, Y., & Başhan, İ. (2017). Evaluation of Medication Adherence in Adults Who Use Multiple Medications in The Context of Illness Perception, Acknowledgement and Attitude Characteristics. *Turkish Journal of Family Medicine and Primary Care*, *11*(4), 227–234. https://doi.org/10.21763/tjfmpc.359675

Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, *79*(6), 506-513. https://doi.org/10.1016/j.jpsychores.2015.10.006

De Nicola, L., & Zoccali, C. (2016). Chronic kidney disease prevalence in the general population: Heterogeneity and concerns. *Nephrology Dialysis Transplantation*, *31*(3), 331–335. http://doi.org/10.1093/ndt/gfv427

Denzin, N.K, & Lincoln, Y.S. (2000). The discipline and practice of qualitative research. In *Handbook of Qualitative Research*, N.K. Denzin and Y.S. Lincoln (eds). 1–28. Sage Publications

DePasquale, N., Cabacungan, A., Ephraim, P. L., Lewis-Boyér, L., Diamantidis, C. J., Powe, N. R., & Boulware, L. E. (2019). "I Wish Someone Had Told Me That Could Happen": A Thematic Analysis of Patients' Unexpected Experiences With End-Stage Kidney Disease Treatment. *Journal of Patient Experience*, 237437351987208. https://doi.org/10.1177/2374373519872088

Dinsa, G. D., Goryakin, Y., Fumagalli, E., & Suhrcke, M. (2012). Obesity and socioeconomic status in developing countries: a systematic review. *Obesity Reviews*, *13*(11), 1067-1079.

Dion, K. K. & Dion, K. L. (1993). Individualistic and collectivistic perspectives on gender and the cultural context of love and intimacy. *Journal of Social Issues, 49,* 53-69.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, *6*(1), 1-13.

Dobbles, F., Duerinckx, N., Breunig, C. &De Geest, S. (2019). What every renal nurse should know about depression. *Journal of Renal Nursing, 2*(1), 6–11. https://doi.org/10.12968/jorn.2010.2.1.46317

Dong, S. T., Butow, P. N., Agar, M., Lovell, M. R., Boyle, F., Stockler, M., … Tong, A. (2016). Clinicians' Perspectives on Managing Symptom Clusters in Advanced Cancer: A Semistructured Interview Study. *Journal of Pain and Symptom Management, 51*(4), 706-717.e5. https://doi.org/10.1016/j.jpainsymman.2015.11.021

Doyle, L., Brady, A. M., & Byrne, G. (2016). An overview of mixed methods research–revisited. *Journal of Research in Nursing*, *21*(8), 623-635. DOI: 10.1177/1744987116674257

Duncan, G. (2000). Mind-body dualism and the biopsychosocial model of pain: what did Descartes really say?. *The Journal of Medicine and Philosophy*, *25*(4), 485-513.

Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of Health Psychology*, *16*(2), 332–341. https://doi.org/10.1177/1359105310377537

Durie, M. H. (1994). Maori perspectives of health and illness. In J. Spicer, A. Trlin, and J. A. Walton (Eds.), *Social Dimensions of Health and Disease: New Zealand Perspectives* (pp. 194-203). Dunmore Press. Elliot,

Easterling, D. V., & Leventhal, H. (1989). Contribution of concrete cognition to emotion: Neutral symptoms as elicitors of worry about cancer. *Journal of Applied*

Psychology, *74*(5), 787. https://doi.org/10.1037/0021-9010.74.5.787

Ebefors, K., Lassén, E., Anandakrishnan, N., Azeloglu, E. U., & Daehn, I. S. (2021). Modeling the glomerular filtration barrier and intercellular crosstalk. *Frontiers in Physiology*, *12*, 772. https://doi.org/10.3389/fphys.2021.689083

Eckardt, K. U., Coresh, J., Devuyst, O., Johnson, R. J., Köttgen, A., Levey, A. S., & Levin, A. (2013). Evolving importance of kidney disease: from subspecialty to global health burden. *The Lancet*, *382*(9887), 158-169. https://doi.org/10.1016/S0140-6736(13)60439-0

Ekenler, Ş. (2017). *Kronik obstrüktif akciğer hastalarında hastalık algısı ve ilişkili faktörler* (Doctoral thesis), Selçuk Üniversitesi Sağlık Bilimleri Enstitüsü, Turkey.

El Nahas, A. M., & Bello, A. K. (2005). Chronic kidney disease: the global challenge. *The Lancet, 365*(9456), 331-340.

Engebretson, J. (2003). Cultural constructions of health and illness: Recent cultural changes toward a holistic approach. *Journal of Holistic Nursing*, *21*(3), 203-227.

Engelgau, M. M., El-Saharty, S., Kudesia, P., Rajan, V., Rosenhouse, S., & Okamoto, K. (Eds.). (2011). *Capitalizing on the demographic transition: tackling noncommunicable diseases in South Asia*. The World Bank.

ERA-EDTA Registry (2021). ERA-EDTA Registry Annual Report 2019 (updated Sep 7, 2021). https://www.era-online.org/registry/AnnRep2019.pdf

Estruch, R., Ros, E., Salas-Salvadó, J., Covas, M. I., Corella, D., Arós, F., ... & Lamuela-Raventos, R. M. (2013). Primary prevention of cardiovascular disease with a Mediterranean diet. *New England Journal of Medicine, 368*(14), 1279-1290.0

Falodia, J., & Singla, M. K. (2012). CKD epidemiology and risk factors. *Clinical Queries Nephrology*, *1*(4), 9–12. http://doi.org/10.1016/j.cqn.2012.09.004

Fan, L., Sarnak, M. J., Tighiouart, H., Drew, D. A., Kantor, A. L., Lou, K. V., ... & Weiner, D. E. (2014). Depression and all-cause mortality in hemodialysis patients. *American Journal of Nephrology, 40*(1), 12-18.

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 Diseases*, *63*(4), 623-635.

Feehally, J. (2005). Ethnicity and renal disease. *Kidney international*, *68*(1), 414-424.

Firat Kilic, H., & Kaptanogullari, H. (2017). A Bicommunal Study: Burden of Caregivers of Hemodialysis Patients. *International Journal of Caring Sciences,10*(3),1382-1390.

Fırat Kılıç, H., & Ecevit Alpar, Ş. (2016). The effect of group training implemented on hemodialysis patients for their stress management, psychosocial adjustment and self-care strength. *International Journal of Human Sciences, 13*(1), 755-766. https://doi.org/10.14687/ijhs.v13i1.3422

Fischer, M. J., Wiesenhaan, M. E., Heijer, A. D. D., Kleijn, W. C., Nortier, J. W., & Kaptein, A. A. (2013). From despair to hope: A longitudinal study of illness perceptions and coping in a psycho-educational group intervention for women with breast cancer. *British Journal of Health Psychology*, *18*(3), 526-545.

Flemming, K., & Noyes, J. (2021). Qualitative Evidence Synthesis: Where Are We at? *International Journal of Qualitative Methods*, *20*, 1–13. https://doi.org/10.1177/1609406921993276

Flythe, J. E., Dorough, A., Narendra, J. H., Forfang, D., Hartwell, L., & Abdel-Rahman, E. (2018). Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis. Nephrology Dialysis Transplantation, 33(10), 1842–1852. https://doi. org/10.1093/ndt/gfy069

Frazier, P. A., Davis-Ali, S. H., & Dahl, K. E. (1994). Correlates of noncompliance among renal transplant recipients. *Clinical Transplantation*, *8*(6), 550-557.

Franz, M., Lujić, C., Koch, E., Wüsten, B., Yürük, N., & Gallhofer, B. (2007). Subjektive Krankheitskonzepte türkischer Migranten mit psychischen Störungen-Besonderheiten im Vergleich zu deutschen Patienten. *Psychiatrische Praxis*, *34*(07), 332-338.

Freedman, B. I., Volkova, N. V., Satko, S. G., Krisher, J., Jurkovitz, C., Soucie, J. M., & McClellan, W. M. (2005). Population-based screening for family history of end-stage renal disease among incident dialysis patients. *American Journal of Nephrology*, *25*(6), 529-535.

French, D. P., & Weinman, J. (2008). Current issues and new directions in Psychology and Health: "Assessing illness perceptions: Beyond the IPQ." *Psychology and Health*, *23*(1), 5–9. https://doi.org/10.1080/08870440701616714

Friend, R., Hatchett, L., Wadhwa, N. K., & Suh, H. (1997). Serum albumin and depression in end-stage renal disease. *Advances in Peritoneal Dialysis*, *13*, 155-157.

Foley, R. N., Herzog, C. A., & Collins, A. J. (2003). Smoking and cardiovascular outcomes in dialysis patients: the United States Renal Data System Wave 2 study. *Kidney International*, *63*(4), 1462-1467. doi: 10.1046/j.1523-1755.2003.00860.x [PubMed: 12631362]

Folkman, S. (1984). Personal control and stress and coping processes. Journal of Personality and Social Psychology. 46.839- 852. https://doi.org/10.1177/1609406921993276

Foote, E. F., & Manley, H. J. (2008). Hemodialysis and peritoneal dialysis. *Pharmacotherapy: A Pathophysiologic Approach*, Oth103–17. http://doi.org/10.1002/9781444304183.ch31

Fortenberry, K. T., Berg, C. A., King, P. S., Stump, T., Butler, J. M., Pham, P. K., & Wiebe, D. J. (2014). Longitudinal trajectories of illness perceptions among adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, *39*(7), 687-696.

Fortin, M., Lapointe, L., Hudon, C., & Vanasse, A. (2005). Multimorbidity is common to family practice: is it commonly researched?. *Canadian Family Physician*, *51*(2), 244-245.

Fortin, M., Hudon, C., Haggerty, J., van den Akker, M., & Almirall, J. (2010). Prevalence estimates of multimorbidity: a comparative study of two sources. *BMC Health Services Research*, *10*(1), 111.

Frostholm, L., Oernboel, E., Christensen, K. S., Toft, T., Olesen, F., Weinman, J., & Fink, P. (2007). Do illness perceptions predict health outcomes in primary care patients? A 2-year follow-up study. *Journal of Psychosomatic Research*, *62*(2), 129–138. https://doi.org/10.1016/j.jpsychores.2006.09.003

Foxwell, R., Morley, C., & Frizelle, D. (2013). Illness perceptions, mood and quality of life: A systematic review of coronary heart disease patients. *Journal of Psychosomatic Research*, *75*(3), 211–222. https://doi.org/10.1016/j.jpsychores.2013.05.003

Fu, E., Coresh, J., Grams, M., M. Clase, C., Elinder, C. G., Paik, J., ... & Jesus Carrero, J. (2022). FC078: Impact of Removing Race from the CKD-EPI Equation: Analysis of 1.6 Million Swedish Adults. *Nephrology Dialysis Transplantation*, *37*(Supplement_3), gfac114-002. https://doi.org/10.1093/ndt/gfac114.002

Gale, D.P., Oygar, D.D., Lin, F., Oygar, P.D., Khan ,N., Connor, T.M., …, Neild, G.H. (2016). A novel COL4A1 frameshift mutation in familial kidney disease: the importance of the C-terminal NC1 domain of type IV collagen. *Nephrology, Dialysis and Transplantation, 31*(11), 1908-1914.

Gansevoort, R. T., Matsushita, K., Van Der Velde, M., Astor, B. C., Woodward, M., Levey, A. S., ... & Coresh, J. (2011). Lower estimated GFR and higher albuminuria are associated with adverse kidney outcomes. A collaborative meta-analysis of general and high-risk population cohorts. *Kidney International*, *80*(1), 93-104.

Gardner, D. G., Cummings, L. L., Dunham, R. B., & Pierce, J. L. (1998). Single-item versus

multiple-item measurement scales: An empirical comparison. *Educational and Psychological Measurement*, *58*(6), 898-915. https://doi.org/10.1177/0013164498058006003

Garofalo, C., Borrelli, S., Provenzano, M., De Stefano, T., Vita, C., Chiodini, P., ... & Conte, G. (2018). Dietary salt restriction in chronic kidney disease: a meta-analysis of randomized clinical trials. *Nutrients*, *10*(6), 732. doi:10.3390/nu10060732

Gebrie, M. H., & Ford, J. (2019). Depressive symptoms and dietary non-adherence among end stage renal disease patients undergoing hemodialysis therapy: systematic review. *BMC Nephrology, 20*(1), 1–7. https://doi.org/10.1186/s12882-019-1622-5

Gerogianni, G., Polikandrioti, M., Babatsikou, F., Zyga, S., Alikari, V., Vasilopoulos, G., … Grapsa, E. (2019). Anxiety–Depression of Dialysis Patients and Their Caregivers. *Medicina*, *55*(5), 168. https://doi.org/10.3390/medicina55050168

Ghane Shahrbaf, F., & Assadi, F. (2015). Drug-induced renal disorders. *Journal of Renal Injury Prevention*, *4*(3), 57–60. https://doi.org/10.12861/jrip.2015.12

Gibbons, C. J., Kenning, C., Coventry, P. A., Bee, P., Bundy, C., Fisher, L., & Bower, P. (2013). Development of a Multimorbidity Illness Perceptions Scale (MULTIPleS). *PLoS ONE*, *8*(12), 1–12. https://doi.org/10.1371/journal.pone.0081852

Gilbert, S.J., & Weiner, D., E. (2018). *National Kidney's Foundation's Primer on Kidney Diseases (*7th ed.). Philadelphia, PA (USA); Elsevier Inc.

Gilbert, S.J., & Weiner, D., E. (2018). *National Kidney's Foundation's Primer on Kidney Diseases (*7th ed.). Philadelphia, PA (USA); Elsevier Inc.

Goh, Z. S., & Griva, K. (2018). Anxiety and depression in patients with end-stage renal disease: impact and management challenges–a narrative review. *International Journal of Nephrology and Renovascular Disease*, *11*, 93. doi: 10.2147/IJNRD.S126615

Gomez, R. (1998). Locus of control and avoidant coping: Direct, interactional and mediational effects on maladjustment in adolescents. *Personality and Individual Differences*, *24*(3), 325-334.

Gough, D., Oliver, S., & Thomas, J. (2013). *Learning from research: Systematic reviews for informing policy decisions*. https://apo.org.au/sites/default/files/resource-files/2013-12/apo-nid71119.pdf

Gough, B., & Deatrick, J. A. (2015). Qualitative health psychology research: Diversity, power, and impact. *Health Psychology*, *34*(4), 289–292. https://doi.org/10.1037/hea0000206

Goyal, E., Chaudhury, S., & Saldanha, D. (2018). Psychiatric comorbidity in patients undergoing hemodialysis. *Industrial Psychiatry Journal*, *27*(2), 206. doi: 10.4103/ipj.ipj_5_18

Grams, M. E., Coresh, J., Segev, D. L., Kucirka, L. M., Tighiouart, H., & Sarnak, M. J. (2012). Vascular disease, ESRD, and death: interpreting competing risk analyses. *Clinical Journal of the American Society of Nephrology*, *7*(10), 1606-1614. doi: 10.2215/CJN.03460412 [PubMed: 22859747]

Griva, K., Jayasena, D., Davenport, A., Harrison, M., & Newman, S. P. (2009). Illness and treatment cognitions and health related quality of life in end stage renal disease. *British Journal of Health Psychology*, *14*(1), 17-34.

Griva, K., Davenport, A., Harrison, M., & Newman, S. (2010). An evaluation of illness, treatment perceptions, and depression in hospital- vs. home-based dialysis modalities. *Journal of Psychosomatic Research*, *69*(4), 363–370. https://doi.org/10.1016/j.jpsychores.2010.04.008

Griva, K., Ng, H. J., Loei, J., Mooppil, N., McBain, H., & Newman, S. P. (2013). Managing treatment for end-stage renal disease - A qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychology and Health,*

28(1), 13–29. https://doi.org/10.1080/08870446.2012.703670

Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2005). The impact of illness representations and disease activity on adjustment in women with rheumatoid arthritis: A longitudinal study. *Psychology & Health*, *20*(5), 597-613.

Gullion, C. M., Keith, D. S., Nichols, G. A., & Smith, D. H. (2006). Impact of Comorbidities on Mortality in Managed Care Patients With CKD. *American Journal of Kidney Diseases*, *48*(2), 212–220. http://doi.org/10.1053/j.ajkd.2006.04.083

Gunzler, D., Chen, T., Wu, P., & Zhang, H. (2013). Introduction to mediation analysis with structural equation modeling. *Shanghai Archives of Psychiatry*, *25*(6), 390–394. https://doi.org/10.3969/j.issn.1002-0829.2013.06.009

Güner, P., Hiçdurmaz, D., Kocaman Yıldırım, N., & İnci, F. (2018). Psychosocial care from the perspective of nurses working in oncology: A qualitative study. *European Journal of Oncology Nursing, 34*(4), 68–75. https://doi.org/10.1016/j.ejon.2018.03.005

Haftanin Potresi: Dr Duriye Deren Oygar (2011, January 31). *Haber Kibris*. Retrieved from https://haberkibris.com/haftanin-portresi-dr.-duriye-deren-oygar-2011-01-31.html

Hagey, R. (1984). The phenomenon, the explanations and the responses: metaphors surrounding diabetes in urban Canadian Indians. *Social Science & Medicine*, *18*(3), 265-272. https://doi.org/10.1016/0277-9536(84)90089-3

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, *18*(2), 141–184. https://doi.org/10.1080/088704403100081321

Hagren, B., Pettersen, I. M., Severinsson, E., Lützén, K., & Clyne, N. (2001). The haemodialysis machine as a lifeline: Experiences of suffering from end-stage renal disease. *Journal of Advanced Nursing*, *34*(2), 196-202.

Hailpern, S. M., Melamed, M. L., Cohen, H. W., & Hostetter, T. H. (2007). Moderate chronic kidney disease and cognitive function in adults 20 to 59 years of age: Third National Health and Nutrition Examination Survey (NHANES III). *Journal of the American Society of Nephrology*, *18*(7), 2205-2213.

Hajmohammadi, R., & Shirazi, M. (2017). Predicting resilience via social support and illness perceptions among patients undergoing Hemodialysis. *Jundishapur Journal of Chronic Disease Care*, *6*(3).

Hale, E. D., Treharne, G. J., & Kitas, G. D. (2007). The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?. *Rheumatology*, *46*(6), 904-906. https://doi.org/10.1093/rheumatology/kem060

Hall, S. F. (2006). A user's guide to selecting a comorbidity index for clinical research. *Journal of Clinical Epidemiology*, *59*(8), 849-855.

Hansen, M. C., & Cabassa, L. J. (2012). Pathways to depression care: Help-seeking experiences of low-income Latinos with diabetes and depression. *Journal of Immigrant and Minority Health, 14*(6), 1097–1106. https://doi.org/10.1007/s10903-012-9590-x

Hansen, M. S., Tesfaye, W., Sud, K., Sewlal, B., Mehta, B., Kairaitis, L., ... & Castelino, R. (2022). Psychosocial factors in patients with kidney failure and role for social worker: A secondary data audit. *Journal of Renal Care*. https://doi.org/10.1111/jorc.12424

Hariharan, S., McBride, M. A., Cherikh, W. S., Tolleris, C. B., Bresnahan, B. A., & Johnson, C. P. (2002). Post-transplant renal function in the first year predicts long-term kidney transplant survival. *Kidney International*, *62*(1), 311–318. http://doi.org/10.1046/j.1523-1755.2002.00424.x

Harris, M. (1975). *Culture, people, nature: An introduction to General Anthropology*. New York: Thomas Y. Crowell.

Hayes, A. F., & Rockwood, N. J. (2017). Regression-based statistical mediation and moderation analysis in clinical research: Observations, recommendations, and implementation. *Behaviour Research and Therapy*, *98*, 39–57. https://doi.org/10.1016/j.brat.2016.11.001

Hedayati SS, Bosworth HB, Briley LP, et al. Death or hospitalization of patients on chronic hemodialysis is associated with a physician-based diagnosis of depression. Kidney Int. 2008;74(7):930–936.

Heerspink, H. J. L., Holtkamp, F. A., Parving, H. H., Navis, G. J., Lewis, J. B., Ritz, E., … De Zeeuw, D. (2012). Moderation of dietary sodium potentiates the renal and cardiovascular protective effects of angiotensin receptor blockers. *Kidney International*, *82*(3), 330–337. http://doi.org/10.1038/ki.2012.74

Heine, M., Lategan, F., Erasmus, M., Lombaard, C. M., Mc Carthy, N., Olivier, J., ... & Hanekom, S. (2021). Health education interventions to promote health literacy in adults with selected non-communicable diseases living in low-to-middle income countries: A systematic review and meta-analysis. *Journal of Evaluation in Clinical Practice*. 27, 1417–1428. DOI: 10.1111/jep.13554

Helman C.G. (1990). *Culture, Health and Illness* (2nd ed). Butterwoth Heinemann https://doi.org/10.1016/B978-0-7236-1991-8.50012-7

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioral and Brain Sciences*, *33*(2–3), 61–83. https://doi.org/10.1017/S0140525X0999152X

Hemmelgarn, B. R., Zhang, J., Manns, B. J., Tonelli, M., Larsen, E., Ghali, W. A., ... & Culleton, B. F. (2006). Progression of kidney dysfunction in the community-dwelling elderly. *Kidney International*, *69*(12), 2155-2161.

Heredia Montesinos, A., Rapp, M., Temur-Erman, S., Heinz, A., Hegerl, U., & Schouler-Ocak, M. (2012). The influence of stigma on depression, overall psychological distress, and somatization among female Turkish migrants. European Psychiatry, 27(S2), S22-S26. doi:10.1016/S0924-9338(12)75704-8

Heyvaert, M., Hannes, K., & Onghena, P. (2016) *Using mixed methods research synthesis for literature reviews: the mixed methods research synthesis approach.* (pp.185-192) Sage Publications

Higgings, J. P. T., & Green, S. (2011). Cochrane handbook for systematic reviews of interventions. *Cochrane Handbook for Systematic Reviews of Interventions. Version*, *5*.

Hill, N. R., Fatoba, S. T., Oke, J. L., Hirst, J. A., Callaghan, A. O., Lasserson, D. S., & Hobbs, F. D. R. (2016). Global Prevalence of Chronic Kidney Disease – A Systematic Review and Meta-Analysis. *Plosone*, 1–18. http://doi.org/10.5061/dryad.3s7rd.Funding

Hnatiuk, J. A., Brown, H. E., Downing, K. L., Hinkley, T., Salmon, J., & Hesketh, K. D. (2019). Interventions to increase physical activity in children 0–5 years old: a systematic review, meta-analysis and realist synthesis. *Obesity Reviews*, *20*(1), 75-87.

Hoffman, L. (2015). *Longitudinal analysis: Modeling within-person fluctuation and change*. Routledge.

Holley, J. L., Nespor, S. H. E. R. Y. L., & Rault, R. A. Y. M. O. N. D. (1991). Characterizing sleep disorders in chronic hemodialysis patients. *ASAIO Transactions*, *37*(3), M456-7.

Homma, M., Ishikawa, H., & Kiuchi, T. (2018). Illness perceptions and negative responses from medical professionals in patients with fibromyalgia: Association with patient satisfaction and number of hospital visits. *Patient Education and Counseling*, *101*(3), 532–540. https://doi.org/10.1016/j.pec.2017.08.014

Hong, Y. Y., Ip, G., Chiu, C. Y., Morris, M. W., & Menon, T. (2001). Cultural identity and dynamic construction of the self: Collective duties and individual rights in Chinese and American cultures. *Social Cognition*, *19*(3: Special issue), 251-268.

Horigan, A. E., Schneider, S. M., Docherty, S., & Barroso, J. (2013). The experience and self-management of fatigue in patients on hemodialysis. *Nephrology Nursing Journal*, *40*(2), 113.

Hrdy, S. B. (2009): *Mothers and Others*. Harvard University Press.

Hoshino, J., Muenz, D., Zee, J., Sukul, N., Speyer, E., Guedes, M., ... & Young, E. (2020). Associations of hemoglobin levels with health-related quality of life, physical activity, and clinical outcomes in persons with stage 3-5 nondialysis CKD. *Journal of Renal Nutrition*, *30*(5), 404-414. https://doi.org/10.1053/j.jrn.2019.11.003

Howren, M. Bryant, Ashley J. Cozad, and Alan J. Christensen. "The interactive effects of patient control beliefs on adherence to fluid-intake restrictions in hemodialysis: results from a randomized controlled trial." *Journal of Health Psychology,* 22, 13 (2017): 1642-1651.

Hox, J. J., Moerbeek, M., & Van de Schoot, R. (2017). *Multilevel analysis: Techniques and Applications*. Routledge.

Huang, X., Jiménez-Moleón, J.J., Lindholm, B., Cederholm, T., Ärnlöv, J., Risérus, U., … Carrero, J.J. .(2013). Mediterranean diet, kidney function, and mortality in men with CKD. *Clinical Journal of American Society of Nephrology, 8*, 1548–1555. doi: 10.2215/CJN.01780213.

Hucker, A., Bunn, F., Carpenter, L., Lawrence, C., Farrington, K., & Sharma, S. (2017). Non-adherence to immunosuppressants following renal transplantation: a protocol for a systematic review. BMJ open, 7(9), e015411. http://dx.doi.org/10.1136/bmjopen-2016-015411

Hucker, A., Lawrence, C., Sharma, S., & Farrington, K. (2019). Adherence behavior in subjects on hemodialysis is not a clear predictor of posttransplantation adherence. *Kidney International Reports, 4*(8), 1122-1130. https://doi.org/10.1016/j.ekir.2019.04.028

Hudson, J. L., Bundy, C., Coventry, P. A., & Dickens, C. (2014). Exploring the relationship between cognitive illness representations and poor emotional health and their combined association with diabetes self-care. A systematic review with meta-analysis. *Journal of Psychosomatic Research*, *76*(4), 265–274. http://doi.org/10.1016/j.jpsychores.2014.02.004

Hudson, J. L., Moss-Morris, R., Game, D., Carroll, A., McCrone, P., Hotopf, M., Yardley, L., & Chilcot, J. (2016). Improving distress in dialysis (iDiD): A feasibility two-arm parallel randomised controlled trial of an online cognitive behavioural therapy intervention with and without therapist-led telephone support for psychological distress in patients undergoing ha. *BMJ Open*, *6*(4), e011286. https://doi.org/10.1136/bmjopen-2016-011286

Hudson, J. L., Moss-Morris, R., Norton, S., Picariello, F., Game, D., Carroll, A., ... & Chilcot, J. (2017). Tailored online cognitive behavioural therapy with or without therapist support calls to target psychological distress in adults receiving haemodialysis: a feasibility randomised controlled trial. *Journal of Psychosomatic Research*, *102*, 61-70. http://dx.doi.org/10.1016/j.jpsychores.2017.09.009

Huggett, C., Birtel, M.D., Awenat, Y.F., Flemming, S.W., Williams, S. & Haddock, G. (2018). A qualitative study: experiences of stigma by people with mental health problems. *Psychology and Psychotherapy: Theory, Research and Practice, 91*(3), 380–397. https://doi.org/10.1111/papt.12167

Hughes, J., Wood, E., & Smith, G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations*, *12*(4), 396-406.

Ibrahim, M. M., & Damasceno, A. (2012). Hypertension in developing countries. *The Lancet*, *380*(9841), 611-619.

Ibrahim, N., Chiew-Thong, N. K., Desa, A., & Razali, R. (2013). Depression and coping in adults undergoing dialysis for end-stage renal disease. *Asia-Pacific Psychiatry*, *5*, 35-40.

Ikizer, E. G., Ramírez-Esparza, N., & Quinn, D. M. (2018). Culture and concealable stigmatized identities: Examining anticipated stigma in the United States and Turkey. Stigma and Health, 3(2), 152–158. https://doi.org/10.1037/sah0000082

Ikizler, T. A., Robinson-Cohen, C., Ellis, C., Headley, S. A., Tuttle, K., Wood, R. J., ... & Himmelfarb, J. (2018). Metabolic effects of diet and exercise in patients with moderate to severe CKD: a randomized clinical trial. *Journal of the American Society of Nephrology*, *29*(1), 250-259. https://doi.org/10.1681/ASN.2017010020

Imai, E., Horio, M., Yamagata, K., Iseki, K., Hara, S., Ura, N., ... & Matsuo, S. (2008). Slower decline of glomerular filtration rate in the Japanese general population: a longitudinal 10-year follow-up study. *Hypertension Research*, *31*(3), 433.

Inker, L. A., Astor, B. C., Fox, C. H., Isakova, T., Lash, J. P., Peralta, C. A., ... & Feldman, H. I. (2014). KDOQI US commentary on the 2012 KDIGO clinical practice guideline for the evaluation and management of CKD. *American Journal of Kidney Diseases*, *63*(5), 713-735. https://www.ajkd.org/article/S0272-6386(14)00491-0/fulltext

Irwin, J., Saunier, J., Strouss, K., Paintner, C., Diegoli, T., Sturk, ., ... & Parsons, T. J. (2008). Mitochondrial control region sequences from northern Greece and Greek Cypriots. *International Journal of Legal Medicine*, *122*(1), 87-89.

Iskandarsyah, A., de Klerk, C., Suardi, D. R., Sadarjoen, S. S., & Passchier, J. (2014). Health locus of control in Indonesian women with breast cancer: a comparison with healthy women. *Asian Pacific Journal of Cancer Prevention*, *15*(21), 9191-9197.

Iyasere, O., Brown, E., Gordon, F., Collinson, H., Fielding, R., Fluck, R., ... & Davenport, A. (2019). Longitudinal trends in quality of life and physical function in frail older dialysis patients: a comparison of assisted peritoneal dialysis and in-center hemodialysis. *Peritoneal Dialysis International*, *39*(2), 112-118. https://doi.org/10.3747/pdi.2018.00086

Jacobs, J. R., Banthia, R., Sadler, G. R., Varni, J. W., Malcarne, V. L., Greenbergs, H. L., ... & Johnstone, P. A. (2002). Problems associated with prostate cancer: differences of opinion among health care providers, patients, and spouses. *Journal of Cancer Education, 17*(1), 33-36.

Jager, K. J., Kramer, A., Chesnaye, N. C., Couchoud, C., Sánchez-Álvarez, J. E., Garneata, L., ... & Massy, Z. A. (2020). Results from the ERA-EDTA Registry indicate a high mortality due to COVID-19 in dialysis patients and kidney transplant recipients across Europe. *Kidney International*, *98*(6), 1540-1548. DOI: 10.1016/j.kint.2020.09.006

James, M. T., Quan, H., Tonelli, M., Manns, B. J., Faris, P., Laupland, K. B., ... & Alberta Kidney Disease Network. (2009). CKD and risk of hospitalization and death with pneumonia. *American Journal of Kidney Diseases*, *54*(1), 24-32.

James, M. T., Hemmelgarn, B. R., Wiebe, N., Pannu, N., Manns, B. J., Klarenbach, S. W., ... & Alberta Kidney Disease Network. (2010). Glomerular filtration rate, proteinuria, and the incidence and consequences of acute kidney injury: a cohort study. *The Lancet*, *376*(9758), 2096-2103.

Jankowska-Polańska, B., Duczak, A., Świątoniowska, N., Karniej, P., Seń, M., & Rosińczuk, J. (2019). The influence of selected psychological variables on quality of life of chronically dialysed patients. *Scandinavian Journal of Caring Sciences*, (5). https://doi.org/10.1111/scs.12680

Janosevic, D., Wang, A.X. & Wish, J.B. (2019) Difficult patient behaviour in dialysis facilities. *Blood Purification, 47,* 254–258. Available at

https://doi.org/10.1159/000494592

Jansen, D. L., Grootendorst, D. C., Rijken, M., Heijmans, M., Kaptein, A. A., Boeschoten, E. W., & Dekker, F. W. (2010). Pre-dialysis patients' perceived autonomy, self-esteem and labor participation: associations with illness perceptions and treatment perceptions. A cross-sectional study. *BMC Nephrology*, *11*, 35. https://doi.org/10.1186/1471-2369-11-35

Jansen, D. L., Heijmans, M. J. W. M., Rijken, M., Spreeuwenberg, P., Grootendorst, D. C., Dekker, F. W., Boeschoten, E. W., Kaptein, A. A., & Groenewegen, P. P. (2013). Illness perceptions and treatment perceptions of patients with chronic kidney disease: Different phases, different perceptions? *British Journal of Health Psychology*, *18*(2), 244–262. https://doi.org/10.1111/bjhp.12002

Jayanti, A., Foden, P., Wearden, A., & Mitra, S. (2016). Illness Beliefs in End Stage Renal Disease and Associations with Self-Care Modality Choice. *PloS One*, *11*(7), e0154299. https://doi.org/10.1371/journal.pone.0154299

Jha, V. (2004). End-stage renal care in developing countries: the India experience. *Renal Failure*, *26*(3), 201-208.

Jha, V., Garcia-Garcia, G., Iseki, K., Li, Z., Naicker, S., Plattner, B., … Yang, C. W. (2013). Chronic kidney disease: Global dimension and perspectives. *The Lancet*, *382*(9888), 260–272. http://doi.org/10.1016/S0140-6736(13)60687-X

Jhamb, M., Abdel-Kader, K., Yabes, J., Wang, Y., Weisbord, S. D., Unruh, M., & Steel, J. L. (2019). Comparison of Fatigue, Pain, and Depression in Patients With Advanced Kidney Disease and Cancer—Symptom Burden and Clusters. *Journal of Pain and Symptom Management*, *57*(3), 566-575.e3. https://doi.org/10.1016/j.jpainsymman.2018.12.006

Joanna Briggs Institute. (2014). Joanna Briggs Institute reviewers' manual: 2014 edition. *Australia: The Joanna Briggs Institute*.

Johnson, B., & Turner, L. A. (2003). Data collection strategies in mixed methods research. *Handbook of Mixed Methods in Social and Behavioral Research*, 297-319.

Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, *1*(2), 112-133. https://doi.org/10.1177/1558689806298224

Jones-Burton, C., Mishra, S. I., Fink, J. C., Brown, J., Gossa, W., Bakris, G. L., & Weir, M. R. (2006). An in-depth review of the evidence linking dietary salt intake and progression of chronic kidney disease. *American Journal of Nephrology*, *26*(3), 268-275.

Jones, D. J. W., Harvey, K., Harris, J. P., Butler, L. T., & Vaux, E. C. (2018). Understanding the impact of haemodialysis on UK National Health Service patients' well-being: A qualitative investigation. *Journal of Clinical Nursing*, *27*(1–2), 193–204. https://doi.org/10.1111/jocn.13871

Jørgensen, I. L., Frederiksen, K., Boesen, E., Elsass, P., & Johansen, C. (2009). An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer. *Acta Oncologica*, *48*(8), 1119-1127. https://doi.org/10.3109/02841860903033922

Juergens, M. C., Seekatz, B., Moosdorf, R. G., Petrie, K. J., & Rief, W. (2010). Illness beliefs before cardiac surgery predict disability, quality of life, and depression 3 months later. *Journal of Psychosomatic Research, 68*(6), 553-560.

Jung, H. Y., Jeon, Y., Park, Y., Kim, Y. S., Kang, S. W., Yang, C. W., ... & Kim, Y. L. (2019). Better quality of life of peritoneal dialysis compared to hemodialysis over a two-year period after dialysis initiation. *Scientific reports*, *9*(1), 1-10. https://doi.org/10.1038/s41598-019-46744-1

Jungers, P., Joly, D., Nguyen-Khoa, T., Mothu, N., Bassilios, N., & Grünfeld, J. P. (2006). Continued late referral of patients with chronic kidney disease. Causes, consequences, and approaches to improvement. *Presse Medicale (Paris, France: 1983)*, *35*(1 Pt 1), 17-22.

Juster, F. T., & Suzman, R. (1995). An overview of the Health and Retirement Study. *Journal of Human Resources*, S7-S56.

Kalfoss, M., Schick-Makaroff, K., & Molzahn, A. E. (2019). Living with chronic kidney disease: Illness perceptions, symptoms, coping, and quality of life. *Nephrology Nursing Journal*, *46*(3), 277-291.

Kalaycı, B., Erten, Y. T., Akgün, T., Karabag, T., & Kokturk, F. (2019). The relationship of age-adjusted Charlson comorbidity ındex and diurnal variation of blood pressure. *Clinical and Experimental Hypertension*, *41*(2), 113-117.

Kamody, R. C., Berlin, K. S., Rybak, T. M., Klages, K. L., Banks, G. G., Ali, J. S., ... & Diaz Thomas, A. M. (2018). Psychological flexibility among youth with type 1 diabetes: relating patterns of acceptance, adherence, and stress to adaptation. *Behavioral Medicine*, *44*(4), 271-279.

Kanji, Z., Powe, C. E., Wenger, J. B., Huang, C., Ankers, E., Sullivan, D. A., ... & Bernhardy, A. J. (2011). Genetic variation in APOL1 associates with younger age at hemodialysis initiation. *Journal of the American Society of Nephrology*, *22*(11), 2091-2097.

Kao, W. L., Klag, M. J., Meoni, L. A., Reich, D., Berthier-Schaad, Y., Li, M., ... & Fink, N. E. (2008). MYH9 is associated with nondiabetic end-stage renal disease in African Americans. *Nature Genetics*, *40*(10), 1185.

Kaptein, A. A., Bijsterbosch, J., Scharloo, M., Hampson, S. E., Kroon, H. M., & Kloppenburg, M. (2010). Using the common sense model of illness perceptions to examine osteoarthritis change: A 6-year longitudinal study. *Health Psychology*, *29*(1), 56.

Kaptein, A. A., Yamaoka, K., Snoei, L., Kobayashi, K., Uchida, Y., van der Kloot, W. A., ... & Kaajan, H. (2011). Illness perceptions and quality of life in Japanese and Dutch patients with non-small-cell lung cancer. *Lung Cancer*, *72*(3), 384-390.

Kaptein, A. (2008). Illness perceptions in dialysis patients and their association with quality of life. *Psychology and Health*, *23*(6), 679-690.

Kaptein, A. D., & Weinman, J. (2004). *Health psychology: Some Introductory Remarks*. Blackwell Publishing.

Kaptein, A. A., Hughes, B. M., Scharloo, M., Fischer, M. J., Snoei, L., Weinman, J., & Rabe, K. F. (2008). Illness perceptions about asthma are determinants of outcome. *Journal of Asthma*, *45*(6), 459-464. https://doi.org/10.1080/02770900802040043

Kaptein, A. A., Schoones, J. W., Fischer, M. J., Thong, M. S., Kroep, J. R., & van der Hoeven, K. J. (2015). Illness perceptions in women with breast cancer—a systematic literature review. *Current breast cancer reports*, *7*(3), 117-126.

Karabulutlu, E., Tan, M., Erdem, N., & Okanli, A. (2005). Social support and coping with the stress in hemodialysis patients. *Anadolu Hemşirelik ve Sağlık Bilim Dergisi, 8*(3), 56-66.

Karabulutlu, E. Y. (2011). *Hemodiyaliz hastalarinda hastalik algisinin değerlendirilmesi*. 25–31.

Karadag, E., Sevinc, S., & Karatay, G. (2016). The Relationship Between Illness Perception and Disability in Hemodialysis Patients. *Turkiye Klinikleri Journal of Nursing Sciences*, *8*(3), 213–223. https://doi.org/10.5336/nurses.2015-46162

Karadag, E., Ugur, O., Mert, H., & Erunal, M. (2019). The Relationship Between Psychological Resilience and Social Support Levels in Hemodialysis Patients. *The Journal of Basic and Clinical Health Sciences*, *3*(1), 9–15.

https://doi.org/10.30621/jbachs.2019.469

Karamanidou, C., Weinman, J., & Horne, R. (2014). A qualitative study of treatment burden among haemodialysis recipients. *Journal of Health Psychology*, *19*(4), 556–569. https://doi.org/10.1177/1359105313475898

Karataş, T., Özen, Ş. & Kutlutürkan, S. (2017). Factor Structure and Psychometric Properties of the Brief Illness Perception Questionnaire in Turkish Cancer Patients. *Asia-Pacific Journal of Oncology Nursing*, *4*(1), 77–83. https://doi.org/10.4103/2347-5625.199080

Karimi, M., & Brazier, J. (2016). Health, health-related quality of life, and quality of life: what is the difference?. *Pharmacoeconomics*, *34*(7), 645-649. doi: 10.1007/s40273-016-0389-9.

Karataş, T., Özen, Ş., & Kutlutürkan, S. (2017). Factor structure and psychometric properties of the brief illness perception questionnaire in Turkish cancer patients. *Asia-Pacific Journal of Oncology Nursing*, *4*, 77–83. https://doi.org/10.4103/2347-5625.199080

Kawanishi, Y. (1992). Somatization of Asians: An artifact of Western medicalization?. *Transcultural Psychiatric Research Review*, *29*(1), 5-36. https://doi.org/10.1177/136346159202900101

Kearney, P. M., Whelton, M., Reynolds, K., Muntner, P., Whelton, P. K., & He, J. (2005). Global burden of hypertension: analysis of worldwide data. *The Lancet*, *365*(9455), 217-Keith, D. S., Nichols, G. A., Gullion, C. M., Brown, J. B., & Smith, D. H. (2004). Longitudinal follow-up and outcomes among a population with chronic kidney disease in a large managed care organization. *Archives of Internal Medicine*, *164*(6), 659-663.223.

Keskindag, B., Farrington, K., Oygar, D. D., Mertan, B., Hucker, A., & Sharma, S. (2021). Illness perceptions of Turkish Cypriot patients receiving haemodialysis: A qualitative study. *Journal of Renal Care*, *47*(2), 113-122. https://doi.org/10.1111/jorc.12351

Khalil, A. A., Frazier, S. K., Lennie, T. A., & Sawaya, P. (2011). Depressive Symptoms and Dietary Adherence in Patients with End-Stage Renal Disease. *Journal of Renal Care, 37*(1), 30–39. https://doi.org/10.1128/JVI.00542-11

Kharame, Z. T., Zamanian, H., Foroozanfar, S., & Afsahi, S. (2014). Religious wellbeing as a predictor for quality of life in Iranian hemodialysis patients. *Global Journal of Health Science*, *6*(4), 261. https://doi.org/10.5539/gjhs.v6n4p261

Khatri, M., Moon,Y.P., Scarmeas, N., Gu, Y., Gardener, H., Cheung, K., … Elkind, M.S. (2014). The association between a Mediterranean-style diet and kidney function in the Northern Manhattan Study cohort. *Clinical Journal of American Society of Nephrology, 9,* 1868–1875. doi: 10.2215/CJN.01080114.

Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group (2012). Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney International Suppl.3*, 1-150

Kieft, R. A., de Brouwer, B. B., Francke, A. L., & Delnoij, D. M. (2014). How nurses and their work environment affect patient experiences of the quality of care: a qualitative study. *BMC Health Services Research*, *14*(1), 1-10. https://doi.org/10.1186/1472-6963-14-249

Kim, B., & Kim, J. (2019). Influence of uncertainty, depression, and social support on self-care compliance in hemodialysis patients. *Therapeutics and Clinical Risk Management*, *15*, 1243–1251. https://doi.org/10.2147/TCRM.S218934

Kim, Y., & Evangelista, L. S. (2010). Relationship between illness perceptions, treatment adherence, and clinical outcomes in patients on maintenance hemodialysis. *Nephrology Nursing Journal: journal of the American Nephrology Nurses' Association*, *37*(3), 271.

Kim, Y., Evangelista, L. S., Phillips, L. R., Pavlish, C., & Kopple, J. D. (2012). Racial/ethnic differences in illness, perceptions in minority patients undergoing maintenance

hemodialysis. *Nephrology Nursing Journal : Journal of the American Nephrology Nurses' Association*, *39*(1), 39–48.

Kim, H. S., Sherman, D. K., Ko, D., & Taylor, S. E. (2006). Pursuit of comfort and pursuit of harmony: Culture, relationships, and social support seeking. *Personality and Social Psychology Bulletin, 32*(12), 1595–1607. https://doi.org/10.1177/0146167206291991

Kim, H. S., Sherman, D. K., & Taylor, S. E. (2008). Culture and social support. *American Psychologist*, *63*(6), 518. doi: 10.1037/0003-066x

Kimmel, P. L., Peterson, R. A., Weihs, K. L., Simmens, S. J., Alleyne, S., Cruz, I., & Veis, J. H. (1998a). Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney international*, *54*(1), 245-254.

Kimmel, P. L., Thamer, M., Richard, C. M., & Ray, N. F. (1998b). Psychiatric illness in patients with end-stage renal disease. *The American journal of medicine*, *105*(3), 214-221.

Kimmel, P. L. (2000a). Just whose quality of life is it anyway? Controversies and consistencies in measurements of quality of life. *Kidney International*, *57*, S113-S120.

Kimmel, P. L. P. (2000b). Psychosocial factors in adult end-stage renal disease patients treated with hemodialysis: correlates and outcomes. *American Journal of Kidney Diseases, 35*(4), 132–140. https://doi.org/10.1016/S0272-6386(00)70240-X

Kimmel, P. L., Peterson, R. A., Weihs, K. L., Simmens, S. J., Alleyne, S., Cruz, I., & Veis, J. H. (2000). Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis outpatients. *Kidney International*, *57*(5), 2093-2098.

Kimmel, P. L. (2001). Psychosocial factors in dialysis patients. *Kidney International*, *59*(4), 1599–1613. http://doi.org/10.1046/j.1523-1755.2001.0590041599.x

Kimmel, P. L., Emont, S. L., Newmann, J. M., Danko, H., & Moss, A. H. (2003). ESRD patient quality of life: symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *American Journal of Kidney Diseases*, *42*(4), 713-721.

Kimmel, P. L., Fwu, C. W., Abbott, K. C., Moxey-Mims, M. M., Mendley, S., Norton, J. M., & Eggers, P. W. (2019). Psychiatric Illness and Mortality in Hospitalized ESKD Dialysis Patients. *Clinical journal of the American Society of Nephrology : CJASN*, *14*(9), 1363–1371. https://doi.org/10.2215/CJN.14191218

King, N. (2012). Doing template analysis. *Qualitative organizational research: Core Methods and Current Challenges*, *426*, 77-101.

King, N., & Brooks, J. (2018). Thematic analysis in organisational research. *The SAGE Handbook of Qualitative Business nd Management Research Methods: Methods Anad Challenges*. SAGE inc.

Killien, M., & Newton, K. (1990). Longitudinal research-The challenge of maintaining continued involvement of participants. *Western Journal of Nursing Research*, *12*(5), 689-692.

Kirmayer, L. J., & Young, A. (1998). Culture and somatization: clinical, epidemiological, and ethnographic perspectives. *Psychosomatic Medicine*, *60*(4), 420-430. https://doi.org/10.1097/00006842-199807000-00006

Kittiskulnam, P., Sheshadri, A., & Johansen, K. L. (2017). Consequences of CKD on Functioning. *Seminars in Nephrology*, *36*(4), 305–318. http://doi.org/10.1016/j.semnephrol.2016.05.007.Consequences

Kizilhan, J. I. (2012). Changes in disease perception, coping strategies and diagnoses in the case of first and fourth generations of Turkish migrants in Germany. *Europe's Journal of Psychology* 1841-0413 doi:10.5964/ejop.v8i3.473

KKTC'de nefrolog sorunu (2015, July 3). *Haber Kibris*. Retrieved from https://haberkibris.com/kktcde-nefrolog-sorunu-2015-07-03.html

Klag, M. J., Whelton, P. K., Randall, B. L., Neaton, J. D., Brancati, F. L., Ford, C. E., ... & Stamler, J. (1996). Blood pressure and end-stage renal disease in men. *New England Journal of Medicine*, *334*(1), 13-18. doi: 10.1056/NEJM199601043340103 [PubMed: 7494564]

Kleinman, A., Good, B. J., & Good, B. (Eds.). (1985). *Culture and depression: Studies in the Anthropology and Cross-Cultural Psychiatry of Affect and Disorder*. University of California Press. https://doi.org/10.1525/9780520340923

Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS medicine*, *3*(10), e294.

Knight, E. L., Stampfer, M. J., Hankinson, S. E., Spiegelman, D., & Curhan, G. C. (2003). The impact of protein intake on renal function decline in women with normal renal function or mild renal insufficiency. *Annals of Internal Medicine*, *138*(6), 460-467.

Knowles, S., Swan, L., Psych, H., Salzberg, M., Castle, D., & Langham, R. (2018). Exploring the Relationships Between Health Status , Illness Perceptions , Coping Strategies and Psychological Morbidity in a Chronic Kidney Disease Cohort. *The American Journal of the Medical Sciences, 348*(4), 271–276. https://doi.org/10.1097/MAJ.0000000000000242

Kocaman Yildirim, N., Okanli, A., Yilmaz Karabulutlu, E., Karahisar, F., & Özkan, S. (2013). Hemodiyaliz hastalarının anksiyete ve depresyon belirtilerine hastalık algısının etkisi: Çok merkezli bir çalışma. *Anatolian Journal of Psychiatry/Anadolu Psikiyatri Dergisi*, 14(3).

Kohli, N., & Dalal, A. K. (1998). Culture as a factor in causal understanding of illness: A study of cancer patients. *Psychology and Developing Societies*, *10*(2), 115-129. https://doi.org/10.1177/097133369801000202

Komenda, P., Ferguson, T. W., Macdonald, K., Rigatto, C., Koolage, C., Sood, M. M., & Tangri, N. (2014). Cost-effectiveness of primary screening for CKD: a systematic review. *American Journal of Kidney Diseases*, *63*(5), 789-797. http://dx.doi.org/10.1053/j.ajkd.2013.12.012

Köttgen, A., Glazer, N. L., Dehghan, A., Hwang, S. J., Katz, R., Li, M., ... & Smith, A. V. (2009). Multiple loci associated with indices of renal function and chronic kidney disease. *Nature genetics*, *41*(6), 712.

Kramer, A., Pippias, M., Noordzij, M., Stel, V. S., Afentakis, N., Ambühl, P. M., … Jager, K. J. (2018). The European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) Registry Annual Report 2015: A summary. *Clinical Kidney Journal*, *11*(1), 108–122. http://doi.org/10.1093/ckj/sfx149

Krespi, M.R., Bone, M., Ahmad, R., Worthington, B., & Salmon, P. (2008). Hemodiyaliz Hastalarinin Yaşamlarinin Değerlendirmesi. *Turk Psikiyatri Dergisi*, *19*(4), 365–372.

Krespi, M., & Kuntuz, I. (2017). Hemodiyaliz Hastalarında Psikososyal Faktörlerin Duygusal İyilik Durumu ve Yaşam Kalitesine Etkileri. *Turkiye Klinikleri Journal of Internal Medicine*, *2*(1), 1–10. https://doi.org/10.5336/intermed.2016-51842

Krespi, Margorit Rita. (2018). Psychosocial interventions to improve outcomes among dialysis patients. *Seminars in Dialysis*, *31*(1), 65–71. https://doi.org/10.1111/sdi.12638

Kristensen, I. V., Henriksen, J., Birkelund, R., & Norlyk, A. (2020). Existential contradictions in living with end-stage renal disease: A qualitative metasynthesis. *Advances in Nursing Science*, *43*(2), 159–171. https://doi.org/10.1097/ANS.0000000000000312

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613.

Kucukarslan, S. N. (2012). A review of published studies of patients' illness perceptions and medication adherence: lessons learned and future directions. *Research in Social and*

Administrative Pharmacy, 8(5), 371-382. https://doi.org/10.1016/j.sapharm.2011.09.002

Kuhl, J. (2000) 'A functional-design approach to motivation and self-regulation: the dynamics of personality systems and interactions,' In M. Boekaerts, P.R. Pintrich and M. Zeidner (eds) *Handbook of Self-Regulation*, Academic Press. https://doi.org/10.1016/b978-012109890-2/50034-2

Kurella, M., Chertow, G. M., Luan, J., & Yaffe, K. (2004). Cognitive impairment in chronic kidney disease. *Journal of American Geriatric Society*, 52(11), 1863–1869. http://doi.org/10.1093/ndt/gfl572

Kusek, J. W., Greene, P., Wang, S. R., Beck, G., West, D., Jamerson, K., ... & Level, B. (2002). Cross-sectional study of health-related quality of life in African Americans with chronic renal insufficiency: The African American Study of Kidney Sisease and Hypertension Trial. *American Journal of Kidney Diseases*, 39(3), 513-524. doi: S0272638602298996 [pii]

Kvåle, K., & Bondevik, M. (2008). What is important for patient centred care? A qualitative study about the perceptions of patients with cancer. *Scandinavian Journal of Caring Sciences*, 22(4), 582-589.

Landrine, H. and Klonoff, E.A. (2001) 'Cultural diversity and health psychology,' in A. Baum, T.A. Revensen and J.E. Singer (eds), *Handbook of Health Psychology*, Lawrence Erlbaum Associates. https://doi.org/10.4135/9781446221129.n16

Lang, E. V. (2012). A better patient experience through better communication. *Journal of Radiology Nursing*, 31(4), 114-119. https://doi.org/10.1016/j.jradnu.2012.08.001

Larsen, R., Mangrio, E., & Persson, K. (2021). Interpersonal communication in transcultural nursing care in India: A descriptive qualitative study. *Journal of Transcultural Nursing*, 32(4), 310-317. https://doi.org/10.1177/1043659620920693

Laupacis, A., Keown, P., Pus, N., Krueger, H., Fergunson, B., Wong, C., & Muirhead, N. (1996). A Study of Quality of Life and Cost Utility Analysis of renal transplantation. *Kidney International*, 50, 235–242.

Lee, S. H., & Molassiotis, A. (2002). Dietary and fluid compliance in Chinese hemodialysis patients. *International journal of nursing studies*, 39(7), 695-704. https://doi.org/10.1016/s0020-7489(02)00007-x

Lehnert, T., Heider, D., Leicht, H., Heinrich, S., Corrieri, S., Luppa, M., ... & König, H. H. (2011). Health care utilization and costs of elderly persons with multiple chronic conditions. *Medical Care Research and Review*, 68(4), 387-420.

Leininger M.M. (1995) *Transcultural Nursing. Concepts, Theories, Research and Practices*, 2nd (ed). McGraw-Hill.

Levenson, J. L., & Glocheski, S. (1991). Psychological factors affecting end-stage renal disease: A review. *Psychosomatics*, 32(4), 382-389.

Leventhal, H., Meyer, D. & Nerenz, D.R. (1980) 'The common sense representa- tion of illness danger,' In S. Rachman (ed.) *Contributions to Medical Psychology*, Pergamon Press.

Leventhal, E. A. (1984). Aging and the perception of illness. *Research on Aging 6,* 119–135. doi: 10.1177/0164027584006001007

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness Representations: Theoretical Foundations. *Perceptions of Health and Illness*, 2, 19-46. Harwood Publishers.

Leventhal, H., Brissette, I. & Leventhal, E. (2003) The common-sense model of self-regulation of health and illness. In: Cameron, L. & Leventhal, H. (Eds.) *The self-regulation of health and illness behaviour*. London: Routledge, pp. 42–65.

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-

management. *Journal of Behavioral Medicine*, *39*(6), 935-946.

Levey, A. S., Coresh, J., Bolton, K., Culleton, B., Harvey, K. S., Ikizler, T. A., ... & Levin, A. (2002). National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *American Journal of Kidney Disease*, *39*(Suppl 1), S1-S266.

Levey, A.S., Stevens, L.A., Schmid, C.H., Zhang, Y.L., Castro, A.F., Feldman, H.I.,… Coresh, J. (2009). A new equation to estimate glomerular filtration rate. *Annals of Internal Medicine, 150*(9), 604- 612. Retreived from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2763564/

Levey, A. S., Eckardt, K. U., Dorman, N. M., Christiansen, S. L., Hoorn, E. J., Ingelfinger, J. R., ... & Winkelmayer, W. C. (2020). Nomenclature for kidney function and disease: report of a Kidney Disease: Improving Global Outcomes (KDIGO) Consensus Conference. *Kidney International*, *97*(6), 1117-1129. doi: 10.1016/j.kint.2020.02.010.

Levin, A., Djurdjev, O., Barrett, B., Burgess, E., Carlisle, E., Ethier, J., ... & Thompson, C. (2001). Cardiovascular disease in patients with chronic kidney disease: getting to the heart of the matter. *American Journal of Kidney Diseases*, *38*(6), 1398-1407.

Levin, A., Stevens, P. E., Bilous, R. W., Coresh, J., De Francisco, A. L., De Jong, P. E., ... & Levey, A. S. (2013). Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney International Supplements*, *3*(1), 1-150.

Leysen, M., Nijs, J., Meeus, M., Paul van Wilgen, C., Struyf, F., Vermandel, A., Kuppens, K., & Roussel, N. A. (2015). Clinimetric properties of illness perception questionnaire revised (IPQ-R) and brief illness perception questionnaire (Brief IPQ) in patients with musculoskeletal disorders: A systematic review. In *Manual Therapy* (Vol. 20, Issue 1). Elsevier Ltd. https://doi.org/10.1016/j.math.2014.05.001

Lien, Y. Y., Lin, H. S., Lien, Y. J., Tsai, C. H., Wu, T. T., Li, H., & Tu, Y. K. (2021). Challenging mental illness stigma in healthcare professionals and students: A systematic review and network meta-analysis. Psychology & Health, 36(6), 669-684. https://doi.org/10.1080/08870446.2020.1828413

List of cities, towns and villages in Cyprus. (2022, March 7). In *Wikipedia. https://en.wikipedia.org/wiki/List_of_cities,_towns_and_villages_in_Cyprus*

Lin, C. C., Chen, M. C., Hsieh, H. F., & Chang, S. C. (2013). Illness representations and coping processes of Taiwanese patients with early-stage chronic kidney disease. *Journal of Nursing Research*, *21*(2), 120-128. DOI: 10.1097/jnr.0b013e3182921fb8

Lip, G. Y. H., Khan, H., Bhatnagar, A., Brahmabhatt, N., Crook, P., & Davies, M. K. (2004). Ethnic differences in patient perceptions of heart failure and treatment: the West Birmingham heart failure project. *Heart*, *90*(9), 1016-1019. https://doi.org/10.1136/hrt.2003.025742

Liu, X., Yang, X., Yao, L., Zhang, Q., Sun, D., Zhu, X., … Wang, L. (2017). Prevalence and related factors of depressive symptoms in hemodialysis patients in northern China. *BMC Psychiatry*, *17*(128), 1–7. https://doi.org/10.1186/s12888-017-1294-2

Loosman, W. L., Rottier, M. A., Honig, A., & Siegert, C. E. H. (2015). Association of depressive and anxiety symptoms with adverse events in Dutch chronic kidney disease patients: A prospective cohort study. *BMC Nephrology*, *16*(1), 1–8. https://doi.org/10.1186/s12882-015-0149-7

Lorah, J. (2018). Effect size measures for multilevel models: definition, interpretation, and TIMSS example. *Large-Scale Assessments in Education*, *6*(1). https://doi.org/10.1186/s40536-018-0061-2

Lowenthal, E., Matesva, M., Marukutira, T., Bayani, O., Chapman, J., Tshume, O., ... & Gross, R. (2021). Psychological reactance is a novel risk factor for adolescent

antiretroviral treatment failure. *AIDS and Behavior*, *25*(5), 1474-1479.

Lubensky, I. A., Schmidt, L., Zhuang, Z., Weirich, G., Pack, S., Zambrano, N., ... & Zbar, B. (1999). Hereditary and sporadic papillary renal carcinomas with c-met mutations share a distinct morphological phenotype. *The American Journal of Pathology*, *155*(2), 517-526.

Lucas, P. J., Baird, J., Arai, L., Law, C., & Roberts, H. M. (2007). Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology*, *7*, 1–7. https://doi.org/10.1186/1471-2288-7-4

Luyas, G.T. (1991) 'An explanatory model of diabetes,' *Western Journal of Nursing Research 13*, 681–693.

Luyckx, V. A., Cherney, D. Z., & Bello, A. K. (2020). Preventing CKD in developed countries. *Kidney international reports*, *5*(3), 263-277. doi: 10.1016/j.ekir.2019.12.003

Lynn, P., Couper, M., & Watson, N. (2019). Longitudinal surveys–unique opportunities and unique methodological challenges. *Longitudinal and Life Course Studies*, *10*(4), 415-420.

MacKinnon, H. J., Feehally, J., & Smith, A. C. (2015). A review of the role of exercise and factors affecting its uptake for people with chronic kidney disease (CKD) not requiring renal replacement therapy. *Prilozi*, *36*(1).

Mallamaci, F., Pisano, A., & Tripepi, G. (2020). Physical activity in chronic kidney disease and the EXerCise Introduction To Enhance trial. *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association*, *35*(Suppl 2), ii18–ii22. https://doi.org/10.1093/ndt/gfaa012

Malterud, K., Siersma, V. K., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753–1760. https://doi.org/10 .1177/1049732315617444

Marcussen, K. (2006). Identities, self-esteem, and psychological distress: An application of identity-discrepancy theory. *Sociological Perspectives*, *49*(1), 1-24. https://doi.org/10.1525/sop.2006.49.1.1

Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, *98*(2), 224.

Marks, D. F., & Yardley, L. (2003). Qualitative data collection: interviews and focus groups. In, Marks, David F. and Yardley, Lucy (eds.) *Research Methods for Clinical and Health Psychology*. SAGE Publications, pp. 39-55.

Masina, T., Chimera, B., Kamponda, M., & Dreyer, G. (2016). Health related quality of life in patients with end stage kidney disease treated with haemodialysis in Malawi: a cross sectional study. *BMC nephrology, 17*(1), 61.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Social Research, 11*(3). http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027

Matsuzawa, Y., Lee, Y. S. C., Fraser, F., Langenbahn, D., Shallcross, A., Powers, S., ... & Minen, M. (2019). Barriers to behavioral treatment adherence for headache: an examination of attitudes, beliefs, and psychiatric factors. *Headache: The Journal of Head and Face Pain*, *59*(1), 19-31.

May, K. A. (1991). Interview techniques in qualitative research: Concerns and challenges. *Qualitative Nursing Research: A Contemporary Dialogue*, 188-201.

McDade-Montez, E. A., Christensen, A. J., Cvengros, J. A., & Lawton, W. J. (2006). The role of depression symptoms in dialysis withdrawal. *Health Psychology*, *25*(2), 198.

McDonald, S. P., Maguire, G. P., & Hoy, W. E. (2003). Renal function and cardiovascular risk markers in a remote Australian Aboriginal community. *Nephrology Dialysis Transplantation*, *18*(8), 1555-1561.

McMahon, E. J., Bauer, J. D., Hawley, C. M., Isbel, N. M., Stowasser, M., Johnson, D. W., & Campbell, K. L. (2013). A Randomized Trial of Dietary Sodium Restriction in CKD. *Journal of the American Society of Nephrology*, *24*(12), 2096–2103. http://doi.org/10.1681/ASN.2013030285

Mechanic, D. (1995) 'Sociological dimensions of illness behavior,' *Social Science and Medicine 41*, 1207–1216.

MedicineNET (2018). Kidney Failure (Symptoms, Signs, Stages, Causes, Treatment, and Life Expectancy). Retrived from https://www.medicinenet.com/kidney_failure/article.htm#kidney_failure_definition_and_facts

Medin, D. L. (2017). Psychological Science as a Complex System: Report Card. *Perspectives on Psychological Science*, *12*(4), 669–674. https://doi.org/10.1177/1745691616687746

Menard, S. (2002). *Longitudinal Research* (Vol. 76). Sage.

Menard, S. (Ed.). (2008). *Handbook of longitudinal research: Design, measurement, and analysis*. Elsevier.

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: official publication of the European Dialysis and Transplant Association-European Renal Association*, *14*(5), 1163-1170.

Mertan, B., Özeylem, F., Tüfekçioğlu, H., Güler, Ö., & Maner, U. (2014, July 11-14). *Beliefs toward mental illness mediates the relationship between self-stigma and attitudes toward seeking psychological help* [Poster session] 9th International Conference on Child and Adolescent Psychopathology, UK

Meuleman, Y., de Goeij, M. C., Halbesma, N., Chilcot, J., Dekker, F. W., & van Dijk, S. (2015). Illness perceptions in patients on pre-dialysiscare: Associations with time until start of dialysis and decline of kidney function. *Psychosomatic Medicine, 77,*946–954. https://doi.org/10.1097/PSY.0000000000000220

Meuleman, Y., Chilcot, J., Dekker, F. W., Halbesma, N., & van Dijk, S. (2017). Health-related quality of life trajectories during predialysis care and associated illness perceptions. *Health Psychology*, *36*(11), 1083.

Meyer, T. W., & Hostetter, T. H. (2007). Uremia. *New England Journal of Medicine*, *357*(13), 1316-1325. doi: 357/ 13/1316 [pii];10.1056/NEJMra071313

Middleton, J., Perry, K. N., & Craig, A. (2014). A Clinical Perspective on the Need for Psychosocial Care Guidelines in Spinal Cord Injury Rehabilitation. *International Journal of Physical Medicine & Rehabilitation, 02*(05). https://doi.org/10.4172/2329-9096.1000226

Mills, K.T., Xu, Y., Zhang, W., Bundy, J.D., Chen, C.S., Kelly, T.N., … He. J. (2015). A systematic analysis of worldwide population-based data on the global burden of chronic kidney disease in 2010. *Kidney International, 88*, 950–957. doi: 10.1038/ki.2015.230.

Moerman, D. E. (2002). Explanatory mechanisms for placebo effects: cultural influences and the meaning response. *The science of the placebo: Toward an interdisciplinary research agenda. London: BMJ Books*, 77-107

Mohammed, S., Nagla, S., Morten, S., Asma, E., & Arja, A. (2015). Illness perceptions and quality of life among tuberculosis patients in gezira, sudan. *African Health Sciences*, *15*(2), 385–393. https://doi.org/10.4314/ahs.v15i2.11

Mora, P. A., Robitaille, C., Leventhal, H., Swigar, M., & Leventhal, E. A. (2002). Trait negative affect relates to prior-week symptoms, but not to reports of illness episodes, illness symptoms, and care seeking among older persons. *Psychosomatic*

Medicine, *64*(3), 436-449. https://doi.org/10.1097/00006842-200205000-00007

Morehouse, R. E., Colvin, E., Maykut, P., & Frauman, A. C. (2001). Nephrology nurse-patient relationships in the outpatient dialysis setting/commentary and response. *Nephrology Nursing Journal*, *28*(3), 295. https://www.proquest.com/openview/1f524ddfcc01d23bb527cf3c96e7409e/1?pq-origsite=gscholar&cbl=45638

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, *25*(9), 1212-1222. https://doi.org/10.1177/1049732315588501

Morton, R. L., Tong, A., Howard, K., Snelling, P., & Webster, A. C. (2010a). The views of patients and carers in treatment decision making for chronic kidney disease: Systematic review and thematic synthesis of qualitative studies. *BMJ (Online)*, *340*(7742), 350. https://doi.org/10.1136/bmj.c112

Morton, Rachael L., Devitt, J., Howard, K., Anderson, K., Snelling, P., & Cass, A. (2010b). Patient Views About Treatment of Stage 5 CKD: A Qualitative Analysis of Semistructured Interviews. *American Journal of Kidney Diseases*, *55*(3), 431–440. https://doi.org/10.1053/j.ajkd.2009.11.011

Moskovitch, J. T., Mount, P. F., & Davies, M. R. (2020). Changes in symptom burden in dialysis patients assessed using a symptom-reporting questionnaire in clinic. *Journal of Palliative Care*, *35*(1), 59-65. https://doi.org/10.1177/0825859719827315

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, *17*(1), 1–16. https://doi.org/10.1080/08870440290001494

Moța, E., Popa, S. G., Moța, M., Mitrea, A., Penescu, M., Tuță, L., ... & Mihai, B. (2015). Prevalence of chronic kidney disease and its association with cardio-metabolic risk factors in the adult Romanian population: the PREDATORR study. *International Urology and Nephrology*, *47*(11), 1831-1838. DOI 10.1007/s11255-015-1109-7

Mula-Abed, W. A. S., Al Rasadi, K., & Al-Riyami, D. (2012). Estimated glomerular filtration rate (eGFR): A serum creatinine-based test for the detection of chronic kidney disease and its impact on clinical practice. *Oman Medical Journal*, *27*(2), 108. https://doi.org/10.5001/omj.2012.23

Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*, *18*(1), 1-9.

Muntner, P., Newsome, B., Kramer, H., Peralta, C. A., Kim, Y., Jacobs, D. R., … Lewis, C. E. (2012). Racial differences in the incidence of chronic kidney disease. *Clinical Journal of the American Society of Nephrology*, *7*(1), 101–107. http://doi.org/10.2215/CJN.06450611

Muscat, P., Chilcot, J., Weinman, J., & Hudson, J. (2018). Exploring the relationship between illness perceptions and depression in patients with chronic kidney disease: A systematic literature review. *Journal of Renal Care*. https://doi.org/10.1111/jorc.12243

Muscat, P., Weinman, J., Farrugia, E., Callus, R., & Chilcot, J. (2021). Illness perceptions predict distress in patients with chronic kidney disease. *BMC Psychology*, 1–13. https://doi.org/10.1186/s40359-021-00572-z

Muscat, P., Weinman, J., Farrugia, E., Camilleri, L., & Chilcot, J. (2020). Illness perceptions predict mortality in patients with predialysis chronic kidney disease: a prospective observational study. *BMC Nephrology*, *21*(1), 4–11. https://doi.org/10.1186/s12882-020-02189-7

Nabolsi, M.M., Wardam, L., & Al-Halabi, J.O. (2015). Quality of life, depression, adherence

to treatment and illness perception of patients on haemodialysis. *International Journal of Nursing Practice*, *21*(1), 1-10.

Naidoo, N., Nguyen, V. T., Ravaud, P. et al (2020) The research burden of randomized controlled trial participation: a systematic thematic synthesis of qualitative evidence. *BMC Medicine, 18*(1), 6. https://doi.org/10.1186/s12916-019-1476-5

Nápoles, A. M., & Chadiha, L. A. (2011). Advancing the science of recruitment and retention of ethnically diverse populations. *The Gerontologist, 51*(suppl_1), S142-S146.,

National Clinical Guideline Centre (UK). (2014). *Chronic Kidney Disease (Partial Update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care*. National Institute for Health and Care Excellence (UK).

National Institutes of Health. (1999). US Renal Data System: 1999 Annual Data Report. *Bethesda, MD: National Institute of Diabetes and Kidney Diseases*.

National Kidney Foundation (2022). How Your Kidneys Work? Retrieved from https://www.kidney.org/kidneydisease/howkidneyswrk

National service framework: kidney disease (2004). *National Service Framework for Renal Services: Dialysis and Transplantation. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/199001/National_Service_Framework_for_Renal_Services_Part_One_-_Dialysis_and_Transplantation.pdf*

Naz, I., Sahin, H., Varol, Y., & Kömürcüoğlu, B. (2018). The effect of comorbidity severity on pulmonary rehabilitation outcomes in chronic obstructive pulmonary disease patients. *Chronic Respiratory Disease*, *16*, 1479972318809472.

Nese, J. F. T., & Lai, C. (2012). Technical Report # 1320 A Primer on Longitudinal Data Analysis In Education University of Oregon University of Oregon • 175 Education 5262 University of Oregon • Eugene , OR 97403-5262. *Behavioral Research and Teaching*.

Ng, C. H. (1997). The stigma of mental illness in Asian cultures. *Australian & New Zealand Journal of Psychiatry*, *31*(3), 382-390. https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.908.4881&rep=rep1&type=pdf

Ng, H. J., Tan, W. J., Mooppil, N., Newman, S., & Griva, K. (2015). Prevalence and patterns of depression and anxiety in hemodialysis patients: A 12-month prospective study on incident and prevalent populations. *British Journal of Health Psychology*, *20*(2), 374–395. https://doi.org/10.1111/bjhp.12106

Ng, M. S. N., Wong, C. L., Ho, E. H. S., Hui, Y. H., Miaskowski, C., & So, W. K. W. (2020). Burden of living with multiple concurrent symptoms in patients with end-stage renal disease. *Journal of Clinical Nursing*, *29*(13–14), 2589–2601. https://doi.org/10.1111/jocn.15282

Nicca, D., Fierz, K., Happ, M. B., Moody, K., & Spirig, R. (2012). Symptom management in HIV/AIDS: A mixed methods approach to describe collaboration and concordance between persons living with HIV and their close support persons. *Journal of Mixed Methods Research*, *6*(3), 217-235. https://doi.org/10.1177/1558689811421773

Nielsen, M., Haun, D., Kärtner, J., & Legare, C. H. (2017). The persistent sampling bias in developmental psychology: A call to action. *Journal of Experimental Child Psychology*, *162*, 31–38. https://doi.org/10.1016/j.jecp.2017.04.017

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies.* Sage.

Noureddine, S., & Froelicher, E. S. (2013). Psychometric testing of an Arabic version of the Illness Perception Questionnaire for heart disease. *Heart and Lung: Journal of Acute and Critical Care*, *42*(1), 51–58. https://doi.org/10.1016/j.hrtlng.2012.08.002

Novembre, J., Johnson, T., Bryc, K., Kutalik, Z., Boyko, A. R., Auton, A., ... & Stephens, M. (2008). Genes mirror geography within Europe. *Nature*, *456*(7218), 98.

Nopsopon, T., Kittrakulrat, J., Takkavatakarn, K., Eiamsitrakoon, T., Kanjanabuch, T., & Pongpirul, K. (2021). Covid-19 in end-stage renal disease patients with renal replacement therapies: a systematic review and meta-analysis. *PLOS Neglected Tropical Diseases*, *15*(6), e0009156. https://doi.org/10.1371/journal.pntd.0009156

O'Brien, C. W., & Moorey, S. (2010). Outlook and adaptation in advanced cancer: a systematic review. *Psycho-oncology*, *19*(12), 1239-1249.

O'Connor, P. J., Martin, B., Weeks, C. S., & Ong, L. (2014). Factors that influence young people's mental health help-seeking behaviour: a study based on the Health Belief Model. *Journal of Advanced Nursing*, *70*(11), 2577-2587. doi: 10.1111/jan.12423

O'Connor, C., & Joffe, H. (2020). Intercoder reliability in qualitative research: debates and practical guidelines. *International Journal of Qualitative Methods*, *19*, 1609406919899220.

O'Donnell, K., & Chung, J. Y. (1997). The diagnosis of major depression in end-stage renal disease. *Psychotherapy and Psychosomatics*, *66*(1), 38-43.

Oflaz, S., Yüksel, Ş., Şen, F., Özdemiroğlu, F., Kurt, R., Oflaz, H., & Kaşikcioğlu, E. (2014). Hastalik algisi myokard İnfarktüsü geçiren hastalarda travma sonrasi stres bozukluğunu öngörebilir mi? *Noropsikiyatri Arsivi*, *51*(2), 103–109. https://doi.org/10.4274/npa.y6394

Ogden, J. (1995). Changing the subject of health psychology. *Psychology & Health*, *10*(4), 257-265. https://doi.org/10.1080/08870449508400238

Ogden, J. (2000). *Health Psychology* (2nd ed.). Open University Press

Ogden, J. (2012). *Health Psychology* (5th ed.). McGraw Hill Education.

Oh, T. R., Choi, H. S., Suh, S. H., Kim, C. S., Bae, E. H., Sung, S., ... & Kim, S. W. (2022). The Association between Health-Enhancing Physical Activity and Quality of Life in Patients with Chronic Kidney Disease: Propensity Score Matching Analysis. *International Journal of Environmental Research and Public Health*, *19*(3), 1318. https://doi.org/10.3390/ijerph19031318

Ok, E., & Isil, O. (2019). Assessment of the mental status of chronic kidney patients. *Journal of Psychiatric Nursing*, *10*(3), 181–189. https://doi.org/10.14744/phd.2019.35119

Oliver, S. R., Rees, R. W., Clarke-Jones, L., Milne, R., Oakley, A. R., Gabbay, J., ... & Gyte, G. (2008). A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations*, *11*(1), 72-84.

Onsoz, H. B., & Usta Yesilbalkan, O. (2013). Reliability and validity of the Turkish version of the dialysis symptom index in chronic hemodialysis patients. *Turkish Nephrology, Dialysis and Transplantation Journal*, *22*(1), 60-7.

Onwuegbuzie, A. J., & Leech, N. L. (2004). Enhancing the Interpretation of " Significant " Findings : The Role of Mixed Methods Research. *The Qualitative Report*, *9*(4), 770–792. http://carbon.videolectures.net/v005/de/32jy3suaxgv6xtmtvivthk7nm7wtroi7.pdf

Orford J (1995). Qualitative research for applied psychologists. *Clinical Psychology Forum, 1*, 19-26.

Orth, S. R., & Hallan, S. I. (2008). Smoking: a risk factor for progression of chronic kidney disease and for cardiovascular morbidity and mortality in renal patients—absence of evidence or evidence of absence?. *Clinical Journal of the American Society of Nephrology*, *3*(1), 226-236. doi: 10.2215/CJN.03740907 [PubMed: 18003763]

Oyserman, D., Coon, H. M., & Kemmelmeier, M. (2002). Rethinking individualism and collectivism: evaluation of theoretical assumptions and meta-analyses. *Psychological bulletin*, *128*(1), 3. DOI: 10.1037//0033-2909.128.1.3

Ozgur, B., Kursat, S., & Aydemir, O. (2003). Hemodiyaliz Hastalarinda Yaşam Kalitesi İle

Anksiyete Ve Depresyon Düzeyleri Yönünden Değerlendirilmesi. *Türk Nefroloji Diyaliz ve Transplantasyon Dergisi*, *12*(2), 113–116.

Ozturk, O. M., & Goksel, F. A. (1964). Folk treatment of mental illness in Turkey. *Magic, Faith and Healing*, 343-363.

Ozturk, O. M., & Volkan, V. D. (1971). Psychiatry in a Changing World: The Theory and Practice of Psychiatry in Turkey. *American Journal of Psychotherapy*, *25*(2), 240-271.

Östlund, U., Kidd, L., Wengström, Y., & Rowa-Dewar, N. (2011). Combining qualitative and quantitative research within mixed method research designs: A methodological review. *International Journal of Nursing Studies*, *48*(3), 369–383. https://doi.org/10.1016/j.ijnurstu.2010.10.005

Özelsel, M. (1994). Die „andere Mentalität ". Eine empirische Untersuchung zur sekundären Krankheitssicht türkischer MitbürgerInnen. *Verhaltenstherapie & Psychosoziale Praxis*, *3*, 349-356.

Pae, C. U., Lim, H. K., Han, C., Patkar, A. A., Steffens, D. C., Masand, P. S., & Lee, C. (2007). Fatigue as a core symptom in major depressive disorder: overview and the role of bupropion. *Expert Review of Neurotherapeutics*, *7*(10), 1251-1263.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *British Medical Journal*, *372*.

Pagels, A. A. (2012). *Living With Chronic Kidney Disease – Perceptions of Illness and Health-Related*.

Pagels, A. A., Söderquist, B. K., & Heiwe, S. (2015). Differences in illness representations in patients with chronic kidney disease. *Journal of Renal Care*, *41*(3), 146-155.

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 Diseases*, *65*(4), 559–573. https://doi.org/10.1053/j.ajkd.2014.09.012

Papadopoulos, I. (1999). Health and illness beliefs of Greek Cypriots living in London. *Journal of Advanced Nursing*, *29*(5), 1097-1104. doi: 10.1046/j.1365-2648.1999.00994.x

Parfeni, M., Nistor, I., & Covic, A. (2013). A systematic review regarding the association of illness perception and survival among end-stage renal disease patients. *Nephrology, Dialysis, Transplantation : Official Publication of the European Dialysis and Transplant Association - European Renal Association*, *28*(10), 2407–2414. https://doi.org/10.1093/ndt/gft194

Patel, S. S., Shah, V. S., Peterson, R. A., & Kimmel, P. L. (2002). Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. *American Journal of Kidney Diseases*, *40*(5), 1013-1022.

Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods*, 2nd ed., Newbury Park: Sage.

Pavon Blanco, A., Turner, M. A., Petrof, G., & Weinman, J. (2019). To what extent do disease severity and illness perceptions explain depression, anxiety and quality of life in hidradenitis suppurativa?. *British Journal of Dermatology*, *180*(2), 338-345.

Pedreira Robles, G., & Aguayo-González, M. P. (2019). From physical to emotional pain in chronic kidney disease: Nurses' perceptions. *Journal of Renal Care, 45*(4), 212–222. https://doi.org/10.1111/jorc.12302

Pelletier-Hibbert, M., & Sohi, P. (2001). Sources of uncertainty and coping strategies used by family members of individuals living with end stage renal disease. *Nephrology Nursing Journal*, *28*(4), 411.

Peña, M., & Frehill, L. M. (1998). Latina religious practice: Analyzing cultural dimensions in

measures of religiosity. *Journal for the Scientific Study of Religion*, 620-635.

Perales Montilla, C. M., Duschek, S., & Reyes del Paso, G. A. (2016). Health-related quality of life in chronic kidney desease: Predictive relevance of mood and somatic symptoms. *Nefrología (English Edition)*, (x x), 1–8. http://doi.org/10.1016/j.nefroe.2016.06.003

Perlman, R. L., Finkelstein, F. O., Liu, L., Roys, E., Kiser, M., Eisele, G., ... & Port, F. K. (2005). Quality of life in chronic kidney disease (CKD): a cross-sectional analysis in the Renal Research Institute-CKD study. *American Journal of Kidney Diseases*, *45*(4), 658-666. doi: 658–666. S0272638605000053 [pii].

Perry, E., Swartz, J., Brown, S., Smith, D., Kelly, G., & Swartz, R. (2005). Peer mentoring: a culturally sensitive approach to end-of-life planning for long-term dialysis patients. *American Journal of Kidney Diseases*, *46*(1), 111-119.

Peterson, R. A., Kimmel, P. L., Sacks, C. R., Mesquita, M. L., Simmens, S. J., & Reiss, D. (1991). Depression, perception of illness and mortality in patients with end-stage renal disease. *The International Journal of Psychiatry in Medicine*, *21*(4), 343-354.

Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: longitudinal study. *Bmj*, *312*(7040), 1191-1194.

Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosomatic Medicine*, *64*(4), 580-586.

Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, *6*(6), 536–539. https://doi.org/10.7861/clinmedicine.6-6-536

Petrie, K. J., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions in patients with medical conditions. *Current Opinion in Psychiatry*, *20*(2), 163–167. https://doi.org/10.1097/YCO.0b013e328014a871

Picariello, F., Hudson, J. L., Moss-Morris, R., Macdougall, I. C., & Chilcot, J. (2017a). Examining the efficacy of social-psychological interventions for the management of fatigue in end-stage kidney disease (ESKD): a systematic review with meta-analysis. *Health Psychology Review*, *11*(2), 197-216.

Picariello, F., Moss-Morris, R., Macdougall, I. C., & Chilcot, J. (2017b). The role of psychological factors in fatigue among end-stage kidney disease patients: A critical review. *Clinical Kidney Journal*, *10*(1), 79–88. https://doi.org/10.1093/ckj/sfw113

Picariello, F., Moss-Morris, R., Macdougall, I. C., & Chilcot, J. (2018). 'It's when you're not doing too much you feel tired': A qualitative exploration of fatigue in end-stage kidney disease. *British Journal of Health Psychology*, *23*(2), 311–333. https://doi.org/10.1111/bjhp.12289

Picariello, F., Norton, S., Moss-Morris, R., Macdougall, I. C., & Chilcot, J. (2019). A prospective study of fatigue trajectories among in-centre haemodialysis patients. *British Journal of Health Psychology*. https://doi.org/10.1111/bjhp.12395

Plano Clark, V. L., Anderson, N., Wertz, J. A., Zhou, Y., Schumacher, K., & Miaskowski, C. (2015). Conceptualizing Longitudinal Mixed Methods Designs: A Methodological Review of Health Sciences Research. *Journal of Mixed Methods Research*, *9*(4), 297–319. https://doi.org/10.1177/1558689814543563

Pope, C., Van Royen, P., & Baker, R. (2002). Qualitative methods in research on healthcare quality. *BMJ Quality & Safety*, *11*(2), 148-152.

Port, F. K., Wolfe, R. A., Mauger, E. A., Berling, D. P., & Jiang, K. (1993). Comparison of survival probabilities for dialysis patients vs cadaveric renal transplant recipients. *Jama*, *270*(11), 1339-1343.

Poss, J., & Jezewski, M. A. (2002). The role and meaning of susto in Mexican Americans' explanatory model of type 2 diabetes. *Medical Anthropology Quarterly, 16*, 360-377

Preacher, K. J. (2019). Latent Growth Curve Models. *The Reviewer's Guide to Quantitative Methods in the Social Sciences*, 178–192. https://doi.org/10.4324/9781315755649-13

Price, M., & Dalgleish, J. (2013). Help-seeking among indigenous Australian adolescents: exploring attitudes, behaviours and barriers. *Youth Studies Australia*, *32*(1), 10-18.

Rad, M. S., Martingano, A. J., & Ginges, J. (2018). Toward a psychology of Homo sapiens: Making psychological science more representative of the human population. *Proceedings of the National Academy of Sciences of the United States of America*, *115*(45), 11401–11405. https://doi.org/10.1073/pnas.1721165115

Rajulton, F. (2001). The fundamentals of longitudinal research: An overview. *Canadian Studies in Population [ARCHIVES]*, 169-185.

Rastad, H., Ejtahed, H. S., Shafiee, G., Safari, A., Shahrestanaki, E., Khodaparast, Z., ... & Qorbani, M. (2021). The risk factors associated with COVID-19-Related death among patients with end-stage renal disease. *BMC Nephrology*, *22*(1), 1-8. https://doi.org/10.1186/s12882-020-02221-w

Rees, J., Chilcot, J., Donnellan, W., & Soulsby, L. (2018). Exploring the nature of illness perceptions in people with end-stage kidney disease. *Journal of Renal Care*, *44*(1), 19–29. https://doi.org/10.1111/jorc.12225

Regan, T., Levesque, J. V., Lambert, S. D., & Kelly, B. (2015). A qualitative investigation of health care professionals', patients' and partners' views on psychosocial issues and related interventions for couples coping with cancer. *PLoS ONE, 10*(7), 1–23. https://doi.org/10.1371/journal.pone.0133837

Regmi, K., Naidoo, J., & Pilkington, P. (2010). Understanding the Processes of Translation and Transliteration in Qualitative Research. *International Journal of Qualitative Methods*, *9*, 16–26. https://doi.org/10.1177/160940691000900103

Reid, C., Seymour, J., & Jones, C. (2016). A thematic synthesis of the experiences of adults living with hemodialysis. *Clinical Journal of the American Society of Nephrology*, *11*(7), 1206-1218.

Richardson, E. M., Schüz, N., Sanderson, K., Scott, J. L., & Schüz, B. (2016). Illness representations, coping, and illness outcomes in people with cancer: a systematic review and meta-analysis. *Psycho-Oncology*, *26*(6), 724–737. https://doi.org/10.1002/pon.4213

Ring, N., Ritchie, K., Mandava, L., & Jepson, R. (2011). *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews*. NHS Quality Improvement Scotland.

Ritchie, J., Spencer, L., Bryman, A., & Burgess, R. G. (1994). *Analysing Qualitative Data.*

Robinson, B. M., Akizawa, T., Jager, K. J., Kerr, P. G., Saran, R., & Pisoni, R. L. (2016). Factors affecting outcomes in patients reaching end-stage kidney disease worldwide: differences in access to renal replacement therapy, modality use, and haemodialysis practices. *The Lancet*, *388*(10041), 294-306. doi:10.1016/S0140-6736(16)30448-2

Rogers, R.W. (1983) Cognitive and physiological processes in fear appeals and attitude change: A *Revised Theory Of Protection Motivation*. In: Cacioppo J and Petty R (eds) Social Psychophysiology. Guilford Press.

Rozas, L. W., & Klein, W. C. (2010). The value and purpose of the traditional qualitative literature review. *Journal of Evidence-Based Social Work*, *7*(5), 387-399. : https://doi.org/10.1080/15433710903344116

Ruspini, E. (2003). *An Introduction to Longitudinal Research*. Routledge.

Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. *International Journal of Therapy and Rehabilitation, 16*, 6, 309-314. https://doi.org/10.12968/ijtr.2009.16.6.42433

Ryder, A. G., Yang, J., Zhu, X., Yao, S., Yi, J., Heine, S. J., & Bagby, R. M. (2008). The cultural shaping of depression: somatic symptoms in China, psychological symptoms in

North America?. *Journal of Abnormal Psychology*, *117*(2), 300.

Sak, J., Dryl-Rydzyńska, T., & Książek, A. (2015). Relationships Between Perception of Illness, Social Support and Hemodialysis Adequacy. *Polish Journal of Public Health*, *124*(4), 174–177. https://doi.org/10.1515/pjph-2015-0002

Salovey, P., & Birnbaum, D. (1989). Influence of mood on health-relevant cognitions. *Journal of Personality and Social Psychology*, *57*(3), 539. https://doi.org/10.1037/0022-3514.57.3.539

Santos, P. R., Júnior, J. R. F. G. C., Cavalcante Filho, J. R. M., Ferreira, T. P., dos Santos Filho, J. N. G., & da Silva Oliveira, S. (2017). Religious coping methods predict depression and quality of life among end-stage renal disease patients undergoing hemodialysis: a cross-sectional study. *BMC Nephrology*, *18*(1), 1-8. https://doi.org/10.1186/s12882-017-0619-1

Sarafidis, P., Faitatzidou, D., & Papagianni, A. (2021). Benefits and risks of frequent or longer haemodialysis: weighing the evidence. *Nephrology Dialysis Transplantation*, *36*(7), 1168-1176. doi: 10.1093/ndt/gfaa023

Saran, R., Robinson, B., Abbott, K.C., …Shahinian, V. (2019). US renal data system 2018 annual data report: epidemiology of kidney disease in the United States. *American Journal of Kidney Disease, 3:*A7–8. doi: 10.1053/j.ajkd.2019.01.001

Sararoudi, R. B., Motmaen, M., Maracy, M. R., Pishghadam, E., & Kheirabadi, G. R. (2016). Efficacy of illness perception focused intervention on quality of life, anxiety, and depression in patients with myocardial infarction. *Journal of Research in Medical Sciences: the Official Journal of Isfahan University of Medical Sciences*, *21*.

Sarıkoç, G., & Öz, F. (2016). The effects and stigma of mental illness in Turkey. *Community Mental Health Journal*, *52*(3), 353-360. https://doi.org/10.1007/s10597-015-9960-7

Sarnak, M. J., Levey, A. S., Schoolwerth, A. C., Coresh, J., Culleton, B., Hamm, L. L., ... & Parfrey, P. (2003). Kidney disease as a risk factor for development of cardiovascular disease: a statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. *Circulation*, *108*(17), 2154-2169.

Sav, A., Salehi, A., Mair, F. S., & McMillan, S. S. (2017). Measuring the burden of treatment for chronic disease: Implications of a scoping review of the literature. *BMC Medical Research Methodology*, *17*(1), 1–14. https://doi.org/10.1186/s12874-017-0411-8

Sawyer, A. T., Harris, S. L., & Koenig, H. G. (2019). Illness perception and high readmission health outcomes. *Health Psychology Open*, *6*(1). https://doi.org/10.1177/2055102919844504

Schick-Makaroff, K., Molzahn, A. E., & Kalfoss, M. (2018). Symptoms, coping, and quality of life of people with chronic kidney disease. *Nephrology Nursing Journal*, *45*(4).

Schieppati, A., & Remuzzi, G. (2005). Chronic renal diseases as a public health problem: epidemiology, social, and economic implications. *Kidney International*, *68*, S7-S10.

Schnuelle, P., Lorenz, D., Trede, M., & Van Der Woude, F. J. (1998). Impact of renal cadaveric transplantation on survival in end-stage renal failure: evidence for reduced mortality risk compared with hemodialysis during long-term follow-up. *Journal of the American Society of Nephrology*, *9*(11), 2135-2141.

Schouten, B., Bergs, J., Vankrunkelsven, P., & Hellings, J. (2019). Healthcare professionals' perspectives on the prevalence, barriers and management of psychosocial issues in cancer care: A mixed methods study. *European Journal of Cancer Care, 28*(1), 1–9. https://doi.org/10.1111/ecc.12936

Schreuder, M. F. (2018). Life with one kidney. *Pediatric Nephrology*, *33*(4), 595-604. https://doi.org/10.1007/s00467-017-3686-4

Seibel, I., de Figueiredo, C. E. P., Telöken, C., & Moraes, J. F. (2002). Efficacy of oral

sildenafil in hemodialysis patients with erectile dysfunction. *Journal of the American Society of Nephrology*, *13*(11), 2770-2775.

Seidel, U. K., Gronewold, J., Volsek, M., Todica, O., Kribben, A., Bruck, H., & Hermann, D. M. (2014). Physical, cognitive and emotional factors contributing to quality of life, functional health and participation in community dwelling in chronic kidney disease. *PloS one*, *9*(3), e91176. doi:10.1371/journal.pone.0091176

Sein, K., Damery, S., Baharani, J., Nicholas, J., & Combes, G. (2020). Emotional distress and adjustment in patients with end-stage kidney disease: A qualitative exploration of patient experience in four hospital trusts in the West Midlands, UK. *Plos One*, *15*(11), e0241629. https://doi.org/10.1371/journal.pone.0241629

Sesso, R., & Yoshihiro, M. M. (1997). Time of diagnosis of chronic renal failure and assessment of quality of life in haemodialysis patients. *Nephrology, dialysis, transplantation: official publication of the European Dialysis and Transplant Association-European Renal Association*, *12*(10), 2111-2116.

Sevindik, G., & Yuruyen, B. (2017). The identification of the perceived family support of patients treated by hemodialysis therapy due to chronic kidney failure in North Cyprus. *International Journal of Innovation Research and Education, 4*(3), 127-134. https://doi.org/10.18844/ijire.v4i3.2550

Seyyedrasooli, A., Parvan, K., Rahmani, A., & Rahimi, Z. (2013). Effect of illness perception promoting interventions on treatment adherence in hemodialysis patients: A randomized controlled trial. *Iranian Journal Critical Care Nursing, 6*(2)77-86.

Shannon-Baker, P. (2016). Making Paradigms Meaningful in Mixed Methods Research. *Journal of Mixed Methods Research*, *10*(4), 319–334. https://doi.org/10.1177/1558689815575861

Sharma, S., King, M., Mooney, R., Davenport, A., Day, C., Duncan, N., … Farrington, K. (2019). How do patients from South Asian backgrounds experience life on haemodialysis in the UK? A multicentre qualitative study. *BMJ Open*, *9*(5). https://doi.org/10.1136/bmjopen-2018-024739

Sharma, S. et al. (2020). Exploring illness perceptions of South Asian haemodialysis patients living in the UK (preprint).

Sharma, S., Norton, S., Bhui, K., Mooney, R., Bansal, T., Day, C., ... & Farrington, K. (2022). *The use of culturally adapted and translated depression screening questionnaires with South Asian haemodialysis patients in England*. PsyArXiv file:///C:/Users/BAU/Downloads/MODEST%20Final.pdf

Shavitt, S., Johnson, T. P., & Zhang, J. (2011). Horizontal and vertical cultural differences in the content of advertising appeals. *Journal of International Consumer Marketing*, *23*(3-4), 297-310.

Shaw, J. E., Sicree, R. A., & Zimmet, P. Z. (2010). Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice*, *87*(1), 4-14.

Shefer, G., Rose, D., Nellums, L., Thornicroft, G., Henderson, C., & Evans-Lacko, S. (2013). 'Our community is the worst': The influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *International Journal of Social Psychiatry*, *59*(6), 535-544. https://doi.org/10.1177/0020764012443759

Shirazian, S., Grant, C. D., Aina, O., Mattana, J., Khorassani, F., & Ricardo, A. C. (2017). Depression in chronic kidney disease and end-stage renal disease: similarities and differences in diagnosis, epidemiology, and management. *Kidney International Reports*, *2*(1), 94-107.

Shlipak, M. G., Fried, L. F., Cushman, M., Manolio, T. A., Peterson, D., Stehman-Breen, C., ... & Psaty, B. (2005). Cardiovascular mortality risk in chronic kidney disease: comparison of traditional and novel risk factors. *Jama*, *293*(14), 1737-1745. doi: 10.1001/ jama.293.14.1737 [PubMed: 15827312]

Shrout, P. E., & Bolger, N. (2002). Mediation in experimental and nonexperimental studies: New procedures and recommendations. *Psychological Methods*, *7*(4), 422–445. https://doi.org/10.1037/1082-989X.7.4.422

Sijpkens, Y. W. J., Berkhout-Byrne, N. C., & Rabelink, T. J. (2008). Optimal predialysis care. *NDT Plus*, *1*(SUPPL. 4). http://doi.org/10.1093/ndtplus/sfn117

Silva Junior, G. B., Daher, E. F., Buosi, A. P. A., Lima, R. S., Lima, M. M., Silva, E. C., ... & Araújo, S. M. (2014). Depression among patients with end-stage renal disease in hemodialysis. *Psychology, Health & Medicine*, *19*(5), 547-551.

Simon, G. E., VonKorff, M., Piccinelli, M., Fullerton, C., & Ormel, J. (1999). An international study of the relation between somatic symptoms and depression. *New England Journal of Medicine*, *341*(18), 1329-1335.

Singer, S. S. J. E., & Schachter, S. (1962). Cognitive, social, and physiological determinants of emotional state. *Psychological Review*, *69*(5), 379-399. https://doi.org/10.1037/h0046234

Singer, J. D., & Willett, J. B. (2003). *Applied longitudinal data analysis: Modeling change and event occurrence*. New York: Oxford University Press

Skapinakis, P., Lewis, G., & Meltzer, H. (2003). Clarifying the relationship between unexplained chronic fatigue and psychiatric morbidity: results from a community survey in Great Britain. *International Review of Psychiatry*, *15*(1-2), 57-64.

Slagman, M. C. J., Waanders, F., Hemmelder, M. H., Woittiez, A. J., Janssen, W. M. T., Lambers Heerspink, H. J., … Laverman, G. D. (2011). Moderate dietary sodium restriction added to angiotensin converting enzyme inhibition compared with dual blockade in lowering proteinuria and blood pressure: Randomised controlled trial. *BMJ (Online)*, *343*(7818), 1–10. http://doi.org/10.1136/bmj.d4366

Smith, T. W., & MacKenzie, J. (2006). Personality and risk of physical illness. *Annual. Review of Clinical. Psychology*, *2*, 435-467.

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method, Research*. London: Sage

Smith, B. (2018). Generalizability in qualitative research: Misunderstandings, opportunities and recommendations for the sport and exercise sciences. *Qualitative Research in Sport, Exercise and Health*, *10*(1), 137-149. https://www.tandfonline.com/doi/full/10.1080/2159676X.2017.1393221

Snijders, T.A.B., and Bosker, R.J. (1999). *Multilevel Analysis: An Introduction to Basic and Advanced Multilevel Modeling*. London etc.: Sage

Snyder, J.J., Foley, R.N., & Collins, A.J. (2009). Prevalence of CKD in the United States: a sensitivity analysis using the National Health and Nutrition Examination Survey (NHANES) 1999-2004. *American Journal of Kidney Disease, 53*(2), 218-228

Sladdin, I., Chaboyer, W., & Ball, L. (2018). Patients' perceptions and experiences of patient-centred care in dietetic consultations. *Journal of Human Nutrition and Dietetics*, *31*(2), 188-196.

Soilemezi, D., & Linceviciute, S. (2018). Synthesizing Qualitative Research: Reflections and Lessons Learnt by Two New Reviewers. *International Journal of Qualitative Methods*, *17*(1), 1–14. https://doi.org/10.1177/1609406918768014

Song, M. K., Paul, S., Ward, S. E., Gilet, C. A., & Hladik, G. A. (2018). One-year linear trajectories of symptoms, physical functioning, cognitive functioning, emotional well-

being, and spiritual well-being among patients receiving dialysis. *American Journal of Kidney Diseases*, *72*(2), 198-204. https://doi.org/10.1053/j.ajkd.2017.11.016

Song, M. K., Paul, S., Plantinga, L., Henry, C., & Turberville-Trujillo, L. (2019). Social Networks of Self-care and Perceived Treatment Burden Among Patients on In-Center Hemodialysis. *Kidney Medicine*, *1*(3), 97–103. https://doi.org/10.1016/j.xkme.2019.04.001

Spendelow, J. S., Joubert, H. E., Lee, H., & Fairhurst, B. R. (2018). Coping and adjustment in men with prostate cancer: a systematic review of qualitative studies. *Journal of Cancer Survivorship*, *12*(2), 155-168. https://doi.org/10.1007/s11764-017-0654-8

Stanifer, J. W., Muiru, A., Jafar, T. H., & Patel, U. D. (2016). Chronic kidney disease in low- and middle-income countries. *Nephrology Dialysis Transplantation*, *31*(6), 868-874. https://doi.org/10.1093/ndt/gfv466

Staplin, N., Haynes, R., Herrington, W. G., Reith, C., Cass, A., Fellström, B., ... & Walker, R. (2016). Smoking and adverse outcomes in patients with CKD: The Study of Heart and Renal Protection (SHARP). *American Journal of Kidney Diseases*, *68*(3), 371-380.

Steginga, S. K., Hutchison, S. D., Turner, J., & Dunn, J. (2006). Translating psychosocial care: guidelines into action. In *Cancer Forum* (Vol. 30, No. 1, pp. 28-31).

Stel, V. S., van de Luijtgaarden, M. W. M., Wanner, C., & Jager, K. J. (2011). The 2008 ERA-EDTA Registry Annual Report. *Nephrology Dialysis Transplantation Plus*, *4*(1), 1–13. http://doi.org/10.1093/ndtplus/sfq191

Stenman, U., Hakama, M., Knekt, P., Aromaa, A., Teppo, L., Leinonen, J., ... & Tang, Z. (2010). Measurement and modeling of health-related quality of life. *Epidemiological Demography in Public Health*, *195*. https://escholarship.org/content/qt70x7m955/qt70x7m955.pdf

Stevens, L.A., & Levey, A.S. (2005). Chronic kidney disease in the elderly—how to assess risk. *New England Journal of Medicine, 352*(2), 122–2124. [PubMed: 15901867]

Stevens, L. A., Li, S., Wang, C., Huang, C., Becker, B. N., Bomback, A. S., ... & Norris, K. C. (2010). Prevalence of CKD and comorbid illness in elderly patients in the United States: results from the Kidney Early Evaluation Program (KEEP). *American Journal of Kidney Diseases*, *55*(3), S23-S33. doi:10.1053/j.ajkd.2009.09.035.

Stewart, S., Guillen, A. G., Taylor, W. J., Gaffo, A., Slark, J., Gott, M., & Dalbeth, N. (2020). The experience of a gout flare: a meta-synthesis of qualitative studies. *Seminars in Arthritis and Rheumatism*, *50*(4), 805–811. https://doi.org/10.1016/j.semarthrit.2020.06.001

Stoop, C., Pouwer, F., Pop, V., Den Oudsten, B., & Nefs, G. (2019). Psychosocial health care needs of people with type 2 diabetes in primary care: Views of patients and health care providers. *Journal of Advanced Nursing, 75*(8), 1702–1712. https://doi.org/10.1111/jan.13996

Strugała, M., Talarska, D., Kalfoss, M., Niewiadomski, T., Rozmarynowska, B., & Dyk, D. (2019). Perception of illness by patients treated with haemodialysis. *Medical Research Journal*, *4*(4), 193-200.

Stuckey, H. L. (2013). Three types of interviews: Qualitative research methods in social health. *Journal of Social Health and Diabetes*, *1*(02), 056-059.

Stuckey, H. L., Vallis, M., Kovacs Burns, K., Mullan-Jensen, C. B., Reading, J. M., Kalra, S., … Peyrot, M. (2015). "I Do My Best to Listen to Patients": Qualitative Insights Into DAWN2 (Diabetes Psychosocial Care From the Perspective of Health Care Professionals in the Second Diabetes Attitudes, Wishes and Needs Study). *Clinical Therapeutics, 37*(9), 1986-1998.e12. https://doi.org/10.1016/j.clinthera.2015.06.010

Sturgiss, E. A., & Clark, A. M. (2020). Using critical realism in primary care research: An overview of methods. *Family Practice*, *37*(1), 143–145.

https://doi.org/10.1093/fampra/cmz084

Suls, J., Martin, R., & Leventhal, H. (1997). Social comparison, lay referral, and the decision to seek medical care. In B. P. Buunk & F. X. Gibbons (Eds.), *Health, Coping, and Well-Being: Perspectives from Social Comparison Theory* (pp. 195–226). Lawrence Erlbaum Associates Publishers.

Süleymanlar, G., Ateş, K., & Seyhani, N. (2018). *Registry of the Nephrology, Dialysis and Transplantation in Turkey 2017 Report Published by the Turkish Society of Nephrology, Turkey.*

Swift, O., Sharma, S., Ramanarayanan, S., Umar, H., Laws, K. R., Vilar, E., & Farrington, K. (2021). Prevalence and outcomes of chronic liver disease in patients receiving dialysis: systematic review and meta-analysis. *Clinical Kidney Journal.*

Taber, K. S. (2018). The use of Cronbach's alpha when developing and reporting research instruments in science education. *Research in Science Education*, *48*(6), 1273-1296.

Tanaka, K., Nakayama, M., Kanno, M., Kimura, H., Watanabe, K., Tani, Y., ... & Sato, K. (2013). Skin autofluorescence is associated with the progression of chronic kidney disease: a prospective observational study. *PLoS One*, *8*(12), e83799. doi: 10.1371/journal.pone.0083799 [PubMed: 24349550]

Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *Journal of the Royal Society of Medicine Short Reports, 4*(6), DOI: 10.1177/2042533313479197.

Taris, T.W. (2000). *A Primer in Longitudinal Data Analysis*. London: Sage Publications

Tasmoc, A., Hogas, S., & Covic, A. (2013). A longitudinal study on illness perceptions in hemodialysis patients: changes over time. *Archives of Medical Science : AMS*, *9*(5), 831–836. https://doi.org/10.5114/aoms.2013.38678

Temple, B., & Young, A. (2004). *Qualitative research and translation dilemmas*. *SAGE Publications* (Vol. 4). https://doi.org/10.1177/1468794108095079

Ten Have, M., De Graaf, R., Ormel, J., Vilagut, G., Kovess, V., & Alonso, J. (2010). Are attitudes towards mental health help-seeking associated with service use? Results from the European study of epidemiology of mental disorders. *Social Psychiatry and Psychiatric Epidemiology, 45*(2), 153–163. https://doi.org/10.1007/s00127-009-0050-4

Tezel, A., Karabulutlu, E., & Şahin, Ö. (2011). Depression and perceived social support from family in Turkish patients with chronic renal failure treated by hemodialysis. *Journal of Research in Medical Sciences: the official journal of Isfahan University of Medical Sciences*, *16*(5), 666.

The Illness Perception Questionnaire, (n.d). *The Illness Perception Questionnaire*, https://ipq.h.uib.no/

The jamovi project (2021). *jamovi* (Version 1.6) [Computer Software]. Retrieved from https://www.jamovi.org

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 1–10. https://doi.org/10.1186/1471-2288-8-45

Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: providing the research evidence for public health nursing

Thurlow, J. S., Joshi, M., Yan, G., Norris, K. C., Agodoa, L. Y., Yuan, C. M., & Nee, R. (2021). Global epidemiology of end-stage kidney disease and disparities in kidney replacement therapy. *American Journal of Nephrology*, *52*(2), 98-107. https://doi.org/10.1159/000514550

Tiggelman, D., van de Ven, M. O. M., van Schayck, O. C. P., Kleinjan, M., & Engels, R. C. M. E. (2014). The Common Sense Model in early adolescents with asthma: Longitudinal relations between illness perceptions, asthma control and emotional problems mediated by coping. *Journal of Psychosomatic Research*, *77*(4), 309–315.

https://doi.org/10.1016/j.jpsychores.2014.07.010

Timmers, L., Thong, M., Dekker, F. W., Boeschoten, E. W., Heijmans, M., Rijken, M., ... & Kaptein, A. (2008). Illness perceptions in dialysis patients and their association with quality of life. *Psychology and Health*, *23*(6), 679-690.

Timmermans, I., Versteeg, H., Meine, M., Pedersen, S. S., & Denollet, J. (2017). Illness perceptions in patients with heart failure and an implantable cardioverter defibrillatorDimensional structure, validity, and correlates of the brief illness perception questionnaire in Dutch, French and German patients. *Journal of Psychosomatic Research*, *97*(March), 1–8. https://doi.org/10.1016/j.jpsychores.2017.03.014

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.

Tong, A., Sainsbury, P., Chadban, S., Walker, R. G., Harris, D. C., Carter, S. M., … Craig, J. C. (2009). Patients' Experiences and Perspectives of Living With CKD. *American Journal of Kidney Diseases*, *53*(2), 689–700. https://doi.org/10.1053/j.ajkd.2008.10.050

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(1), 181.

Tong, A., Winkelmayer, W. C., & Craig, J. C. (2014). Qualitative research in CKD: An overview of methods and applications. *American Journal of Kidney Diseases*, *64*(3), 338–346. https://doi.org/10.1053/j.ajkd.2014.02.026

Tong, Allison, & Craig, J. C. (2016). Tuning into qualitative research-a channel for the patient voice. *Clinical Journal of the American Society of Nephrology*, *11*(7), 1128–1130. https://doi.org/10.2215/CJN.05110516

Tsai, Y. C., Hung, C. C., Hwang, S. J., Wang, S. L., Hsiao, S. M., Lin, M. Y., ... & Chen, H. C. (2009). Quality of life predicts risks of end-stage renal disease and mortality in patients with chronic kidney disease. *Nephrology Dialysis Transplantation*, *25*(5), 1621-1626. doi: gfp671 [pii];10.1093/ ndt/gfp671

Turkmen, K., Yazici, R., Solak, Y., Guney, I., Altintepe, L., Yeksan, M., & Tonbul, H. Z. (2012). Health-related quality of life, sleep quality, and depression in peritoneal dialysis and hemodialysis patients. *Hemodialysis International*, *16*(2), 198–206. https://doi.org/10.1111/j.1542-4758.2011.00648.x

Turner, J., Zapart, S., Pedersen, K., Rankin, N., Luxford, K., & Fletcher, J. (2005). Clinical practice guidelines for the psychosocial care of adults with cancer. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *14*(3), 159-173.

Uc bolgeye hemodiyaliz hizmeti saglanacak, (2014, March 12). *Yeniduzen*. Retreived from http://www.yeniduzen.com/3-bolgeye-hemodiyaliz-hizmeti-saglancak-36067h.htm

United States Renal Data System (USRDS). (2017). Chapter 11 : International Comparisons. *USRDS ANNUAL DATA REPORT*, *2*.

Unruh, M., Yan, G., Radeva, M., Hays, R. D., Benz, R., Athienites, N. V., ... & Meyer, K. B. (2003). Bias in assessment of health-related quality of life in a hemodialysis population: a comparison of self-administered and interviewer-administered surveys in the HEMO study. *Journal of the American Society of Nephrology*, *14*(8), 2132-2141.

Unruh, M., Benz, R., Greene, T., Yan, G., Beddhu, S., Devita, M., ... & Rehm-Mcgillicuddy, J. (2004). Effects of hemodialysis dose and membrane flux on health-related quality of life in the HEMO Study. *Kidney International*, *66*(1), 355-366.

Unruh, M. L., Weisbord, S. D., & Kimmel, P. L. (2005). Psychosocial factors in patients with chronic kidney disease: Health-related quality of life in nephrology research and clinical practice. In *Seminars in dialysis* (Vol. 18, No. 2, pp. 82-90). Oxford, UK: Blackwell

Science Inc.

Uskul, Ayse K. (2010) Socio-cultural aspects of health and illness. In: French, David and Kaptein, Ad A. and Vedhara, Kavita and Weinman, John, eds. *Health Psychology* (2nd edition). Wiley-Blackwell.

Uskul, A. K., & Hynie, M. (2007). Self-Construal and Concerns Elicited by Imagined and Real Health Problems 1. *Journal of Applied Social Psychology*, *37*(9), 2156-2189. https://doi.org/10.1111/j.1559-1816.2007.00283.x

Uzmanlar Kibris'ta yeni bir bobrek hastaligi tanimladi (2016, November 29). *Gundem Kibris*. Retrieved from https://www.gundemkibris.com/mansetler/uzmanlar-kuzey-kibrista-yeni-bir-bobrek-hastaligi-tanimladi-h194538.html

Qaseem, A., Hopkins, R. H., Sweet, D. E., Starkey, M., & Shekelle, P. (2013). Screening, monitoring, and treatment of stage 1 to 3 chronic kidney disease: a clinical practice guideline from the American College of Physicians. *Annals of Internal Medicine*, *159*(12), 835-847. doi: 10.7326/0003-4819-159-12-201312170-00726 2013

Van Camp, Y. P., Huybrechts, S. A., Van Rompaey, B., & Elseviers, M. M. (2012). Nurse-led education and counselling to enhance adherence to phosphate binders. *Journal of Clinical Nursing*, *21*(9-10), 1304-1313. https://doi.org/10.1111/j.1365-2702.2011.03967.x

Van De Luijtgaarden, M. W. M., Noordzij, M., Tomson, C., Couchoud, C., Cancarini, G., Ansell, D., … Jager, K. J. (2012). Factors influencing the decision to start renal replacement therapy: Results of a survey among European nephrologists. *American Journal of Kidney Diseases*, *60*(6), 940–948. http://doi.org/10.1053/j.ajkd.2012.07.015

Van Der Velde, M., Matsushita, K., Coresh, J., Astor, B. C., Woodward, M., Levey, A. S., ... & Chronic Kidney Disease Prognosis Consortium. (2011). Lower estimated glomerular filtration rate and higher albuminuria are associated with all-cause and cardiovascular mortality. A collaborative meta-analysis of high-risk population cohorts. *Kidney International*, *79*(12), 1341-1352.

Van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: Is meaning lost in translation? *European Journal of Ageing*, *7*(4), 313–316. https://doi.org/10.1007/s10433-010-0168-y

Van Os, S., Norton, S., Hughes, L. D., & Chilcot, J. (2012). Illness perceptions account for variation in positive outlook as well as psychological distress in rheumatoid arthritis. *Psychology, Health & Medicine*, *17*(4), 427-439.

Vázquez, I., Valderrábano, F., Fort, J., Jofré, R., López-Gómez, J. M., Moreno, F., & Sanz-Guajardo, D. (2005). Psychosocial factors and health-related quality of life in hemodialysis patients. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *14*(1), 179–90. http://doi.org/10.1007/s11136-004-3919-4

Van Oort, L., Schröder, C., & French, D. P. (2011). What do people think about when they answer the Brief Illness Perception Questionnaire? A 'think-aloud'study. *British journal of health psychology*, *16*(2), 231-245. DOI:10.1348/135910710X500819

Vitell, S. J., King, R. A., Howie, K., Toti, J. F., Albert, L., Hidalgo, E. R., & Yacout, O. (2016). Spirituality, moral identity, and consumer ethics: A multi-cultural study. *Journal of Business Ethics*, *139*(1), 147-160.

Vohs, K. D., & Baumeister, R. F. (2004). Understanding self-regulation. *Handbook of Self Regulation*, *19*.

Vijay, V. R., & Kang, H. K. (2021). The worldwide prevalence of non-adherence to diet and fluid restrictions among hemodialysis patients: A systematic review and meta-analysis. *Journal of Renal Nutrition*. https://doi.org/10.1053/j.jrn.2021.11.007

Vitetta, L., Anton, B., Cortizo, F., & Sali, A. (2005). Mind-body medicine: Stress and its

impact on overall health and longevity. *Annals of the New York Academy of Sciences, 1057*(1), 492-505. doi: 10.1196/annals.1322.038

Vernon, G., Baranova, A., & Younossi, Z.M. (2011). Systematic review: the epidemiology and natural history of non-alcoholic fatty liver disease and non-alcoholic steatohepatitis in adults. *Alimentary Pharmacology and Therapeutics. 34*(3):274-85.

Vogl, D., Rosenfeld, B., Breitbart, W., Thaler, H., Passik, S., McDonald, M., & Portenoy, R. K. (1999). Symptom prevalence, characteristics, and distress in AIDS outpatients. *Journal of pPain and Symptom Management*, *18*(4), 253-262.

Von Lersner, U., Gerb, J., Hizli, S., Waldhuber, D., Wallerand, A. F., Bajbouj, M., ... & Hahn, E. (2019). Stigma of mental illness in Germans and Turkish immigrants in Germany: the effect of causal beliefs. *Frontiers in Psychiatry*, *10*, 46. https://doi.org/10.3389/fpsyt.2019.00046

Walker, R. C., Tong, A., Howard, K. & Palmer, S. C. (2019). Patient expectations and experiences of remote monitoring for chronic diseases: systematic review and thematic synthesis of qualitative studies. International Journal of Medical Informatics, 12478-85. https://doi.org/10.1016/j.ijmedinf.2019.01.013 interventions. *Worldviews on Evidence-Based Nursing*, *1*(3), 176-184.

Wang, L.-J., Wu, M.-S., Hsu, H.-J., Wu, I.-W., Sun, C.-Y., Chou, C.-C., … Chen, C.-K. (2012). The Relationship between Psychological Factors, Inflammation, and Nutrition in Patients with Chronic Renal Failure Undergoing Hemodialysis. *The International Journal of Psychiatry in Medicine*, *44*(2), 105–118. http://doi.org/10.2190/PM.44.2.b

Waterman, A. D., Stanley, S. L., Covelli, T., Hazel, E., Hong, B. A., & Brennan, D. C. (2006). Living donation decision making: recipients' concerns and educational needs. *Progress in Transplantation*, *16*(1), 17-23.

Webster. A.C., Nagler, E.V., Morton, R.L., & Masson, P. (2017). Chronic Kidney Disease. *Lancet, 389*(10075), 1238-52.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & Health*, *11*(3), 431–445. https://doi.org/10.1080/08870449608400270

Weisbord, S. D., Fried, L. F., Arnold, R. M., Rotondi, A. J., Fine, M. J., Levenson, D. J., & Switzer, G. E. (2004). Development of a symptom assessment instrument for chronic hemodialysis patients: the Dialysis Symptom Index. *Journal of Pain and Symptom Management*, *27*(3), 226-240.

Weisbord, S. D., Fried, L. ., Arnold, R. B., Fine, M. J., Levenson, D. J., Peterson, R. A., & Switzer, G. A. (2005). Prevalence, Severity, and Importance of Physical and Emotional Symptoms in Chronic Hemodialysis Patients. *Journal of the American Society of Nephrology*, *16*(8), 2487–2494. http://doi.org/10.1681/ASN.2005020157

Weisbord, S. D., Fried, L. F., Mor, M. K., Resnick, A. L., Unruh, M. L., Palevsky, P. M., Levenson, D. J., Cooksey, S. H., Fine, M. J., Kimmel, P. L., & Arnold, R. M. (2007). Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clinical journal of the American Society of Nephrology : CJASN*, *2*(5), 960–967. https://doi.org/10.2215/CJN.00990207

Weisbord, S. D., Mor, M. K., Sevick, M. A., Shields, A. M., Rollman, B. L., Palevsky, P. M., ... & Fine, M. J. (2014). Associations of depressive symptoms and pain with dialysis adherence, health resource utilization, and mortality in patients receiving chronic hemodialysis. *Clinical Journal of the American Society of Nephrology*, *9*(9), 1594-1602.

Weisbord, S. D. (2016). Patient-centered dialysis care: Depression, pain, and quality of life. *Seminars in Dialysis*, *29*(2), 158-164.

White, S. L., Chadban, S. J., Jan, S., Chapman, J. R., & Cass, A. (2008). How can we achieve global equity in provision of renal replacement therapy?. *Bulletin of the World Health*

Organization, *86*, 229-237.

Whitehead, L., Jacob, E., Towell, A., Abu-qamar, M. E., & Cole-Heath, A. (2018). The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *Journal of Clinical Nursing*, *27*(1-2), 22-30. https://doi.org/10.1111/jocn.13775

Whitmarsh, A., Koutantji, M., & Sidell, K. (2003). Illness perceptions, mood and coping in predicting attendance at cardiac rehabilitation. *British Journal of Health Psychology*, *8*(2), 209-221. https://doi.org/10.1348/135910703321649178

Wild, S., Roglic, G., Green, A., Sicree, R., & King, H. (2004). Global prevalence of diabetes: estimates for the year 2000 and projections for 2030. *Diabetes Care*, *27*(5), 1047-1053.

Wilund, K. R., Thompson, S., Viana, J. L., & Wang, A. Y. M. (2021). Physical Activity and Health in Chronic Kidney Disease. *Nephrology and Public Health Worldwide*, *199*, 43-55. https://doi.org/10.1159/000517696

Wong, D. F. K., & Li, J. C. M. (2014). Cultural influence on Shanghai Chinese people's help-seeking for mental health problems: implications for social work practice. *British Journal of Social Work*, *44*(4), 868-885. https://doi.org/10.1093/bjsw/bcs180

Wu, H., Zhao, X., Fritzsche, K., Salm, F., Leonhart, R., Jing, W., Yang, J., & Schaefert, R. (2014). Negative illness perceptions associated with low mental and physical health status in general hospital outpatients in China. *Psychology, Health and Medicine*, *19*(3), 273–285. https://doi.org/10.1080/13548506.2013.802358

Wu, C. C., Lin, C. C., Hsieh, H. F., & Chang, S. C. (2015). Lived experiences and illness representation of Taiwanese patients with late-stage chronic kidney disease. *Journal of Health Psychology*, *21*(12), 2788–2798. https://doi.org/10.1177/1359105315587134

Wuerth, D., Finkelstein, S.H., & Finkelstein, F.O. (2005). The identification and treatment of depression in patients maintained on dialysis. Seminars in Dialysis, 18(2), 142–6

Xu, R., Zhang, L., Zhang, P., Wang, F., Zuo, L., & Wang, H. (2009). Comparison of the prevalence of chronic kidney disease among different ethnicities: Beijing CKD survey and American NHANES. *Nephrology Dialysis Transplantation*, *24*(4), 1220–1226. http://doi.org/10.1093/ndt/gfn609

Yang, F., Liao, M., Wang, P., Yang, Z., & Liu, Y. (2021). The cost-effectiveness of kidney replacement therapy modalities: a systematic review of full economic evaluations. *Applied Health Economics and Health Policy*, *19*(2), 163-180.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Yavuz, D., Yavuz, R., & Altuno, A. (2012). The Psychiatric Disorders in Hemodialysis Patients. *Turkish Medical Journal*, *6*(1), 33–37.

Yen, S., Robins, C. J., & Lin, N. (2000). A cross-cultural comparison of depressive symptom manifestation: China and the United States. *Journal of Consulting and Clinical Psychology*, *68*(6), 993.

Yeoh, S. H., Tam, C. L., Wong, C. P., & Bonn, G. (2017). Examining depressive symptoms and their predictors in Malaysia: Stress, locus of control, and occupation. *Frontiers in Psychology*, *8*(AUG), 1–10. https://doi.org/10.3389/fpsyg.2017.01411

Yildirim, N. K., Okanli, A., Karabulutlu, E. Y., Karahisar, F., & Ozkan, S. (2013). Effects of illness perception on anxiety and depressive symptoms in hemodialysis patients: a multi-center study. *Anadolu Psikiyatri Dergisi-Anatolian Journal of Psychiatry*, *14*(3), 252–259. https://doi.org/10.5455/apd.40629

Yilmaz Karabulutlu, E., & Karaman, S. (2015). Kanser Hastalarında Hastalık Algısının Değerlendirilmesi. *Sağlık Bilimleri ve Meslekleri Dergisi*, *2*(3), 271–284. https://doi.org/10.17681/hsp.84549

Yodchai, K., Dunning, T., Savage, S., & Hutchinson, A. M. (2017). The role of religion and

spirituality in coping with kidney disease and haemodialysis in Thailand. *Scandinavian Journal of Caring Sciences*, *31*(2), 359–367. https://doi.org/10.1111/scs.12355

Yoong, R. K., Mooppil, N., Khoo, E. Y., Newman, S. P., Lee, V. Y., Kang, A. W., & Griva, K. (2017). Prevalence and determinants of anxiety and depression in end stage renal disease (ESRD). A comparison between ESRD patients with and without coexisting diabetes mellitus. *Journal of Psychosomatic Research*, *94*, 68-72.

Yorulmaz, H., Kececi, N., & Tatar, A. (2014). Kronik Böbrek Yetmezliği Hastalarında Hastalık Algısının Yaşam Kalitesine Olan Etkisi. *Literatur Sempozyum*, *1*(1), 40–45.

Yorulmaz, H., Tatar, A., Saltukoğlu, G., & Soylu, G. (2013). Diyabetli Hastalarda Hastalık Algısını Etkileyen Faktörlerin İncelenmesi. *Insan ve Toplum Bilimleri Dergisi*, *2*, 367–387.

Yoshida, T., Takei, T., Shirota, S., Tsukada, M., Sugiura, H., Itabashi, M., ... & Nitta, K. (2008). Risk factors for progression in patients with early-stage chronic kidney disease in the Japanese population. *Internal Medicine*, *47*(21), 1859-1864.

Yuan, S., Fan, F., van de Klundert, J., & van Wijngaarden, J. (2022). Primary healthcare professionals' perspective on vertical integration of healthcare system in China: a qualitative study. *BMJ Open*, *12*(2), e057063. http://dx.doi.org/10.1136/bmjopen-2021-057063

Yuz yirmi diyaliz hastasi bobrek nakli bekliyor (2017, May 31). *Halkin Sesi Kibris.* Retrieved from http://www.halkinsesikibris.com/ozel-haber/120-diyaliz-hastasi-bobrek-nakli-bekliyor-h77505.html

Zamanian, H. & Kharameh, Z.T. (2015). Translation and psychometric properties of the persian version of the dialysis symptom index in hemodialysis patients. *Nephro-Urology Monthly*, *7*(1).

Zamanian, H., Poorolajal, J., & Taheri-Kharameh, Z. (2018). Relationship between stress coping strategies, psychological distress, and quality of life among hemodialysis patients. *Perspectives in Psychiatric Care*, *54*(3), 410-415. DOI:10.1111/ppc.12284

Zhang, R., & Reisin, E. (2000). Obesity-hypertension: the effects on cardiovascular and renal systems. *American Journal of Hypertension*, *13*(12), 1308-1314.

Zhang, Y., Fritzsche, K., Leonhart, R., Zhao, X., Zhang, L., Wei, J., Yang, J., Wirsching, M., Nater-Mewes, R., Larisch, A., & Schaefert, R. (2014). Dysfunctional illness perception and illness behaviour associated with high somatic symptom severity and low quality of life in general hospital outpatients in China. *Journal of Psychosomatic Research*, *77*(3), 187–195. https://doi.org/10.1016/j.jpsychores.2014.06.005

Zorba, A. B. (2015). Mental illness stigma in Turkish and Greek Cypriot Communities living in Cyprus: A pilot study. *The European Journal of Social & Behavioural Sciences*.

Appendices

Appendix A: UH Ethics approval for patient qualitative interview study

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Buse Keskindag
CC	Dr Shivani Sharma
FROM	Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair
DATE	25/09/2019

Protocol number: **LMS/PGR/UH/03879**

Title of study: Exploring Illness Related Experiences of Patients with Chronic Kidney Disease.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 01/11/2019

To: 31/05/2020

Appendix B: TRNC Ethics approval for patient qualitative interview study

TURKISH REPUBLIC OF NORTHERN CYPRUS
MINISTRY OF HEALTH
MANAGEMENT OF INPATIENT TREATMENT
DR. BURHAN NALBANTOĞLU STATE HOSPITAL

File number: YTIKI1.01-629-19/E.1114   29th March 2019

RE: Ethics Committee decision about Buse Keskindağ's study.

To whom it may concern,

According to the meeting of the Ethics Committee held on 19th December 2018, we have made a decision that it is ethically convenient for the study entitled "Illness Related Experiences of Patients with Chronic Kidney Disease" to be conducted at the Nicosia Dr.Burhan Nalbatoğlu State Hospital, Famagusta State Hospital, and Kyrenia Akçiçek State Hospital.

By respectfully submitting, we wish you success.

e-signed

Sonuç BUYUK

Deputy Chief Physician

To be submitted: Information:

Nicosia Dr.Burhan Nalbatoğlu State Hospital   Management of Inpatient
Famagusta State Hospital   Treatment
Kyrenia Akçiçek State Hospital

Note: This document has been electronically signed in accordance with 6th article of the Regulation of Electronic Signatures (93/2007).

Bedrettin Demirel Street - Ortaköy   For information: Havva GÜNDOĞDU
Tel: (392) 228 54 41   Secretary of Chief Physician
Fax: (392)223 1899

KUZEY KIBRIS TÜRK CUMHURİYETİ
SAĞLIK BAKANLIĞI
YATAKLI TEDAVİ KURUMLARI DAİRESİ MÜDÜRLÜĞÜ
DR. BURHAN NALBANTOĞLU DEVLET HASTANESİ

Sayı   : YTK1.01-629-19-E.1114   29 Mart 2019
Konu   : Buse Keskindağ'ın Etik Kurulu hk.

DAĞITIM YERLERİNE

        Etik Kurulumuzun 19 Aralık 2018 tarihinde yapmış olduğu toplantıda, Lefkoşa Dr.Burhan
Nalbatoğlu Devlet Hastanesi, Mağusa Devlet Hastanesi ve Girne Akçiçek Devlet Hastanesi'nde
"Kronik Böbrek Yetmezliği olan Hastaların Hastalıkla ilgili Deneyimlerinin İncelenmesi"konulu
araştırmanız tarafımızdan değerlendirilmiş olup Etik Kurulumuz tarafından uygun görülmüştür.

        Bilgilerinize saygılarımızla sunulur, başarılar dileriz

                                                        ℞ e-imzalıdır
                                                        Sonuç BÜYÜK
                                                        Başhekim Yrd.(G)

Dağıtım:
Gereği: Bilgi:
Dr. Burhan Nalbantoğlu Devlet Hastanesi   Yataklı Tedavi Kurumları Dairesi Müdürlüğü
Girne Dr. Akçiçek Hastanesi
Gazimağusa Devlet Hastanesi

Not: 93/2007 sayılı Elektronik İmza Yasası 'nın 6.maddesi gereği bu belge elektronik imza ile imzalanmıştır.

Bedrettin Demirel Caddesi - Ortaköy   Bilgi için:Havva GÜNDOĞDU
Tel: (392) 228 54 41   Başhekim Sekreteri
Fax: (392) 223 18 99

Appendix C: Patient qualitative interview study participant information sheet

PARTICIPANT INFORMATION SHEET

Information about the study

A group of local researchers as well as researchers at the University of Hertfordshire, working in the field of healthcare, are interested in understanding illness related experiences of Turkish Cypriot patients receiving haemodialysis (HD). The researchers would like to know about patients thoughts and perceptions around kidney disease.

Title of the project: Exploring illness related experiences of patients with chronic kidney disease

You are being invited to take part in the above study. Before you decide to do so, it is important that you understand the research that is being carried out. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask a member of the research team anything that is not clear. Please take your time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?

The treatment for kidney disease and via dialysis is known to impact several aspects of a patient's life. This includes taking medications, and restrictions on food and fluids. Patients also experience restrictions on their time due to the need to visit hospital frequently for dialysis.The aim of this research is to understand illness related experiences of patients receiving haemodialysis (HD). One to one interviews will be conducted with patients.

Why have I been approached?

You have been invited to take part in this research as you have been receiving haemodialysis for longer than 6 months. Therefore we would like to invite you to share your thoughts about living with kidney disease.

Do I have to take part?

Participation in this study is voluntary. If you decide to take part you are free to withdraw at any time, and without giving a reason. A decision not to take part, or a decision to take part will not, in any way, affect the standard of care that you receive.

What does 'taking part' involve?

If you wish to participate or if you would like to discuss the study further, please contact a member of research team, Buse Keskindag at Tel: 00905338473883 or b.keskindag@herts.ac.uk

The study will take place at the Department of Nephrology at the Hospital. We will arrange a suitable date and time to do the interview, which will take 30 to 40 mins. The interview could be arranged before or after your dialysis session.

Please be aware that if you do decide to take part you should indicate your agreement with written consent form.

During the interview, you will be asked questions about your experience related to your illness. It is expected that interviews will be in a form of casual conversation.

With your permission, the interviews will be audio recorded to make it easier for the research team to learn from the discussion at a later stage. Audio recordings will be kept until the transcription,

verification and analysis of the data is complete, after which they will be securely destroyed. We anticipate that this may take 6 months.

What are the advantages and disadvantages of taking part?

Participating in the research is not anticipated to cause you any discomfort. Although there are no immediate benefits for those people participating in the project, it is hoped that this work will have a positive impact on efforts to design nterventions to enhance the quality of life of patients.

If you feel any discomfort due to sharing your thoughts and feelings about kidney disease, you will be directed to contact a professional who is experienced in helping patients who are experiencing distress. We will provide you with the contact details.

Will my taking part in this project be kept confidential?

All the information collected about you during the study will be kept strictly confidential and anonymised at an early point. Only Buse Keskindag as a member of the research team will have access to information that may identify you. You will not be able to be identified in any reports. Any data collected about you via interview will be stored in a file protected by a password. In addition to Buse, a local supervisor who is part of the study team may have access to audio recordings of interviews but these will be anonymised as well as written transcripts of the interviews. After transcription, verification and analysis, audio recordings will be destroyed. Electronic copies of anonymised transcripts may be stored for up to 5 years for the purpose of publication after which they will also be destroyed.

Who is organising the research?

This project is a part of PhD programme supervised by Dr Shivani Sharma (University of Hertfordshire, UK). The interviews will be conducted by Buse Keskindag.

Who has ethically reviewed the project?

This project is ethically reviewed by the Ethics Committee of Ministry of Health in Turkish Republic of Northern Cyprus. If you have any concerns or questions please do not hesitate to contact the Administrative Department in the State Hospital that you receive your treatment. The research also has ethical approval from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The University's regulations regarding the conduct of studies involving human participants can be found at this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

What will happen with the results of the research?

The results of this study will be used to further knowledge in the study area and to promote understanding and recognition amongst clinicians about the way in which patients think about kidney disease. The results may also be published. Any information that could be used to identify individuals will be removed from published material. If you wish to obtain a copy of the published results, please feel free to request these from Buse Keskindag.

Contact for further information

Buse Keskindag, School of Life and Medical Sciences, University of Herfordshire.

Tel: 00905338473883   b.keskindag@herts.ac.uk

KATILIMCI BİLGİ FORMU

Çalışma ile ilgili bilgi

Sağlık alanında çalışan bazı yerli araştırmacılar ile Hertfordshire Üniversitesi'ndeki araştırmacılar hemodiyaliz alan hastaların hastalık algılarını anlamayı amaçlamaktadırlar.

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalıkla ilgili deneyimlerini incelemenmesi

Sizi bu çalışmaya katılımcı olarak davet ediyoruz. Karar vermeden önce yapılacak olan çalışmayı anlamanız çok önemlidir. Lütfen bu formu dikkatli bir şekilde okuyun, istediğiniz takdirde başkaları ile de tartışabilirsiniz. Sorunuz varsa lütfen araştırmacıya iletiniz. Çalışmaya katılma ile ilgili kararınızı lütfen iyi düşünerek veriniz.

Bu bilgi formunu okuduğunuz için teşekkür ederiz.

Çalışmanın amacı

Böbrek yetmezliği tedavisi hastaların hayatlarının birçok yönünü etkilediği bilinmektedir. Örneğin, ilaç tedavisi ve yeme ve içme düzeninde uygulanan kısıtlanmalar bunlardan bazılarıdır. Ayrıca, hastalar düzenli olarak hastaneyi ziyaret etmek zorunda olduklarından bu da hayatlarını genel anlamda etkileyebilmektedir. Bu çalışmanın amacı kronik böbrek yetmezliği olan hastaların hastalıkları ile ilgili deneyimlerini anlamaktır. Bu nedenle, katılımcılarla birebir görüşmeler yapılacaktır.

Niye davet edildim?

Altı aydan fazla zamandır hemodiyaliz tedavisi aldığınız için bu çalışmaya davet edildiniz. Böbrek yetmezliği olan biri olarak düşücelerinizi bizimle paylaşmaya size davet ediyoruz.

Katılım zorunlu mu?

Çalışmaya katılım gönüllüdür. Çalışmaya katılmaya zorunlu değilsiniz, katılma durumunda bile istediğiniz zaman çekilme hakkınız vardır ve bundan dolayı bir sebep belirtmek zorunda değilsiniz. Bu durum tedavi sürecinizi etkilemeyecektir.

Çalışmaya katılmak

Çalışmaya katılmaya karar verdiyseniz ve/ya daha fazla bilgi edinmek istiyorsanız, araştırma ekibi üyesi Buse Keskindağ'a ulaşabilirsiniz. Tel:05338473883   b.keskindag@herts.ac.uk

Çalışma Hastanenin Diyaliz Bölümü'nde, size uygun gün ve saatte yapılacaktır. Görüşme diyaliz seansından önce veya sonra ayarlanabilir. Görüşmenin 30 - 40 dakika sürmesi beklenmektedir.

Çalışmaya katılmak istiyorsanız, görüşmeden önce yazılı olarak katılmaya gönüllü olduğunuzu aydınlatılmış onam formunda belirtmeniz gerekmektedir.

Görüşme süresince hastalığınız ile ilgili deneyimlerinizi öğrenmek için size sorular sorulacaktır. Görüşmenin günlük bir sohbet gibi ilerleyeceğini düşünüyoruz.

Görüşmeye başlamadan önce görüşmeyi sesli olarak kayıt etmek için izniniz istenecektir. Araştırmacıların tartışmaları daha iyi anlayıp analiz edebilmesi için görüşmeler sesli olarak kaydedilecektir. Ses kayıtları, verilerin transkript, doğrulama ve analiz aşamaları tamamlanana kadar saklanacaktır. Daha sonra kalıcı olarak silinecektir. Bu sürenin 6 ay kadar alması beklenmektedir.

Katılmanın avantaj ve dezavantajları

Bu çalışmaya katılmanızın size bir rahatsızlık yaratacağını düşünmüyoruz. Projeye katılımdan dolayı katılımcıya direkt olarak hemen bir avantaj söz konusu olmasa da bu çalışmanın ilerde hastaların tedavi sürecine ayrıca hastaların yaşam kalitelerini artıran psiko-eğitimsel müdahale programlarına yarar sağlayacağı düşünülmektedir.

Eğer böbrek yetmezliği ile ilgili düşünce ve duygularınızı paylaşmanızdan dolayı herhangi bir şekilde rahatsız hissedecek olursanız, duygusal olarak sıkıntı yaşayan bireylerle çalışmada deneyimli bir profesyonele yönlendirileceksiniz. Bununla ilgili iletişim bilgileri sizinle paylaşılacaktır.

Projeye katılım gizli tutulacak mı?

Sizden elde edilecek tüm veriler kesinlikle gizli tutulacak ve anonim olarak saklanacaktır. Çalışma ekibinden sadece Buse Keskindağ'ın sizi tanıtacak bilgilere erişimi olacaktır. Araştırma raporunda sizi tanıtabilecek hiçbir bilgiye yer verilmeyecektir. Görüşmede elde edilen veriler şifre ile korunan dosyada saklanacaktır. Araştırma ekibinden olan yerli danışmanın görüşmenin anonim olan ses kaydına ve yazılı trankribine erişimi olabilir. Transkript, doğrulama ve analiz aşamalarından sonra ses kayıtları kalıcı olarak silinecektir. Elektronik olarak saklanan anonim transkriptler 5 yıla kadar yayım amacı ile saklanabilir, fakat daha sonra kalıcı olarak silinecektir.

Bu araştırmayı kim düzenledi?

Bu çalışma, Dr Shivani Sharma'nın danışmanı olduğu doktora araştırma programının bir parçasıdır. Görüşmeler araştırma ekibinden Buse Keskindağ tarafından yapılacaktır

Bu araştırmayı etik açıdan kim değerlendirdi?

Bu çalışmanın yapılmasını Lefkoşa Dr Burhan Nalbantoğlu Devlet Hastanesi Etik Kurulu etik açıdan uygun bulmuştur. Çalışma ayrıca Hertfordshire Üniversitesi'nden etik onay almıştır.

Çalışma bulgularına ne olacak?

Çalışma bulguları, ilgili çalışma alanına katkıda bulunması ve klinisyenlerin böbrek yetmezliği olan hastaların düşüncelerini ve algılarını anlamaları için yarar sağlayacaktır. Çalışma bulguları yayımlanabilir. Yayımlanacak olan raporlarda, katılımcıları tanıtabilecek hiçbir bilgiye yer verilmeyecektir. Yayımlandıktan sonra raporun bir kopyasına erişmek istiyorsanız Buse Keskindağ'a ulaşabilirsiniz.

Daha fazla bilgi için iletişim bilgileri

Buse Keskindağ, Fen ve Tıp Bilimleri Fakültesi, Hertfordshire Üniversitesi, Tel: 05338473883; b.keskindag@herts.ac.uk

Appendix D: Patient qualitative interview study informed consent form

INFORMED CONSENT FORM

Title of the project: Exploring illness related experiences of patients with chronic kidney disease

1. I understand that my participation is voluntary and that I may choose to withdraw at any time and without giving a reason.

   Please Initial   **YES**   **NO**

2. I confirm that I have been given enough information about the project and that I am satisfied with the answers given to any questions I have asked about the project.

   Please Initial   **YES**   **NO**

3. I confirm that I have been told that strict confidentiality will be maintained and that all information I provide will be anonymised.

   Please Initial   **YES**   **NO**

4. I give permission for the information I provide being audio-recorded.

   Please Initial   **YES**   **NO**

   a. I understand that audio recordings will be destroyed following the transcription and analysis of the data, and that anonymised quotes from the transcripts may be used in future publications and presentations.

      Please Initial   **YES**   **NO**

5. I agree to take part in this project.

   Please Initial   **YES**   **NO**

Name of Participant   Date   Signature

Name of person taking consent   Date   Signature

When completed: 1 copy for participant; 1 copy for researcher site file

AYDINLATILMIŞ ONAM FORMU

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalık ile ilgili deneyimlerinin incelenmesi

1 . Bu çalışmaya katılımanın gönüllü olduğunu biliyorum. İstediğim zaman herhangi bir sebep göstermeden çalışmadan çekilebilebileceğimi biliyorum.

	Paraf	Evet	Hayır

2. Bana sunulan bilgileri okuyup anladığımı ve proje ile ilgili sorularımın cevaplarını aldığımı onaylıyorum

	Paraf	Evet	Hayır

3. Kesin gizlilik hakkında bilgilendirildiğimi ve paylaşacağım tüm bilgilerin anonim olarak kullanılacağını bildiğimi onaylıyorum.

	Paraf	Evet	Hayır

4. Verdiğim bilgilerin sesli olarak kayıt edilmesi için izin veriyorum.

	Paraf	Evet	Hayır

    a. Ses kayıtlarının, verilerin transkript ve analiz aşamalarından sonra kalıcı olarak silineceğini, gelecekteki yayın ve sunumlar için transkriptlerden anonim olarak alıntı yapılabileceğini biliyorum.

	Paraf	Evet	Hayır

5. Bu projeye katılmayı kabul ediyorum.

	Paraf	Evet	Hayır

Katılımcının adı soyadı	Tarih	İmza

Formu alan kişinin adı soyadı	Tarih	İmza

Form doldurulduğunda, bir kopya katılımcıda, bir kopya araştırmacı dosyasında kalacak şekilde

Appendix E: Patient qualitative interview study topic guide

INTERVIEW TOPIC GUIDE

General Introduction

Thank you for agreeing to take part in this study. Before we begin the
discussion, I'd like to remind you that there are no right or wrong answers to the questions,
and any information you tell me today will be kept confidential. Only in exceptional
circumstances where we have concerns that you or someone else is at risk from harm will
confidentiality be broken. The data will also be anonymised for analysis.

You can let us know at any time if:
   - You do not wish to answer a question
   - You would like the audio recording to be switched off
   - You would like to leave the discussion

Section 1: Illness Perceptions

1. Were you aware that you had kidney disease prior to needing dialysis?
2. Before starting Dialysis what information were you given about Kidney Disease? Did you feel that this was sufficient
3. Do you know what the cause of your kidney disease is? How did you gain information about this?
4. How does having kidney disease impact your day-to-day life?
5. Do you think that there is a cure for kidney disease?
6. Do you think that your experience of having kidney disease has changed you as a person?
7. Do you think having kidney disease has affected your mood?
8. What do you believe the future holds for you in relation to your kidney disease?
9. Do you have any other illnesses aside from kidney disease?
10. How do you think this impacts upon your experience of having kidney disease?

GÖRÜŞME SORULARI

Giriş

Bu çalışmaya katılmayı kabul ettiğiniz için teşekkür ederiz. Çalışmaya başlamadan önce, sorulara doğru veya yanlış cevap olmadığını, ayrıca paylaştığınız bilgilerin gizli kalacağını hatırlatmak isteriz. Sadece sizin veya başkasının zarar görme riski ile karşı karşıya olduğunu düşündüğümüz durumlarda gizlilik ilkesi ihlal edilir.

Herhangi bir soruya cevap vermeyi istemediğinizde,
Ses kaydının kapatılmasını istediğinizde,
Çalışmadan ayrılmak istediğinizde,
   Lütfen bildiriniz.

Hastalık Algısı

1. Diyalize ihtiyaç duymadan önce böbrek hastalığınızın olduğunu farkındamıydınız?
2. Diyalize başlamadan önce böbrek hastalığı ile ilgili sizi nasıl bilgilendirdiler? Bunun yeterli olduğunu düşündünüz mü?
3. Böbrek hastalığınıza neyin sebep olduğunu biliyor musunuz? Bu bilgiyi nasıl edindiniz?
4. Böbrek hastalığınız günlük hayatınızı nasıl etkiliyor?
5. Böbrek hastalığı için çare olduğunu düşünüyor musunuz?
6. Böbrek hastalığından muzdarip olmanızın sizi birey olarak değiştirdiğini düşünüyor musunuz?
7. Sizce böbrek hastalığından muzdarip olmanız ruh halinizi etkiliyor mu?
8. Böbrek hastalığınızla ilgili olarak gelecekte sizi neyin beklediğini düşünüyorsunuz?
9. Böbrek hastalığı dışında başka hastalığınız var mı?
10. Bunun böbrek hastalığı ile ilgili yaşadıklarınızı/deneyimlerinizi nasıl etkilediğini düşünüyorsunuz?

Appendix F: Patient qualitative interview study debrief sheet

PARTICIPANT DEBRIEF SHEET

Title of the project: Exploring illness related experiences of patients with chronic kidney disease

Thank you for participating in this study, which aimed to explore the illness related beliefs of patients living with chronic kidney disease being treated with dialysis. It is hoped that the results of the research will help inform strategies aimed at supporting patients in adjusting to living with a long-term condition.

Should you have any questions or queries about the study, please contact:

Buse Keskindag

Tel: 00905338473883

b.keskindag@herts.ac.uk

It is possible that talking about your illness related beliefs may have raised some issues for you. If as a result of your participation in this study, you experienced any negative feelings, please contact the Barış Psychiatric Hospital at 0392 6085441 - 6085479. As a research student, I am unable myself to offer any further support but would strongly encourage you to discuss your feelings with a trained professional.

Once again thank you for taking part in this study.

KATILIMCI BİLGİ EDİNME FORMU

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalıkla ilgili deneyimlerinin incelenmesi

Çalışmaya katıldığınız için teşekkür ederiz. Bu çalışma kronik böbrek yetmezliği olan ve diyaliz tedavisi alan hastaların hastalıkları ile ilgili inançlarını anlamayı amaçlamaktadır. Cevaplarınız, kronik hastalığına uyum sağlamaya çalışan hastalara yönelik geliştirilecek olan destek odaklı stratejilere katkıda bulunacaktır.

Çalışma ile ilgili herhangi bir sorunuz veya düşünceniz varsa lütfen bizimle iletişime geçiniz.

Buse Keskindağ, Fen ve Tıp Bilimleri Fakültesi, Hertfordshire Üniversitesi
Tel: 05338473883 b.keskindag@herts.ac.uk

Eğer katılımınzla ilgili, çalışma sonucunda, olumsuz hissettiyseniz, lütfen Barış Ruh ve Sinir Hastanesi ile 0392 6085441 – 6085479 numaraları aracılığı ile iletişime geçiniz.

Çalışmaya katıldığınız için tekrardan teşekkür ederiz.

Appendix G: Patient qualitative interview study COREQ checklist

Identifying where COREQ reporting guidelines have been addressed in the study

No. Item	Addressed in Section
Domain 1: Research team and reflexivity	
Personal Characteristics	
1. Interviewer/facilitator	Methods (4.2.4)
2. Credentials	N/A
3. Occupation	Methods (4.2.4)
4. Gender	Methods (4.2.4)
5. Experience and training	Methods (4.2.4)
Relationship with participants	
6. Relationship established	Methods (4.2.2)
7. Participant knowledge of the interviewer	Methods (4.2.2)
8. Interviewer characteristics	Methods (4.2.4)
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and theory	Methods (4.2.5)
Participant selection	
10. Sampling	Methods (4.2.2)
11. Method of approach	Methods (4.2.1)
12. Sample size	Methods (4.2.2)
13. Non-participation	Methods (4.2.2)
Setting	
14. Setting of data collection	Methods (4.2.2)
15. Presence of non-participants	Methods (4.2.2)
16. Description of sample	Methods (4.2.2)
Data collection	
17. Interview guide	Methods (4.2.1)
18. Repeat interviews	N/A
19. Audio/visual recording	Methods (4.2.2)
20. Field notes	Methods (4.2.5)
21. Duration	Methods (4.2.4)
22. Data saturation	N/A
23. Transcripts returned	N/A
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	Methods (4.2.5)
25. Description of the coding tree	N/A
26. Derivation of themes	Findings (4.3) & Table 4.2
27. Software	N/A
28. Participant checking	N/A
Reporting	
29. Quotations presented	Findings (4.3)
30. Data and findings consistent	Findings (4.3)
31. Clarity of major themes	Findings (4.3)
32. Clarity of minor themes	Findings (4.3)

Appendix H: Systematic review study search strategy

Search Strategy

#	Searches
Concept A – Population	
1	Chronic kidney failure (MeSH)
2	End stage renal disease (MeSH)
3	Peritoneal dialysis (MeSH)
4	Dialysis (MeSH)
5	Home hemodialysis (MeSH)
6	Hemodialysis units, hospital (MeSH)
7	Haemodialysis* (tw)
8	Hemodialysis* (tw)
9	"Peritoneal Dialysis*" (tw)
10	renal* (tw)
11	kidney* (tw)
12	"Chronic kidney disease*" (tw)
13	"End stage renal disease*" (tw)
14	"End stage kidney disease*" (tw)
15	"End stage kidney failure" (tw)
16	HD (tw)
17	PD (tw)
18	CKD (tw)
19	ESRD (tw)
20	ESKD (tw)
21	ESKF (tw)
22	OR [1 – 21]
Concept B – Study design	
23	Qualitative research (MeSH)
24	Interview, Psychological (MeSH)
25	Focus Groups (MeSH)
26	Qualitative* (tw)
27	"Interview*" (tw)
28	"Focus groups*" (tw)
29	Experience* (tw)
30	Belief* (tw)
31	Attitude* (tw)
32	View* (tw)
33	Perception* (tw)
34	Aware* (tw)
35	Feeling* (tw)
36	Understand* (tw)
37	Opinion* (tw)
38	Observ*(tw)
39	Recognition (tw)
40	Perspective* (tw)
41	OR [23-40]
Concept C - Experience	
42	"Illness perception*" (tw)
43	"Illness representation*" (tw)
44	"Illness cognition*" (tw)
45	"Illness belief*" (tw)
46	"Common sense model" (tw)
47	CSM (tw)
48	"Self-regulation model" (tw)
49	SRM (tw)
50	"illness experience*" (tw)
51	OR (42- 50)
	22 AND 41 AND 51

Appendix I: Systematic review study CASP checklist

Critical Appraisal Skills Programme Qualitative (CASP) Checklist

Items	Yes	Can't tell	No
Was there a clear statement of the aims of the research?	1, 2, 3, 4		
Is a qualitative methodology appropriate?	1, 2, 3, 4		
Was the research design appropriate to address the aims of the research?	1, 2, 3, 4		
Was the recruitment strategy appropriate to the aims of the research?	1, 2, 4	3	
Was the data collected in a way that addressed the research issue?	1, 2, 3, 4		
Has the relationship between researcher and participants been adequately considered?	1, 2, 4,	3	
Have ethical issues been taken into consideration?	1,2, 3, 4		
Was the data analysis sufficiently rigorous?	1, 2, 3, 4		
Is there a clear statement of findings?	1, 2, 3, 4		
How valuable is the research? (e.g., contribution to existing knowledge)	1, 2, 3, 4		

1, Sharma et al. (2020); 2, Keskindag et al. (2021); 3, Karamanidou et al. (2014); 4, Rees et al. (2018).

Appendix J: Systematic review study COREQ checklist

Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist

Items	Studies
Personal Characteristics	
Interviewer/facilitator identified	1, 2
Occupation	1, 2, 3, 4
Gender	1, 2, 3, 4
Experience and training	2
Relationship with participants	
Relationship established	1, 2, 4
Participant knowledge of the interviewer	1, 3, 4
Theoretical framework	
Methodological orientation and theory	3, 4
Participant selection	
Sampling strategy	2, 4
Method of approach	1, 2, 3
Sample size	1, 2, 3, 4
Non-participation	2, 3
Setting	
Setting of data collection	1, 2, 3
Presence of non-participants	1, 2
Data collection	
Interview guide	1, 2, 3, 4
Audio/visual recording	1, 2, 3, 4
Duration	1, 2, 3
Data saturation	
Data analysis	
Number of data coders	1, 2
Description of the coding tree	2, 3
Derivation of themes	1, 2, 3, 4
Use of software	
Participant checking	
Reporting	
Quotations presented	1, 2, 3, 4
Consistency between data and findings	1, 2, 3, 4
Clarity of major and minor themes	1, 2, 3, 4

1, Sharma et al. (2020); 2, Keskindag et al. (2021); 3, Karamanidou et al. (2014); 4, Rees et al. (2018)

Appendix K: Systematic review studies' representation of illness perception domains

Studies representation in Common Sense Model of Self-Regulation

	Identity	Timeline	Control/Cure	Consequences	Cause
[1]			√	√	√
[2]	√		√	√	√
[3]	√	√	√	√	√
[4]	√	√	√	√	√

1, Sharma et al. (2020); 2, Keskindag et al. (2021); 3, Karamanidou et al. (2014); 4, Rees et al. (2018).

Appendix L: Detailed thematic representation of the synthesis

Detailed thematic representation of the synthesis

Overarching themes	Inductively developed themes/subthemes	
Identity	1. Understanding changes caused by CKD	1.1 Attempts
		1.2 Barriers
Cause	2. Causal beliefs	2.1 Risk factors
		2.2 Differences between patients and HCP' beliefs
Control/Cure	3. Coping with treatment burden	3.1 Avoidance of negative thinking
		3.2 Positive outlook
		3.3 Support sources
Timeline	4. Treatment beliefs	4.1 Conflicting prognosis beliefs
		4.2 External forces/control
		4.3 Benefits of HD at initiation
		4.4 Cure is transplant
Consequences	5. Impact of HD	5.1 Physical functioning
		5.2 Psychological aspect
		5.3 Social life
	6. Adaptation process	6.1 Dialysis vintage
		6.2 Forced adjustment
		6.3 Adherence vs non-adherence
		6.4 Acceptance

Appendix M: UH Ethics approval for longitudinal study

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Buse Keskindag
CC	Dr Shivani Sharma
FROM	Dr Rosemary Godbold, Health, Science, Engineering & Technology ECDA Vice Chair
DATE	27/04/2021

Protocol number: **LMS/PGR/UH/04505**

Title of study: The trajectory of illness perceptions in patients with End Stage Renal Disease being treated by haemodialysis or peritoneal dialysis

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 27/04/2021

To: 31/01/2023

Appendix N: TRNC Ethics approval for longitudinal study

TURKISH REPUBLIC OF NORTHERN CYPRUS
MINISTRY OF HEALTH
MANAGEMENT OF INPATIENT TREATMENT
DR. BURHAN NALBANTOĞLU STATE HOSPITAL

File number: YTIKI1.01-629-20/E.1915   29th June 2020

RE: Ethics Committee decision about Buse Keskindağ's study.

To whom it may concern,

According to the meeting of the Ethics Committee held on 25th June 2020, we have made a decision that it is ethically convenient for the study entitled "Longitudinal Assessment of Illness Experiences of Patients with Chronic Kidney Disease" to be conducted at the Nicosia Dr.Burhan Nalbatoğlu State Hospital, Famagusta State Hospital, Kyrenia Akçiçek State Hospital and Cengiz Topel Hospital.

By respectfully submitting, we wish you success.

e-signed

Sonuç BUYUK

Deputy Chief Physician

To be submitted: Information:

Nicosia Dr.Burhan Nalbatoğlu State Hospital   **Management of Inpatient**
Famagusta State Hospital   **Treatment**
Kyrenia Akçiçek State Hospital
Cengiz Topel Hospital

Note: This document has been electronically signed in accordance with 6th article of the Regulation of Electronic Signatures (93/2007).

Bedrettin Demirel Street - Ortaköy   For information: Havva GÜNDOĞDU
Tel: (392) 228 54 41   Secretary of Chief Physician
Fax: (392)223 1899

KUZEY KIBRIS TÜRK CUMHURİYETİ
SAĞLIK BAKANLIĞI
Yataklı Tedavi Kurumları Dairesi Müdürlüğü
Dr. Burhan Nalbantoğlu Devlet Hastanesi

Sayı : YTK1.01-629-20/E.1915   29 Haziran 2020

Konu : Buse KESKİNDAĞ'ın Etik Kurulu
hk.

DAĞITIM YERLERİNE

Hertfordshire Üniversitesi Yaşam ve Tıp Bilimleri fakültesi Psikoloji bölümü Doktora Tezi Öğrencisi Buse KESKİNDAĞ'ın " Kronik Böbrek Yetmezliği Hastalarının Hastalık Deneyimlerininin Boyamsal olarak incelenmesi" konulu araştırması için, 25 Haziran 2020 tarihinde Etik Kurulunun yapmış olduğu toplantıda , Dr. Burhan Nalbantoğlu Devlet Hastanesi, Girne Akçiçek Hastanesi Gazimağusa Devlet Hastanesi ve Cengiz Toplel Hastanesinde çalışma yapması Etik Kurulunca uygun görülmüştür.

Gereği için bilgilerinize. Saygılarımla arz ederim.

🎖 e-imzalıdır
Sonuç BÜYÜK
Başhekim Baş Yrd.
Etik Kurulu Yönetim Kurulu Üyesi

Ek : 26 Haziran 2020 tarihli sayılı yazı.

Dağıtım:

Gereği: Bilgi:
Dr. Burhan Nalbantoğlu Devlet Hastanesi   Yataklı Tedavi Kurumları Dairesi Müdürlüğü
Girne Dr. Akçiçek Hastanesi
Gazimağusa Devlet Hastanesi
Cengiz Topel Hastanesi

Not: 93/2007 sayılı Elektronik İmza Yasası 'nın 6.maddesi gereği bu belge elektronik imza ile imzalanmıştır.

Bedrettin Demirel Caddesi - Ortaköy   Bilgi için:Havva GÜNDOĞDU
Tel: (392) 228 54 41   Başhekim Sekreteri
Fax: (392) 223 18 99

Appendix O: Longitudinal study participant information sheet

PARTICIPANT INFORMATION SHEET

Information about the study

A group of local researchers as well as researchers at the University of Hertfordshire, working in the field of healthcare, are interested in understanding illness related experiences of CKD patients. The researchers would like to know about patients' thoughts and experiences about kidney disease.

Title of the project: Longitudinal assessment of illness experiences of patients with chronic kidney disease

You are being invited to take part in the above study. Before you decide to do so, it is important that you understand the research that is being carried out. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask a member of the research team anything that is not clear. Please take your time to decide whether you wish to take part. Thank you for reading this information sheet.

What is the purpose of this study?

The treatment for kidney disease is known to impact several aspects of a patient's life. This includes taking medications, and restrictions on food and fluids. Patients also experience restrictions on their time due to the need to visit hospital frequently. The aim of this research is to understand how the beliefs that patients hold about CKD change over time and whether there is a relationship of any changes to other markers of patient well-being such as mood. As we are interested in how illness related beliefs change over-time, patients who agree to participate in the study will be contacted at set time points to identify how they experience their illness. However, joining the study does not mean that you are obligated to participate in it throughout. You may change your mind at any time, and this will not affect that care that you receive.

Why have I been approached?

You have been invited to take part in this research as you have been diagnosed with CKD. Therefore, we would like to invite you to share your beliefs about kidney disease.

Do I have to take part?

Participation in this study is voluntary. A decision not to take part, or a decision to take part will not, in any way, affect the standard of care that you receive.

What does 'taking part' involve?

If you wish to participate or if you would like to discuss the study further, please contact the researcher, Buse Keskindag at Tel: 00905338473883 or b.keskindag@herts.ac.uk

This study will take place at three different time points within one year and you will be asked to complete a questionnaire pack related to your experiences about CKD. Before approaching at each point, the researcher will check whether you are happy to continue.

The researcher will contact you via telephone. We will arrange a suitable date and time to implement the questionnaire, which will take 30 to 40 mins.

Please be aware that if you do decide to take part you should indicate your agreement with informed consent. If you decide to take part you are free to withdraw at any time, and without giving a reason.

Any data you have provided as part of the research up to the point of withdrawal may still be used but will be managed securely at all times, as detailed in the section 'Will my taking part in this project be kept confidential?'.

What are the advantages and disadvantages of taking part?

Participating in the research is not anticipated to cause you any discomfort. Although there are no immediate benefits for those people participating in the project, it is hoped that this work will have a positive impact on efforts to design interventions to enhance the quality of life of patients in future.

If you feel any discomfort due to sharing your thoughts and feelings about kidney disease, you will be directed to contact a professional who is experienced in helping patients who are experiencing distress. We will provide you with the contact details.

Will my taking part in this project be kept confidential?

All the information collected about you during the study will be kept strictly confidential and processed in line with the General Data Protection Regulation (GDPR). The legal basis for processing your data is because it is necessary for the performance of a public function and carried out in the public interest [Article 6(1)(e) GDPR]. Your medical and demographic data requires an additional reason for processing which is that it is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes [Article 9(2)(j)]. To maintain confidentiality your data will be anonymised at an early point. Only Buse Keskindag as a member of the research team will have access to information that may identify you. You will not be able to be identified in any reports. Any data collected about you via the questionnaire will be stored in a file protected by a password. In addition to Buse, the supervisor of this study may have access to anonymised numerical data of the questionnaires. Electronic copies of numerical data may be stored for up to 5 years for the purpose of publication after which they will also be destroyed.

Who is organising the research?

This project is a part of PhD programme supervised by Dr Shivani Sharma ([Principal Investigator], University of Hertfordshire, UK), Prof Ken Farrington (University of Hertfordshire, UK), Dr Deren Oygar (Dr Burhan Nalbantoğlu Nicosia State Hospital, Northern Cyprus) and Prof Biran Mertan (Bahçeşehir Cyprus University, Northern Cyprus). The questionnaires will be implemented by Buse Keskindag.

Who has ethically reviewed the project?

This project is ethically reviewed by the Ethics Committee of Ministry of Health in Turkish Republic of Northern Cyprus (YTIKI 1.01-629-20/E.1915). If you have any concerns or questions, please do not hesitate to contact the Administrative Department in the State Hospital that you receive your treatment. The research also has ethical approval from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (LMS/PGR/UH/04505). The University's regulations regarding the conduct of studies involving human participants can be found at this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

Participation in future research:

Your contact details will be kept separately from this study on a password protected file and agreeing to be contacted does not oblige you to take part in future research.

What will happen with the results of the research?

The results of this study will be used to further knowledge in the study area and to promote understanding and recognition amongst clinicians about the way in which patients think and experience about kidney disease. The results may also be published. Any information that could be used to identify individuals will be removed from published material. If you wish to obtain a copy of the published results, please feel free to request these from Buse Keskindag.

Contact for further information

Buse Keskindag, School of Life and Medical Sciences, University of Hertfordshire. Tel: 00905338473883   b.keskindag@herts.ac.uk

KATILIMCI BİLGİ FORMU

Çalışma ile ilgili bilgi

Sağlık alanında çalışan bazı yerli araştırmacılar ile Hertfordshire Üniversitesi'ndeki araştırmacılar kronik böbrek hastalarının hastalık deneyimlerini ve ilgili inançlarını anlamayı amaçlamaktadır.

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalıkla ilgili deneyimlerinin boylamsal olarak incelenmesi

Sizi bu çalışmaya katılımcı olarak davet ediyoruz. Karar vermeden önce yapılacak olan çalışmayı anlamanız çok önemlidir. Lütfen bu formu dikkatli bir şekilde okuyun, istediğiniz takdirde başkaları ile de tartışabilirsiniz. Sorunuz varsa lütfen araştırmacıya iletiniz. Çalışmaya katılma ile ilgili kararınızı lütfen iyi düşünerek veriniz.

Bu bilgi formunu okuduğunuz için teşekkür ederiz.

Çalışmanın amacı

Böbrek yetmezliği tedavisi hastaların hayatlarının birçok yönünü etkilediği bilinmektedir. Örneğin, ilaç tedavisi ve yeme ve içme düzeninde uygulanan kısıtlanmalar bunlardan bazılarıdır. Ayrıca, hastalar düzenli olarak hastaneyi ziyaret etmek zorunda olduklarından bu da hayatlarını genel anlamda etkileyebilmektedir. Bu araştırmanın amacı, hastaların kronik böbrek hastalığı hakkındaki inançlarının zaman içinde nasıl değiştiğini ve duygu durum gibi iyilik hali yordayıcıları ile ilişkili herhangi bir değişiklik olup olmadığını anlamaktır. Hastalıkla ilgili inançların zaman içinde nasıl değiştiğiyle ilgileneceğimiz için, çalışmaya katılmayı kabul eden hastalarla, hastalıklarını nasıl deneyimlediklerini belirlemek için belirli zamanlarda iletişime geçilecektir. Ancak, bu çalışmaya katılmak, araştırmanın parçası olan diğer çalışmalara katılmak zorunda olduğunuz anlamına gelmez. Fikrinizi istediğiniz zaman değiştirebilirsiniz ve bu değişiklik aldığınız tedavi sürecinizi herhangi bir şekilde etkilemeyecektir.

Niye davet edildim?

Kronik böbrek hastalığı tedavisi aldığınız için bu çalışmaya davet edildiniz. Bu anlamda, bir hasta olarak düşücelerinizi bizimle paylaşmaya size davet ediyoruz.

Katılım zorunlu mu?

Çalışmaya katılım gönüllüdür. Çalışmaya katılmaya zorunlu değilsiniz, katılma durumunda bile istediğiniz zaman çekilme hakkınız vardır ve bundan dolayı bir sebep belirtmek zorunda değilsiniz. Bu durum tedavi sürecinizi etkilemeyecektir.

Çalışmaya katılmak

Çalışmaya katılmaya karar verdiyseniz ve/ya daha fazla bilgi edinmek istiyorsanız, araştırma ekibi üyesi Buse Keskindağ'a ulaşabilirsiniz. Tel: 0533 847 3883   b.keskindag@herts.ac.uk

Bu araştırma bir yıl içinde iki veya üç farklı zamanda yapılacak ve kronik böbrek hastalığı ile ilgili deneyimlerinizle ilgili bir anket doldurmanız istenecektir. Her çalışma zamanında çalışmaya katılacak olan hasta ile iletişime geçilip, katılımcı olmaya halen rızası olup olmadığı araştırmacı tarafından sorulacaktır.

Anketin uygulanması için 30 ila 40 dakika sürmesi beklenmektedir. Bu nedenle önceden size uygun tarih ve saatte telefon aracılığı ile randevu ayarlanacaktır.

Katılmaya karar verirseniz, araştırmacı tarafından hazırlanan yazılı onay formu doldurarak çalışmaya katılmaya rıza gösterdiğinizi belirtmeniz gerekecektir.

Katılmanın avantaj ve dezavantajları

Bu çalışmaya katılmanızın size bir rahatsızlık yaratacağını düşünmüyoruz. Projeye katılımdan dolayı katılımcıya direkt olarak hemen bir avantaj söz konusu olmasa da bu çalışmanın ilerde hastaların

tedavi sürecine ayrıca hastaların yaşam kalitelerini artıran psiko-eğitimsel müdahale programlarına yarar sağlayacağı düşünülmektedir.

Eğer böbrek hastalığı ile ilgili düşünce ve duygularınızı paylaşmanızdan dolayı herhangi bir şekilde rahatsız hissedecek olursanız, duygusal olarak sıkıntı yaşayan bireylerle çalışmada deneyimli bir profesyonele yönlendirileceksiniz. Bununla ilgili iletişim bilgileri sizinle paylaşılacaktır.

Projeye katılım gizli tutulacak mı?

Sizden elde edilecek tüm veriler kesinlikle gizli tutulacak ve anonim olarak saklanacaktır. Çalışma ekibinden sadece Buse Keskindağ'ın sizi tanıtacak bilgilere erişimi olacaktır. Araştırma raporunda sizi tanıtabilecek hiçbir bilgiye yer verilmeyecektir. Görüşmede elde edilen veriler şifre ile korunan dosyada saklanacaktır. Buse Keskindağ dışında, proje danışmanı anonim sayısal veri dosyasına ulaşabilir. Elektronik olarak saklanacak anonim veriler 5 yıla kadar yayım amacı ile saklanabilir, fakat daha sonra kalıcı olarak silinecektir.

Bu araştırmayı kim düzenledi?

Bu çalışma, Dr Shivani Sharma (sorumlu danışman, Hertfordshire Üniversitesi), Prof. Dr. Ken Farrington (danışman, Hertfordshire Üniversitesi), Prof. Dr. Biran Mertan'ın (yerel danışman, Bahçeşehir Kıbrıs Üniversitesi) ve Doç. Dr. Deren Oygar (yerel danışman, Dr Burhan Nalbantoğlu Devlet Hastanesi) danışmanlığında olan doktora araştırma programının bir parçasıdır. Anket, araştırma ekibinden Buse Keskindağ tarafından uygulanacaktır.

Bu araştırmayı etik açıdan kim değerlendirdi?

Bu çalışmanın yapılmasını Lefkoşa Dr Burhan Nalbantoğlu Devlet Hastanesi Etik Kurulu etik açıdan uygun bulmuştur. Sorunuz veya endişelerinizi tedavi aldığınız Hastane'nin İdari Bölümü'ne çekinmeden iletebilirsiniz. Çalışma ayrıca Hertfordshire Üniversitesi'nden etik onay almıştır.

Gelecekteki çalımalara katılmak

İletişim bilgileriniz bu çalışma verilerinden ayrı olarak şifre korumalı bir dosyada saklanacaktır. İleriki çalışmalar için sizinle iletişime geçilmesi çalışmalara katılım zorunluluğu getirmez.

Çalışma bulgularına ne olacak?

Çalışma bulguları, ilgili çalışma alanına katkıda bulunması ve klinisyenlerin böbrek yetmezliği olan hastaların düşüncelerini ve algılarını anlamaları için yarar sağlayacaktır. Çalışma bulguları yayımlanabilir. Yayımlanacak olan raporlarda, katılımcıları tanıtabilecek hiçbir bilgiye yer verilmeyecektir. Yayımlandıktan sonra raporun bir kopyasına erişmek istiyorsanız Buse Keskindağ'a ulaşabilirsiniz.

Daha fazla bilgi için iletişim bilgileri

Buse Keskindağ, Fen ve Tıp Bilimleri Fakültesi, Hertfordshire Üniversitesi, Tel: 0533 847 3883

b.keskindag@herts.ac.uk

Appendix P: Longitudinal study informed consent form

INFORMED CONSENT FORM

Site ID Code: ☐☐

Participant identification number: ☐☐☐☐☐☐

Title of the project: Longitudinal assessment of illness experiences in CKD

6. I understand that my participation is voluntary and that I may choose to withdraw at any time and without giving a reason. I understand that when I withdraw from the study, the researcher can use the data provided after anonymised

Please Initial   **YES**   **NO**
☐   ☐

7. I confirm that I have been given enough information about the project and that I am satisfied with the answers given to any questions I have asked about the project.

Please Initial   **YES**   **NO**
☐   ☐

8. I confirm that I have been told that strict confidentiality will be maintained and that all information I provide will be anonymised.

Please Initial   **YES**   **NO**
☐   ☐

9. I understand that this is a longitudinal study and I may be contacted in future. I understand that agreeing to be contacted does not oblige me to participate in any further studies.

Please Initial   **YES**   **NO**

☐   ☐

10. I agree to take part in this project.

Please Initial   **YES**   **NO**

☐   ☐

Name of Participant   Date   Signature

Name of person taking consent   Date   Signature

AYDINLATILMIŞ ONAM FORMU

Hastane kodu:

Katılımcı numarası:

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalık ile ilgili deneyimlerinin boylamsal incelenmesi

1 . Bu çalışmaya katılımanın gönüllü olduğunu biliyorum. İstediğim zaman herhangi bir sebep göstermeden çalışmadan çekilebilebileceğimi biliyorum. Çalışmadan çekildiğimde, paylaştığım veriyi araştırmacının anonimleştirerek kullanabileciğini anladım.

Paraf	Evet	Hayır

2. Bana sunulan bilgileri okuyup anladığımı ve proje ile ilgili sorularımın cevaplarını aldığımı onaylıyorum

Paraf	Evet	Hayır

3. Kesin gizlilik hakkında bilgilendirildiğimi ve paylaşacağım tüm bilgilerin anonim olarak kullanılacağını bildiğimi onaylıyorum.

Paraf	Evet	Hayır

4. Bu çalışmanın boylamsal bir araştırmanın parçası olduğunu ve ileride tekrardan benimle iletişime geçilebileceğini biliyorum. Fakat benimle iletişime geçmelerinin gelecekteki çalışmalara katılma zorunluğunu getirmeyeceğini anladım.

Paraf	Evet	Hayır

5. Bu projeye katılmayı kabul ediyorum.

Paraf	Evet	Hayır

Katılımcının adı soyadı	Tarih	İmza

Formu alan kişinin adı soyadı	Tarih	İmza

Form doldurulduğunda, bir kopya katılımcıda, bir kopya araştırmacı dosyasında kalacak şekilde

Appendix Q: Longitudinal study questionnaire

QUESTIONNAIRE

DEMOGRAPHIC INFORMATION FORM

1. Site Code: ………………………

2. Participant identification number: ……………………………

3. Gender: Male   Female

4. Age: …………………………………

5. Birthplace: North Cyprus   Turkey   Other ……………………….

6. How many years have you been living in Northern Cyprus? …………………………………...

7. Religion: …………………………………....

8. Marital status: Single   Married   Separated   Divorced   Widow

9. Employment: Retired   Full-time employee   Part-time employee   Housewife

    Unemployed   Other …………………….

10. Significant life event (e.g., divorce, death of loved one, job loss etc.):
    ………
    ………
    ………

11. Primary renal disease: ………………………………………………………..

12. Hospitalisation: ……………………………….   if yes, frequency: ……………………………

13. Dialysis vintage (if appropriate): ……………………………………………

14. Comorbidity status: ………………………………………..

Clinical characteristics:

15. Creatine: …………………………

16. Albumin: …………………………

17. Haemoglobin: ……………………………

18. KT/V (if appropriate): ……………………………

Brief Illness Perceptions Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your kidney disease affect your life?
0   1   2   3   4   5   6   7   8   9   10 no affect at all   severely affects my life

How long do you think your kidney disease will continue?
0 1   2   3   4   5   6   7   8   9   10 a very   forever short time

How much control do you feel you have over your kidney disease?
0   1   2   3   4   5   6   7   8   9   10 absolutely   extreme amount no control   of control

How much do you think your treatment can help your kidney disease?
0 1   2   3   4   5   6   7   8   9   10 not at all   extremely helpful

How much do you experience symptoms from your kidney disease?
0 1   2   3   4   5   6   7   8   9   10 no symptoms   many severe at all   symptoms

How concerned are you about your kidney disease?
0 1   2   3   4   5   6   7   8   9   10 not at all   extremely concerned   concerned

How well do you feel you understand your kidney disease?
0   1   2   3   4   5   6   7   8   9   10 don't understand   understand at all   very clearly

How much does your kidney disease affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?
0 1   2   3   4   5   6   7   8   9   10 not at all   extremely affected   affected emotionally   emotionally

Please list in rank-order the three most important factors that you believe caused your kidney disease. *The most important causes for me:-*

1. _____

2. _____

3. _____

PATIENT HEALTH QUESTIONNAIRE-9
(PHQ-9)

Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems? *(Use "✓" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING ___*0*___ + _____ + _____ + _____

=**Total Score:** _____

If you ticked <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Calder Fatigue Scale

Instructions:

We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the last month. Please answer ALL the questions by ticking the answer which applies to you most closely. If you have been feeling tired for a long while, then compare yourself to how you felt when you were last well. Please tick only one box per line.

	less than usual	no more than usual	more than usual	much more than usual
do you have problems with tiredness?				
do you need to rest more?				
do you feel sleepy or drowsy?				
do you have problems starting things?				
do you lack energy?				
do you have less strength in your muscles?				
do you feel weak?				
do you have difficulties concentrating?				
do you make slips of the tongue when speaking?				
do you find it more difficult to find the right word?				

	better than usual	no worse than usual	worse than usual	much worse than usual
how is your memory?				

Dialysis Symptom Index

Instructions:

If you receive dialysis treatment, below is a list of physical and emotional symptoms that people on dialysis may have. For each symptom, please indicate if you had the symptom during the past week by circling "yes" or "no." If "yes", please indicate how much that symptom bothered you by circling the appropriate number.

During the past week: *Did you experience this symptom?*		*If "yes":* *How much did it bother you?* *Not at all A little bit Some-what Quite a bit Very much*				
1. Constipation	NO					
	YES	1	2	3	4	5
2. Nausea	NO					
	YES	1	2	3	4	5
3. Vomiting	NO					
	YES	1	2	3	4	5
4. Diarrhea	NO					
	YES	1	2	3	4	5
5. Decreased appetite	NO					
	YES	1	2	3	4	5
6. Muscle cramps	NO					
	YES	1	2	3	4	5

		1	2	3	4	5
7. Swelling in legs	NO YES					
8. Shortness of breath	NO YES	1	2	3	4	5
9. Light-headedness or dizziness	NO YES	1	2	3	4	5
10. Restless legs or difficulty keeping legs still	NO YES	1	2	3	4	5

During the past week: Did you experience this symptom?		If "yes": How much did it <u>bother</u> you?				
		Not at all	A little bit	Some-what	Quite a bit	Very much
11. Numbness or tingling in feet	NO YES	1	2	3	4	5
12. Feeling tired or lack of energy	NO YES	1	2	3	4	5
13. Cough	NO YES	1	2	3	4	5
14. Dry mouth	NO YES	1	2	3	4	5
15. Bone or joint pain	NO YES	1	2	3	4	5
16. Chest pain	NO YES	1	2	3	4	5
17. Headache	NO YES	1	2	3	4	5
18. Muscle soreness	NO YES	1	2	3	4	5
19. Difficulty concentrating	NO YES	1	2	3	4	5

		1	2	3	4	5
20. Dry skin	NO					
	YES	1	2	3	4	**5**
21. Itching	NO					
	YES	1	2	3	4	**5**
22. Worrying	NO					
	YES	1	2	3	4	**5**

During the past week: Did you experience this symptom?		If "yes": How much did it <u>bother</u> you?				
		Not at all	A little bit	Some-what	Quite a bit	Very much
23. Feeling nervous	NO					
	YES	1	2	3	4	5
24. Trouble falling asleep	NO					
	YES					
		1	2	3	4	**5**
25. Trouble staying asleep	NO					
	YES	1	2	3	4	**5**
26. Feeling irritable	NO					
	YES	1	2	3	4	5
27. Feeling sad	NO					
	YES					
		1	2	3	4	5
28. Feeling anxious	NO					
	YES					
		1	2	3	4	5
29. Decreased interest in sex	NO					
	YES	1	2	3	4	5
30. Difficulty becoming sexually aroused	NO					
	YES	1	2	3	4	**5**

HASTALIK DENEYİMİ DEĞERLENDİRME ANKETİ

Anket No: _____

Anket Tarihi:_____

Bu anket çalışması, böbrek hastalarının hastalıklarını nasıl deneyimlediğini anlamayı amaçlanmaktadır.

Lütfen bu anketi olabildiğince dürüst, eksiksiz ve doğru bir şekilde tamamlayınız.

DEMOGRAFİK BİLGİ FORMU

1. Hastane kodu: ……………………….

2. Katılımcı ID numarası: ……………………………

3. Cinsiyet :   Erkek   Kadın

4. Yaş: …………………………….

5. Doğum yeri: Kıbrıs   Türkiye   Diğer ……………………………

6. Kaç senedir Kuzey Kıbrıs'ta yaşıyorsunuz? ………………………………..

7. Din: …………………………….

8. Medeni durum: Bekar   Evli   Ayrı   Boşanmış   Dul

9. Çalışma durumu:

Emekli   Tam zamanlı çalışan   Yarı zamanlı çalışan   Ev hanımı   İşsiz
Diğer…………….

10. Deneyimlediğiniz olumsuz yaşam olayı (varsa, örneğin, boşanma, sevdiğiniz birinin ölümü, işinizi kaybetmeniz vb.):
    ……
    ……
    ……
    ………

11. Başlıca böbrek bozukluğu: ………………………………………………….

12. Hastaneye yatırılma: Evet / Hayır -   Evet ise, sıklığı: ……………………………

13. Diyaliz süresi ve çeşidi (eğer diyaliz alıyorsanız): …………………………………… HD /PD/ diet

14. Komorbidite durumu (eş zamanlı başka hastalığınız varsa): …………………………………….

Klinik özellikler:

15. Keratin: …………………………

16. Albumin: …………………………

17. Hemoglobin: ………………………………

18. KT/V (eğer diyaliz alıyorsanız): ……………………………

Kısa Hastalık Algı Ölçeği

Aşağıdaki sorular için, sizin görüşlerinize en fazla uyan numarayı lütfen çember içine alın:

Böbrek hastalığınız hayatınızı ne kadar etkilemekte?
0　　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 hiç　　　　　　　　　　　　　　　　　　yaşamımı ciddi etkilemiyor　　　　　　　　　　　　　　ölçüde etkilemiyor

Böbrek hastalığınızın ne kadar süreceğini düşünüyorsunuz?
0　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 çok kısa　　　　　　　　　　　　　　　ömür boyu süre

Böbrek hastalığınızın üzerinde ne kadar kontrolünüz olduğunu hissediyorsunuz?
0　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 kesinlikle hiçbir　　　　　　　　　　tamamen kontrolüm altında Kontrolüm yok

Tedavinizin böbrek hastalığınıza ne ölçüde yardımcı olabileceğini düşünüyorsunuz?
0　　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 hiç yardımcı　　　　　　　　　　　　oldukça yardımcı değil

Böbrek hastalığınıza bağlı şikayetleri hangi ölçüde yaşıyorsunuz?
0　　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 hiçbir　　　　　　　　　　　　　　　çok ciddi şikayetlerim şikayetim olmuyor　　　　　　　　　oluyor

Böbrek hastalığınız için ne kadar endişelisiniz?
0　　1　　2　　3　　4　　5　　6　　7　　8　　9　　10 hiç endişeli　　　　　　　　　　　　çok endişeliyim değilim

Böbrek hastalığınızın ne olduğunu ne kadar iyi anladınız?

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

hiç
anlamadım

çok net anladım

Böbrek hastalığınız duygusal olarak sizi ne kadar etkilemekte? (ör: Sizi sinirli, ürkek, üzüntülü veya çökkün yapıyor mu?)

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

duygusal olarak hiç
etkilemiyor

duygusal olarak çok
etkiliyor

Lütfen Böbrek hastalığınıza sebep olduğuna inandığınız en önemli üç faktörü (olayı) düzenli bir şekilde listeleyin. Benim için en önemli sebepler :

_____

_____

_____

HASTA SAĞLIK ANKETİ-9 (PHQ-9)

Son 2 hafta içerisinde, aşağıdaki sorunlardan herhangi biri sizi ne sıklıkla rahatsız etti? *(Cevabınızı "✓" işaretiyle gösteriniz)*	**Hiçbir zaman**	**Bazı günler**	**Günlerin yarıdan fazlasında**	**Hemen hemen her gün**
1. Bir şeyleri yapmaya az ilgi veya zevk duymak	0	1	2	3
2. Üzgün, depresif veya umutsuz hissetmek	0	1	2	3
3. Uykuya dalmada veya uyumaya devam etmekte zorluk, veya çok fazla uyumak	0	1	2	3
4. Yorgun hissetmek veya enerjinizin az olması	0	1	2	3
5. İştahsızlık veya çok fazla yemek	0	1	2	3
6. Kendinizi kötü hissetmeniz — veya kendinizi başarısız ya da kendinizi veya ailenizi hayal kırıklığına uğrattığınızı düşünmeniz	0	1	2	3

7. Gazete okumak veya televizyon seyretmek gibi faaliyetlerde dikkatinizi toplamakta güçlük çekmeniz	0	1	2	3	
8. Başkalarının fark edebileceği kadar yavaş hareket etmeniz veya konuşmanız? Veya tam aksine— normalden çok daha fazla hareket edecek kadar kıpır kıpır veya huzursuz olmanız	0	1	2	3	
9. Ölmüş olsanız daha iyi olacağınız veya bir şekilde kendinize zarar verme düşünceleri	0	1	2	3	

___0___ + _____ + _____ + _____

=Total _____

Bu sorunlardan <u>herhangi</u> birini işaretlediyseniz, bu sorunlar işinizi yapmanızda, evinizle ilgili işleri halletmenizde veya diğer insanlarla olan ilişkilerinizde ne kadar <u>zorluk yarattı</u>?

Hiç zorluk derecede yaratmadı yarattı	**Oldukça zorluk yarattı**	**Çok zorluk yarattı**	**Aşırı zorluk**
☐	☐	☐	☐

Chalder Yorgunluk Ölçeği

Yönerge:

Son bir ayda kendinizi yorgun, güçsüz ya da enerjisi azalmış hissetmiş olmanızla ilgili problemler hakkında daha fazla bilgi edinmek istiyoruz. Lütfen TÜM soruları sizin için en uygun olan cevabı işaretleyerek cevaplayınız. Kendinizi uzun zamandır yorgun hissediyorsanız, en son iyi hissettiğiniz zamanla son bir aydaki durumunuzu karşılaştırınız. (Lütfen her satırda yalnızca bir seçeneği işaretleyiniz).

	Her zamankinden daha az	Her zamanki kadar	Her zamankinden daha fazla	Her zamankinden çok daha fazla
1-) Yorgunlukla ilgili sorunlarınız var mı?				
2-) Dinlenmeye ihtiyaç duyuyor musunuz?				

	Her zamankinden daha iyi	Her zamanki gibi	Her zamankinden daha kötü	Her zamankinden çok daha kötü
3-) Kendinizi uykulu veya uyuşuk hissediyor musunuz?				
4-) Bir şeye başlamakta sorun yaşıyor musunuz?				
5-) Enerjinizde azalma hissediyor musunuz?				
6-) Kaslarınızın kuvvetinde azalma hissediyor musunuz?				
7-) Kendinizi güçsüz hissediyor musunuz?				
8-) Konsantre olmakta zorlanıyor musunuz?				
9-) Konuşurken diliniz sürçüyor mu?				
10-) Konuşurken doğru sözcüğü bulmakta zorlanıyor musunuz?				
	Her zamankinden daha iyi	**Her zamanki gibi**	**Her zamankinden daha kötü**	**Her zamankinden çok daha kötü**
11-) Hafızanız nasıl?				

Diyaliz Semptom İndeksi

Yönerge:

Eğer diyaliz tedavisi alıyorsanız, lütfen cevaplayınız. Aşağıdaki listede, diyaliz tedavisi alan hastaların deneyimleyebileceği semptomlar yer almaktadır. Eğer bu semptomları deneyimliyorsanız lütfen size uygun olan cevabı yuvarlak içine alınız.

Geçen hafta boyunca aşağıdaki semptomu yaşadınız mı?		"Evet" ise: Sizi ne kadar etkiledi?				
		Hiç	Biraz	Bazen	Çok Az	Çok Fazla

1. Kabızlık	Hayır					
	Evet→	1	2	3	4	5
2. Bulantı	Hayır					
	Evet→	1	2	3	4	5
3. Kusma	Hayır					
	Evet→	1	2	3	4	5
4. İshal	Hayır					
	Evet→	1	2	3	4	5
5. İştahta azalma	Hayır					
	Evet→	1	2	3	4	5
6. Kas krampları	Hayır					
	Evet→	1	2	3	4	5
7. Bacaklarda şişlik	Hayır					
	Evet→	1	2	3	4	5
8. Nefes darlığı	Hayır					
	Evet→	1	2	3	4	5
9. Sersemlik/baş dönmesi	Hayır					
	Evet→	1	2	3	4	5
10. Bacakları hareketsiz tutmada zorlanma	Hayır					
	Evet→	1	2	3	4	5
11. Ayaklarda uyuşukluk veya karıncalanma	Hayır					
	Evet→	1	2	3	4	5
12. Yorgun hissetme veya enerjide azalma	Hayır					
	Evet→	1	2	3	4	5
13. Öksürme	Hayır					
	Evet→	1	2	3	4	5
14. Ağız kuruluğu	Hayır					
	Evet→	1	2	3	4	5

15. Kemik veya eklem ağrısı	Hayır					
	Evet→	1	2	3	4	5
16. Göğüs Ağrısı	Hayır					
	Evet→	1	2	3	4	5
17. Baş ağrısı	Hayır					
	Evet→	1	2	3	4	5
18. Kas ağrısı	Hayır					
	Evet→	1	2	3	4	5
19. Konsantre olmada zorluk	Hayır					
	Evet→	1	2	3	4	5
20. Deride kuruluk	Hayır					
	Evet→	1	2	3	4	5
21. Kaşıntı	Hayır					
	Evet→	1	2	3	4	5
22. Endişelenme	Hayır					
	Evet→	1	2	3	4	5
23. Sinirli hissetme	Hayır					
	Evet→	1	2	3	4	5
24. Uykuya dalmada zorlanma	Hayır					
	Evet→	1	2	3	4	5
25. Uykuyu sürdürmede zorlanma	Hayır					
	Evet→	1	2	3	4	5
26. Rahatsız hissetme	Hayır					
	Evet→	1	2	3	4	5
27. Üzgün hissetme	Hayır					
	Evet→	1	2	3	4	5
28. Kaygılı hissetme	Hayır					
	Evet→	1	2	3	4	5

29. Sekse ilgide azalma	Hayır					
	Evet→	1	2	3	4	5
30. Cinsel yönden uyarılmada zorluk	Hayır					
	Evet→	1	2	3	4	5

Bu anket formunda sizin geçen hafta yaşadığınız başka semptom belirtilmemiş ise lütfen belirtiniz……………………………………………………………………………………….

Zaman ayırdığınız için teşekkür ederiz.

Appendix R: Longitudinal study debrief sheet

PARTICIPANT DEBRIEF SHEET

Title of the project: Longitudinal assessment of illness experiences in patients with CKD

Thank you for participating in this study, which aimed to explore the illness related experiences of patients living with chronic kidney disease. It is hoped that the results of the research will help inform strategies aimed at supporting patients in adjusting to living with a long-term condition.

Should you have any questions or queries about the study, please contact:

Buse Keskindag

Tel: 00905338473883

b.keskindag@herts.ac.uk

It is possible that talking about your illness related experiences may have raised some issues for you. If as a result of your participation in this study, you experienced any negative feelings, please contact the Barış Psychiatric Hospital at 0392 6085441 - 6085479. As a research student, I am unable myself to offer any further support but would strongly encourage you to discuss your feelings with a trained professional.

Once again thank you for taking part in this study.

KATILIMCI BİLGİ EDİNME FORMU

Proje adı: Kronik böbrek yetmezliği olan hastaların hastalıkla ilgili deneyimlerinin boylamsal olarak incelenmesi

Çalışmaya katıldığınız için teşekkür ederiz. Bu çalışma kronik böbrek yetmezliği olan hastaların hastalıkları ile ilgili inançlarını anlamayı amaçlamaktadır. Cevaplarınız, kronik hastalığına uyum sağlamaya çalışan hastalara yönelik geliştirilecek olan destek odaklı stratejilere katkıda bulunacaktır.

Çalışma ile ilgili herhangi bir sorunuz veya düşünceniz varsa lütfen bizimle iletişime geçiniz.

Buse Keskindağ, Fen ve Tıp Bilimleri Fakültesi, Hertfordshire Üniversitesi
Tel: 0533 847 3883
b.keskindag@herts.ac.uk

Hastalığınız ile ilgili deneyimlerinizi paylaşmanız sizi rahatsız etmiş olabilir. Bu çalışmaya katılımınızdan dolayı olumsuz duygular deneyimlediyseniz, lütfen Barış Ruh ve Sinir Hastanesi ile 0392 6085441 – 6085479 numaraları aracılığı ile iletişime geçiniz. Araştırma öğrencisi olarak size destek verebilecek pozisyonda olmadığımdan, duygularınızı tartışabileceğiniz eğitimli bir profesfonel ile iletişime geçmenizi tavsiye ederim.

Çalışmaya katıldığınız için tekrardan teşekkür ederiz.

Appendix S: UH Ethics approval for healthcare professionals qualitative interview study

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO   Buse Keskindag

CC   Dr Shivani Sharma

FROM   Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair

DATE   10/06/2021

Protocol number: **LMS/PGR/UH/04589**

Title of study: Health care professionals' perspectives on the psychosocial care needs of Turkish Cypriot patients receiving dialysis.

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 10/06/2021

To: 30/11/2021

Appendix T: TRNC Ethics approval for healthcare professionals qualitative interview study

TURKISH REPUBLIC OF NORTHERN CYPRUS
MINISTRY OF HEALTH
MANAGEMENT OF INPATIENT TREATMENT
DR. BURHAN NALBANTOĞLU STATE HOSPITAL

File number: YTIKI1.01-629-21/E.2419   11th August 2021

RE: Ethics Committee decision about Buse Keskindağ's study.

To whom it may concern,

According to the meeting of the Ethics Committee held on 6th August 2021, we have made a decision that it is ethically convenient for the study (code: 40/21) entitled "Health care professionals' perspectives on the psychosocial care needs of Turkish Cypriot patients receiving dialysis" to be conducted at the Nicosia Dr.Burhan Nalbatoğlu State Hospital, Famagusta State Hospital, Kyrenia Akçiçek State Hospital and Cengiz Topel Hospital.

By respectfully submitting, we wish you success.

<div align="right">

e-signed

Sonuç BUYUK

Deputy Chief Physician

</div>

To be submitted: **Information:**

Nicosia Dr.Burhan Nalbatoğlu State Hospital   **Management of Inpatient**
Famagusta State Hospital   **Treatment**
Kyrenia Akçiçek State Hospital
Cengiz Topel Hospital

Note: This document has been electronically signed in accordance with 6th article of the Regulation of Electronic Signatures (93/2007).

Bedrettin Demirel Street - Ortaköy   For information: Havva GÜNDOĞDU
Tel: (392) 228 54 41   Secretary of Chief Physician
Fax: (392)223 1899

KUZEY KIBRIS TÜRK CUMHURİYETİ
SAĞLIK BAKANLIĞI
Yataklı Tedavi Kurumları Dairesi Müdürlüğü
Dr. Burhan Nalbantoğlu Devlet Hastanesi

Sayı : YTK1.01-629-21/E.2419   11 Ağustos 2021

Konu : Buse Keskindağ'ın Etik Kurulu hk.

DAĞITIM YERLERİNE

    Hertfordshire Üniversitesi Psikoloji doktora öğrencisi Buse Keskindağ'ın 40/21 proje kodlu "Sağlık Çalışanlarının Diyaliz Tedavisi Alan Hastaların Psikososyal Bakım Gereksinimleri Hakkındaki Görüşleri" başlıklı doktora tezi 06 Ağustos 2021 tarihinde etik kurulumuzun yapmış olduğu toplantıda Dr.Burhan Nalbantoğlu Devlet Hastanesi, Girne Doktor Akçiçek Hastanesi, Cengiz Topel Hastanesi ve Gazimağusa Devlet Hastanelerinde yapması uygun görülmüştür.

    Gereği için bilgilerinize sunulur.

                            e-imzalıdır
                            Sonuç BÜYÜK
                            Başhekim Yrd
              Etik Kurulu Yönetim Kurulu Üyesi

Dağıtım:

Gereği: Bilgi:

Dr. Burhan Nalbantoğlu Devlet Hastanesi   Yataklı Tedavi Kurumları Dairesi Müdürlüğü

Girne Dr. Akçiçek Hastanesi

Cengiz Topel Hastanesi

Gazimağusa Devlet Hastanesi

Appendix U: Healthcare professionals qualitative interview study participant information

sheet

PARTICIPANT INFORMATION SHEET

1. Title of study
Health care professionals' perspectives on the psychosocial care needs of Turkish Cypriot patients receiving dialysis

2. Information about the study

You are being invited to take part in the above study. Before you decide to do so, it is important that you understand the research that is being carried out. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask a member of the research team anything that is not clear. Please take your time to decide whether or not you wish to take part.

Thank you for reading this information sheet.

3. What is the purpose of this study?

A group of local researchers as well as researchers at the University of Hertfordshire, working in the field of healthcare, are interested in understanding health care professionals' perspectives on the psychological care of patients receiving dialysis in North Cyprus. The treatment for advanced kidney disease and via dialysis is known to impact several aspects of a patient's life, including their mental well-being. The aim of this research is to understand the experiences of healthcare professionals' in caring for patients, with a focus on exploring thoughts around patient well-being and the provision of psychosocial care.

4. Why have I been approached?

You have been invited to take part in this research as you work at the Nephrology Department. Therefore we would like to invite you to share your experience and views on the care needs of patients that extend beyond the provision of kidney replacement therapy.

5. Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect you in any way.

6. What does 'taking part' involve?

If you wish to participate or if you would like to discuss the study further, please contact the researcher Buse Keskindag b.keskindag@herts.ac.uk.

The study will take place online via a university zoom account and involve a 1-1 interview with the researcher. It will be arranged at a time that suits you. Participation is expected to last up to 1 hour.

Please be aware that if you do decide to take part you will be asked to indicate your agreement with written consent form.

During the interview, you will be asked questions about your perspective and experience related to how patients adjust to dialysis, what support is available to help patients cope with the life impact of this and any opportunities to extend psychosocial care.

With your permission, the interviews will be audio recorded to help with transcription as part of the data analysis and looking for themes in the views of health care professionals. Audio recordings will be kept until the transcription, verification and analysis of the data is complete, after which they will be securely destroyed. We anticipate that this may take 6 months.

7. What are the advantages and disadvantages of taking part?

Participating in the research is not anticipated to cause you any discomfort. Although there are no immediate benefits, it is hoped that this work will have a positive impact on strategies to enhance the quality of life of patients. We also expect that you will enjoy sharing your views and experiences on patient care needs.

If you feel any discomfort due to sharing your perspective about patient experience, you will be directed to contact a professional who is experienced in helping individuals who are experiencing distress. We will provide you with the contact details.

8. Will my taking part in this project be kept confidential?

If you agree to take part, you will be asked to sign a consent form. This will include your name but will be stored securely, password protected on university servers during the study period. After this, all forms will be destroyed. Only the researcher and supervisor will have access to this information. If you consent to your interview being audio recorded, the audio file will also be stored on secure university servers. The recording will be located separately to your consent form and deleted after transcription. All information shared will be anonymous, thus not identifying you personally. Only anonymised transcripts will be stored by the supervisor for up to 5 years and then deleted in an irretrievable manner. Your anonymity will only be broken if you disclose anything that raises concerns about you or patients that you support.

9. What will happen to the data collected within this study?

Information will be analysed in order to look for themes across participants and summarised. Data will be stored electronically in a password protected environment for a maximum of 5 years. It will be written up as part of a PhD in Psychology being undertaken by Buse Keskindag via the University of Hertfordshire UK. The data may also be published in an academic journal. In all cases, your anonymity will be maintained.

10. Will the data be required for use in further studies?

The data will not be used in any further studies.

11. Who has reviewed this study?

This project is also ethically reviewed by the Ethics Committee of Ministry of Health in Turkish Republic of Northern Cyprus. If you have any concerns or questions please do not hesitate to contact the Administrative Department in the State Hospital that you work at. The research also has ethical approval from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. The University's

regulations regarding the conduct of studies involving human participants can be found at this link:
 https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

12. Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with the researcher (Buse Keskindag) b.keskindag@herts.ac.uk *or the research supervisor (Dr Shivani Sharma)* s.3.sharma@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Katılımcı Bilgi Formu

1. Proje

Sağlık çalışanlarının diyaliz tedavisi gören hastaların psikososyal bakım ihtiyaçlarına ilişkin bakış açıları

2. Çalışma hakkında bilgiler

Sizi yukarda belirtilen araştırmaya katılmaya davet ediyoruz. Bunu yapmaya karar vermeden önce, yapılmakta olan araştırmayı anlamanız önemlidir. Aşağıdaki bilgileri dikkatlice okumak için zaman ayırıp, dilerseniz başkalarıyla tartışabilirsiniz. Araştırma ekibine soru sormaktan çekinmeyiniz.

3. Bu çalışmanın amacı nedir?

Sağlık hizmetleri alanında çalışan Hertfordshire Üniversitesi'ndeki araştırmacıların yanı sıra bir grup yerel araştırmacı, Kuzey Kıbrıs'ta diyaliz gören hastaların psikolojik bakımına ilişkin sağlık çalışanlarının görüşlerini anlamayı amaçlamaktadır. Son dönem böbrek hastalarının düzenli olarak aldığı diyaliz tedavisi hastaların yaşamını ruh sağlığı da dahil olmak üzere çeşitli yönlerini etkilediği bilinmektedir. Bu araştırmanın amacı, hastaların iyilik hali için psikososyal bakım sağlanması hakkındaki düşüncelerinizi keşfetmeye odaklanarak, hastalarla olan deneyimlerinizi anlamaktır.

4. Neden davet edildim?

Nefroloji Bölümünde çalıştığınızdan dolayı bu araştırmaya katılmak için davet edildiniz. Bu nedenle, sizi hastaların bakımı ve gereksinimleri hakkındaki deneyim ve görüşlerinizi paylaşmaya davet ediyoruz.

5. Katılmak zorunda mıyım?

Bu araştırmaya katılmaya karar vermeniz tamamen size bağlıdır. Katılmaya karar verirseniz, bir onay formunu imzalamanız istenecektir. Çalışmaya katılmayı kabul etmek, onu tamamlamanız gerektiği anlamına gelmez. Herhangi bir aşamada herhangi bir sebep belirtmeksizin çekilmekte özgürsünüz. Herhangi bir zamanda çekilme kararı veya hiç katılmama kararı sizi hiçbir şekilde etkilemeyecektir.

6. "Çalışmaya katılmak" neleri içerir?

Katılmak isterseniz veya çalışmayı daha ayrıntılı tartışmak isterseniz, lütfen araştırmacı Buse Keskindag (b.keskindag@herts.ac.uk) ile iletişime geçmekten çekinmeyiniz.

Çalışma, üniversitenin Zoom hesabı aracılığıyla çevrimiçi olarak gerçekleştirilecek ve araştırmacıyla bire bir görüşme içerecektir. E-görüşme size uygun bir zamanda ayarlanacaktır. Katılımın en fazla 35-40 dk sürmesi beklenmektedir.

Katılmaya karar verirseniz, yazılı onay formu ile çalışmaya katılmayı gönüllü olarak kabul ettiğinizi belirtmeniz istenecektir.

Görüşme sırasında, hastaların diyalize nasıl uyum sağladıklarıyla ilgili bakış açınız ve deneyimleriniz, hastaların zorluklarla daha iyi başa çıkmalarına yardımcı olabilecek ne gibi desteklerin olduğu, ve psikososyal bakımı gereksinimleri hakkında sorular sorulacaktır. İzninizle, görüşmeler, veri analizinin bir parçası olarak transkriptlerin oluşturulmasına yardımcı olmak için sesli olarak kaydedilecektir. Ses kayıtları, verilerin transkripsiyonu, doğrulanması ve analizi tamamlanıncaya kadar saklanacak ve ardından kalıcı şekilde silinecektir. Bu sürecin görüşmeler sonrası 6 ay kadar sürebileceğini tahmin ediyoruz.

7. Katılmanın avantajları ve dezavantajları nelerdir?

Araştırmaya katılmanın size herhangi bir rahatsızlık vermesi beklenmemektedir. Avantajlar hemen görülememesine rağmen, bu çalışmanın hastaların yaşam kalitesini artırmaya yönelik stratejiler üzerinde olumlu bir etkisi olacağı beklenmektedir.

Hasta deneyimi ile ilgili bakış açınızı paylaşmanızdan dolayı herhangi bir rahatsızlık hissederseniz, sıkıntı yaşayan kişilere yardım etme konusunda deneyimli bir uzmanla iletişime geçmeniz için yönlendirileceksiniz.

8. Bu projede yer almam gizli tutulacak mı?

Katılmayı kabul ederseniz, bir onay formu imzalamanız istenecektir. Bu form, adınızı içerecek ancak çalışma süresi boyunca üniversitenin sağladığı Drive hesabında güvenli bir şekilde saklanacak ve parola ile korunacaktır. Analiz aşamasından sonra tüm onam formlar silinecektir. Bu bilgilere sadece görüşmeyi yapan araştırmacı erişebilecektir. Görüşmenizin sesli olarak kaydına izin verirseniz, bu dosya da güvenli üniversite Drive hesabında saklanacaktır. Kayıt, onay formunuzdan ayrı olarak saklanacak ve yazıya döküldükten sonra kalıcı olarak silinecektir. Rapor ve sunum aracılığıyla paylaşılacak olan tüm bilgiler anonim olacak, dolayısıyla sizi kişisel olarak tanımlamayacaktır. Yalnızca anonimleştirilmiş transkriptler, proje danışmanı tarafından 5 yıla kadar saklanacak ve sonra kalıcı şekilde silinecektir. Gizlilik ilkesine bağlılık, yalnızca sizinle veya ilgilendiğiniz hastalarla ilgili hayati ve endişeleri artıran herhangi bir durum söz konusu olduğunda kırılabilir.

9. Bu çalışmada toplanan verilere ne olacak?

Göürşmelerde tekrarlayan ve öne çıkan temaları tanımlamak için bilgiler analiz edilecek ve özetlenecektir. Veriler elektronik olarak parola korumalı bir ortamda maksimum 5 yıl süreyle saklanacaktır. İngiltere Hertfordshire Üniversitesi aracılığıyla yürütülen Psikoloji Doktora programının bir parçası olarak raporlanacaktır. Veriler ayrıca akademik bir dergide de yayınlanabilir. Her durumda, veriler anonim olarak kullanılacak ve kişisel bilgileriniz gizlilik ilkesine bağlılıkla korunacaktır.

10. Veriler daha sonraki çalışmalarda kullanılmak için gerekli olacak mı?

Veriler başka çalışmalarda kullanılmayacaktır.

11. Bu çalışmayı kim inceledi?

Bu proje Kuzey Kıbrıs Türk Cumhuriyeti Sağlık Bakanlığı Etik Kurulu tarafından etik olarak incelenmiş ve yapılması uygun görülmüştür (Dosya No: 40/12). Herhangi bir endişeniz veya sorunuz varsa, lütfen çalıştığınız Devlet Hastanesinin İdari Departmanı ile iletişime geçmekten çekinmeyin. Çalışma ayrıca Hertfordshire Üniversitesi'nden etik onay almıştır.

12. Herhangi bir sorum olursa kiminle iletişime geçebilirim?

Daha fazla bilgi için lütfen araştırmacı (Buse Keskindag – 0533 847 3883) b.keskindag@herts.ac.uk veya proje danışmanı (Dr Shivani Sharma) s.3.sharma@herts.ac.uk ile iletişime geçmekten çekinmeyin.

Bu bilgileri okuduğunuz ve bu araştırmaya katılmayı değerlendirdiğiniz için çok teşekkür ederiz.

Appendix V: Healthcare professionals qualitative interview study informed consent form

INFORMED CONSENT FORM

Title of the project: Health care professionals' perspectives on the psychosocial care needs of Turkish Cypriot patients receiving dialysis

1. I understand that my participation is voluntary and that I may choose to withdraw at any time and without giving a reason.

   Please Initial   **YES**   **NO**

2. I confirm that I have been given enough information about the project and that I am satisfied with the answers given to any questions I have asked about the project.

   Please Initial   **YES**   **NO**

3. I confirm that I have been told that strict confidentiality will be maintained and that all information I provide will be anonymised.

   Please Initial   **YES**   **NO**

4. I give permission for the information I provide being audio-recorded.

   Please Initial   **YES**   **NO**

   a. I understand that audio recordings will be destroyed following the transcription and analysis of the data, and that anonymised quotes from the transcripts may be used in future publications and presentations.

   Please Initial   **YES**   **NO**

5. I agree to take part in this project.

   Please Initial   **YES**   **NO**

Name of Participant   Date   Signature

Name of person taking consent   Date   Signature

When completed: 1 copy for participant; 1 copy for researcher site file

AYDINLATILMIŞ ONAM FORMU

Proje adı: Sağlık çalışanlarının diyaliz tedavisi alan hastaların psikososyal bakım gereksinimleri hakkındaki görüşleri

1 . Bu çalışmaya katılımanın gönüllü olduğunu biliyorum. İstediğim zaman herhangi bir sebep göstermeden çalışmadan çekilebilebileceğimi biliyorum.

	Paraf	Evet	Hayır

2. Bana sunulan bilgileri okuyup anladığımı ve proje ile ilgili sorularımın cevaplarını aldığımı onaylıyorum

	Paraf	Evet	Hayır

3. Kesin gizlilik hakkında bilgilendirildiğimi ve paylaşacağım tüm bilgilerin anonim olarak kullanılacağını bildiğimi onaylıyorum.

	Paraf	Evet	Hayır

4. Verdiğim bilgilerin sesli olarak kayıt edilmesi için izin veriyorum.

	Paraf	Evet	Hayır

    b. Ses kayıtlarının, verilerin transkript ve analiz aşamalarından sonra kalıcı olarak silineceğini, gelecekteki yayın ve sunumlar için transkriptlerden anonim olarak alıntı yapılabileceğini biliyorum.

	Paraf	Evet	Hayır

5. Bu projeye katılmayı kabul ediyorum.

	Paraf	Evet	Hayır

Katılımcının adı soyadı	Tarih	İmza

Formu alan kişinin adı soyadı	Tarih	İmza

Form doldurulduğunda, bir kopya katılımcıda, bir kopya araştırmacı dosyasında kalacak şekilde

Appendix W: Healthcare professionals qualitative interview study topic guide

INTERVIEW TOPIC GUIDE

Thank you for agreeing to take part in this study. Before we start, I would like to remind you that you can withdraw from the study at any time without providing a reason. Your responses will remain confidential and will be anonymised when transcribed prior to analysis.

Part 1: About you
Age:
Gender:
Job Role

Part 2: Views on kidney services generally
1. What is your role in caring for patients with advanced kidney disease?
- How long have you been caring for patients with advanced kidney disease?
2. How accessible are kidney health services locally?
3. What are the key strengths of the kidney health services locally?
4. Is there anything that frustrates you or that you would change about kidney health care provision?

Part 3: Patient adjustment
5. From your previous experiences, what factors do you think contribute to patients adjusting well to receiving dialysis?
- Is this similar or different for those on HD versus PD?
- What support is given to patients by care teams to help adjustment?
- Do you think that patients generally understand their condition and can play an active role in making decisions about their health?
6. From your previous experiences, what factors do you think hinder patients from adjusting well to receiving dialysis?
- Is this similar or different for those on HD versus PD?
7. What is meaning of 'good overall health' to you in relation to the care of dialysis patients?
8. What factors, such as individual, environmental, family, social, health system do you think contribute to patients having good overall health outcomes when receiving dialysis?
9. What in your experience matters most to patients in terms of the symptoms that bother them when receiving dialysis? For example, physical, psychological, both.
10. What has been your experience of the psychological impact of receiving dialysis on patients?
- " Which situations make you feel helpless? (feeling tied, not knowing what to do, feeling stuck?) - How would you describe these challenging interactions?
- What is it like to experience the feeling of being "stuck"? For example, physically, emotionally?
- Do medical staff receive additional training in the psychosocial care of patients?
- What level of involvement do medical staff have in the delivery of psychosocial care, of patients?
o Recognition of psychosocial problem e.g. depression
o Referral to appropriate agency (within in team, community services, psychology/ psychiatry)
o Management of psychosocial issues (medication, treatment)
o Use of basic counselling skills
o Information provision
o Screening patients regularly for depression/psychological issues
o Are there any local guidelines on psychosocial care of patients
- How common do you think low mood/ depression is in patients?

- Are there opportunities to develop these support services further?
- How willing do you believe that patients are to engage?

11. We are interested in the psychological impact of living with advanced kidney disease and the care needs of patients. Is there anything else that you would like to add on this topic?

GÖRÜŞME SORULARI

Bu araştırmaya katılmayı kabul ettiğiniz için teşekkür ederiz. Çalışmaya başlamadan önce, herhangi bir neden göstermeden çalışmadan çekilebileceğinizi hatırlatmak isterim.

Yanıtlarınız gizli kalacaktır. Sizinle yaptığımız görüşmelerin kayıtları, anonim olarak yazıya dökülecek ve sonrasında diğer tüm verilerle analizlerde kullanılacaktır.

Bölüm 1: Sizin hakkınızda

Yaş:

Cinsiyet:

İşteki rolünüz:

Bölüm 2: Diyaliz servisine ilişkin genel görüşler

1. İleri derecede böbrek hastası olanların bakımında sizin rolünüz nedir?

      - İleri derecede böbrek hastası olanlarla ne kadar süredir ilgileniyorsunuz?

      - Ne kadar süreden beri ileri derecede böbrek hastası olanlarla çalışıyorsunuz?

2. KKTC'de, böbrek sağlığı hizmetlerinin erişilebilirliğinin ne kadar olduğunu düşünüyorsunuz?

3. Sizce KKTC'de böbrek sağlığı ile ilgili sağlanan bakımının / hizmetlerin güçlü olduğu yönler nelerdir?

4. Böbrek sağlığı hizmetleri ile ilgili engellenmiş / huzursuz hissettiğiniz oluyor mu? Elinizde olsa, böbrek sağlığıyla ilgili olarak neleri değiştirirdiniz?

Bölüm 3: Hasta uyumu

5. Deneyimlerinize dayanarak, hastaların diyalize sağlıklı bir şekilde uyum sağlamalarında hangi faktörlerin katkıda bulunduğunu düşünüyorsunuz?

      - Bu durum, hemodiyaliz (HD) ve periton diyaliz (PD) kullananlar arasında benzerlik veya farklılıklar gösteriyor mu?

      - Hastaların uyum sağlamalarını kolaylaştırmak için sağlık ekibi tarafından ne gibi destekler verilir?

      - Genel olarak, hastaların durumlarını anladıklarını ve sağlıkları hakkında karar vermede aktif bir rol oynayabileceklerini düşünüyor musunuz?

6. Deneyimlerinize dayanarak, hastaların diyalize sağlıklı bir şekilde uyum sağlamlarında, hangi faktörlerin engel olduğunu düşünüyorsunuz?

     - Bu durum, HD ve PD kullananlar arasında benzerlik veya farklılıklar gösteriyor mu?

7. Size göre "Tümüyle sağlıklı olmak" ifadesi, diyaliz hastası olanlar açısından, ne anlama gelir?

8. Bireysel, çevresel, aile, sosyal, sağlık sistemi gibi faktörlerin, hangisi veya hangileri diyaliz hastası olanların genel sağlık durumlarına olumlu olarak katkıda bulunduğunu düşünüyorsunuz?

9. Deneyimlerinize dayanarak, diyaliz hastası olanları en fazla rahatsız eden belirtiler nelerdir? Örneğin, fiziksel, psikolojik ve/veya her ikisi de.

10. Diyaliz tedavisinin hastalar üzerindeki psikolojik etkisine ilişkin deneyimleriniz nelerdir?

     - " Hangi durumlar kendiniz çaresiz kalmış hissetmenize yol açar? (zorlu hastalarda eli kolu bağlı hissetmek, ne yapacağını bilememe, tıkanmış, çıkmazda, çaresiz hissetme gibi)

          - Bu zorlu etkileşimleri nasıl tanımlarsınız?

          - "Sıkışmış/çıkmazda" olma hissini nasıl bir deneyimdir? Örneğin, fiziksel, duygusal olarak?

          - Hastalara psikososyal destek sağlamak amacıyla sağlık personeli için gerekli ek eğitimler verilir mi?

          - Hastalara psikososyal destek sağlanmasında sağlık ekibi hangi düzeyde katkı koyar?

               o Psikolojik duygu durumundaki farklılaşmanın anlaşılması, örn. Kaygı ve Depresyon belirtileri

               o Kişideki değişikliği/durumu değerlendirerek uygun kuruma yönlendirme (ekip içinde yer alan başka uzmana, psikoloji/ psikiyatri servisine yönlendirme gibi)

               o İlaç tedavisi konusunda nasıl bir destek sağlanır? (Örn. Hastanın düzenli ilaç kullanmasına ve kendi ilaçlı tedavi yönetimine destek)

               o Temel iletişim becerilerinin kullanımı! (Örn. Kullanılan kavramlar, hitap,....)

               o Bilgi sağlama (Örn. Gündemdeki sorulara gerekli yanıtı verme)

               o Düzenli olarak diyaliz hastası olanların psikolojik açıdan değerlendirilmeleri (depresyon / psikolojik sorunlar için taranması)

o Diyaliz hastası olanlara sağlanan psikososyal destek ile ilgili yerel yönergeler var mıdır?

- Diyaliz hastası olanlarda duygudurum bozukluğu / depresyon belirtilerinin hangi yaygınlıkta olduğunu düşünüyorsunuz?

- Psikososyal destek hizmetlerini geliştirmek için kaynakların/fırsatların olduğunu düşünüyor musunuz?

- Diyaliz hastası olanların psikososyal destek almak için ne kadar istekli olduğunu düşünüyorsunuz?

11. İleri derecede böbrek hastası ve tedavi ihtiyacı olan hastaların psikolojik durumlarını önemsiyoruz. Bu konu ile ilgili eklemek istediğiniz başka bir şey var mıdır?

Appendix X: Healthcare professionals qualitative interview study debrief sheet

PARTICIPANT DEBRIEF SHEET

Title of the project: Health care professionals' perspectives on the psychosocial care needs of Turkish Cypriot patients receiving dialysis

Thank you for participating in this study, which aimed to explore healthcare professionals' perspectives on psychosocial care needs of patients living with advanced kidney disease being treated with dialysis. It is hoped that the results of the research will help inform strategies aimed at supporting patients in adjusting to living with a long-term condition.

Should you have any questions or queries about the study, please contact:

Buse Keskindag

b.keskindag@herts.ac.uk

It is possible that talking about your experience with the patients may have raised some issues for you. If as a result of your participation in this study, you experienced any negative feelings, please contact the Barış Psychiatric Hospital at 0392 6085441 - 6085479. Psychologists who work at the hospital are aware of this study and they are happy to provide support when needed.

Once again thank you for taking part in this study.

BİLGİ EDİNME FORMU

Proje: Sağlık çalışanlarının diyaliz tedavisi alan hastaların psikososyal bakım gereksinimleri hakkındaki görüşleri

Sağlık çalışanlarının, diyaliz tedavisi gören son dönem böbrek hastalığı ile yaşayan hastaların psikososyal bakım ihtiyaçlarına ilişkin bakış açılarını keşfetmeyi amaçlayan bu çalışmaya katıldığınız için teşekkür ederiz. Araştırma sonuçları, hastaların kronik sağlık sorunu ile yaşamaya uyum sağlama süreçlerinde desteklemeyi amaçlayan stratejilere katkıda bulunacaktır.

Çalışma hakkında herhangi bir sorunuz varsa, lütfen iletişime geçmekten çekinmeyin

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Hastalarla deneyiminiz hakkında konuşmak sizin rahatsız etmiş olabilir. Bu çalışmaya katılmanız sonucunda herhangi bir olumsuz duygu yaşadıysanız, lütfen +90 392 228 5441 telefon numarasını arayarak Barış Psikiyatri Hastanesi'nde görevli klinik psikolog ile iletişime geçmekten çekinmeyin.

Bu araştırmaya katıldığınız için bir kez daha teşekkür ederiz.