PSYCHOLOGICAL DISTRESS AND PHYSICAL MULTIMORBIDITY – THE EXAMPLE OF COEXISTING DIABETES MELLITUS AND END-STAGE RENAL DISEASE

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DECLARATION

I hereby declare that the thesis is my original work and it has been written by me in its entirety. I have duly acknowledged all the sources of information which have been used in the thesis.

This thesis has also not been submitted for any degree in any university previously.

Augustine Wee Cheng Kang
23 October 2015

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My special thanks goes to Shermin, for being my companion and my rock.

~

In Loving Memory

of

K.T. Kang

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Summary

Introduction: Patients with coexisting Diabetes Mellitus and End-Stage Renal Disease (DM-ESRD) represent the fastest growing and most frail segment of the ESRD population. Multimorbidity can lead to psychological distress, intensify illness perception, impair nutritional Quality of Life (QOL), health literacy and adherence to treatment, but evidence is largely lacking. The study aimed to document prevalence and factors associated with psychological distress outcomes in DM-ESRD.

Methods: This was a mixed-methods study involving N=31 interviews and a cross-sectional questionnaire survey with N=171 DM-ESRD patients using: the Hospital Anxiety and Depression Scale, UCLA Loneliness Scale, Beck Hopelessness Inventory, and measures of Health Literacy, Illness/Treatment Perception, Nutritional Quality-of-Life, and Adherence.

Results: Interpersonal tension and challenges related to diet/appetite dominated patients' narratives. Survey data indicated considerable range of distress (46% ; 53%; 79%; 53% for depression, anxiety, loneliness & hopelessness). Multivariate modelling predominantly revealed that Health Literacy dimensions and Nutrional QOL were associated with distress indicators.

Conclusion: DM-ESRD patients find diet and health care communication/navigation challenging and experience psychological distress. Carefully tailored interventions are needed.

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CHAPTER ONE

Introduction

Research Aims

The present study addresses the following research aims.

1. Produce a rich description of patient perspectives on DM-ESRD comorbidity, challenges in managing treatment aspects and available health services.

2a. Document rates of:

i. Psychological Distress (Depression, Anxiety, Loneliness and Hopelessness), and

ii. Four psychosocial variables identified to be of significance (Health Literacy, Illness Perception, Nutritional QOL and Adherence) to the DM-ESRD population.

2b. Assess the effect of Psychological Distress (e.g. depressed vs non-depressed) on Health Literacy, Illness Perceptions, Nutritional QOL and Adherence.

3. Identify determinants of Psychological Distress.

Significance of the Present Study

The coexisting conditions of Diabetes Mellitus (DM) and End Stage Renal Disease (ESRD) present a myriad of treatment challenges to DM-ESRD patients. To compound the problem further, this segment of the ESRD population is the fastest growing and is the most frail. Multimorbidity can lead to significant psychological distress and additionally, the presence of coexisting conditions may intensify illness perception, impair nutritional Quality of Life (QOL), health literacy and adherence to treatment regimen. However, evidence for these phenomena in the DM-ESRD population remains largely lacking. The present study will be a significant pioneering endeavor for understanding patient perspectives, psychological distress and psychosocial outcomes in this high-risk patient population.

Importantly, understanding the needs of the DM-ESRD population and identifying determinants of psychological distress can facilitate necessary interventions and policy advocacy discussions.

Literature Review

End Stage Renal Disease

Chronic Kidney Disease (CKD) is a debilitating chronic condition characterized by a loss of kidney function over time and ESRD represents the last stage of CKD. The function of the kidneys primarily involve removing waste products of metabolism as well as excess water, maintaining appropriate levels of electrolytes (e.g. potassium, sodium, calcium and magnesium) and reabsorbing blood proteins (e.g. albumin). ESRD patients have kidneys that can no longer support this myriad of critical bodily needs.

Clinical diagnosis of ESRD is made based on tests of Glomerular Filtration Rate (GFR). GFR is a test of the function of the kidneys; specifically, it measures the amount of blood passing through the glomeruli per minute. Clinically, ESRD is marked by a GFR below $15mL/min/1.73m^2$. Normal adults GFR results fall between 90 to $120mL/min/1.73m^2$ (Jones & Lim, 2003).

ESRD is a rapidly escalating global health problem, with the expected number of ESRD patients projected to increase by 40% from 2010 to 2030 (United States Renal Data System, 2010). Prevalence rates of ESRD range from 13 patients per million population in Bangladesh and 350 patients per million population in the United States (USRDS, 2014) to 961 patients per million population in Singapore (Singapore Renal Registry, 2014). The common symptoms of ESRD include fatigue, constipation, pruritus (itchiness), chronic pain, sleep disorders, depression anxiety, and other emotional adjustment problems (Murtagh et al., 2011). The options to restore kidney function and sustain life include kidney transplant and dialysis (Hemodialysis [HD] and Peritoneal Dialysis [PD]).

Transplant

A kidney transplant is considered to be the ideal form of treatment for ESRD patients. Briefly, the process of kidney transplant is classified to be either deceased-donor or living-donor (further classified into genetically-related or genetically-unrelated). The new healthy kidney(s) subsequently assimilates the work of the old dysfunctional kidney(s). Post-transplant patients are required to continually consume immunosuppressants (e.g. Calcineurin Inhibitors, Antiproliferative Agents, mTOR inhibitors and Steroids) to control a natural bodily rejection of the foreign kidney. Other than a strict adherence to the immunosuppressant medication regimen, transplant patients live a relatively normal life compared to dialysis patients (Johnson, McCauley & Copley, 1982).

However, the ratio of prevalence rates for kidney transplant vis-à-vis the number of ESRD patients is critically low. In 2014, less than 1% of the Singapore ESRD population were able to receive a kidney transplant (SRR, 2014). Many patients qualify for being placed on the transplant waitlist. Of the 123,193 patients waiting for a lifesaving organ in the United States, 101,662 of them await kidney transplants, with 3000 new patients added to the waitlist every month (USRDS, 2014). Reasons for the low rates of transplantation include a ubiquitous global shortage of available kidneys (Rosen et al., 2011) and strict medical pre-requisites such as good general health and low comorbidity. Elderly patients may also be precluded because of these pre-requisites, posing a paradox for public health policy considering that the elderly are amongst the fastest rising segment of the renal population (SRR, 2014). In addition, ESRD patients over the age of 60 are ineligible for kidney transplant under Singapore health legislation (Vathsala & Chow, 2009). Disconcertingly,the median wait time for a kidney in Singapore is 9.4 years (Vathsala & Chow, 2009), compared to 3.6 years in the United States (USRDS, 2014).

Given the low rates of kidney transplantation, dialysis thus becomes the primary mode of treatment for ESRD patients.

Dialysis

Compared to transplantation, dialysis (also known as Renal Replacement Therapy) is a necessary but less-than-ideal form of treatment for ESRD patients. The 5-year survival rate for Hemodialysis patients in Singapore is 58.9%, much lower in comparison to the 91.5% 5-year survival rate for transplant patients (SRR, 2014). A study comparing the mortality of ESRD patients in different treatment modalities projected dialysis patients to live 17 years shorter compared to transplant patients (Wolfe et al., 1999). Overall, dialysis patients face poorer survival rates, higher hospitalization rates and poorer psychological outcomes (i.e. depression) (Ogutmen et al., 2006; Basok et al., 2009; Griva et al., 2014). However, these results should be interpreted with some discretion, with the caveat being that transplant patients are usually younger (hence healthier).

Peritoneal Dialysis (PD). The present study examines the hemodialysis population, but for the purposes of providing a rich description of the dialysis population, the PD modality will be briefly discussed.

About 12% of the Singaporean dialysis patients are on PD (SRR, 2013). Amongst developed nations, global prevalence of PD ranges from 2.5 patients per million in Cyprus, 68 patients per million in Greece to 489 patients per million in Hong Kong SAR (Jain et al., 2011). Prevalence rate of PD in Singapore was 177 patients per million in 2013 (SRR, 2014). Within the field of Nephrology, there is an increasing emphasis on increasing the use of PD as the modality of choice (e.g. the “PD First” movement) (Chaudhary et al., 2011). PD has become more widespread since the introduction of continuous ambulatory PD (CAPD) in the 1980s and is presented as an alternative to Hemodialysis with comparable survival but improved quality of life and lower cost (Chaudhary et al., 2011).

Briefly, the process and mechanisms underlying PD is such that the peritoneum in the abdomen is used as a membrane for which fluids and dissolved substances (e.g. albumin and glucose) are exchanged from the blood. Dialysate is infused into the body through a permanent catheter tube inserted into the abdomen of the PD patient (resulting in peritonitis susceptibility), and is drained out either at night whilst the patient is asleep (known as Continuous Cycling Peritoneal Dialysis, usually occurring for 10 hours) or via manual regular exchanges performed by the patients throughout the day (known as Continuous Ambulatory Peritoneal Dialysis, occurring 4 to 6 times daily for 3 to 4 hours each time). The drained dialysate comprises of wastes, toxins and excess water. PD is a continuous treatment modality that is performed every day.

Hemodialysis (HD). The present study examines the HD population. 88% of the Singaporean dialysis patients are on HD (SRR, 2014). In developed nations, global prevalence of HD ranges from 322 per million population in the United States (USRDS, 2013) to 785 per million population in Singapore (SRR, 2013). The 1 and 5 year survival rates for HD patients were 90% and 58.9% respectively (SRR, 2013). While PD has seen increased utilization, HD remains the predominant dialysis modality worldwide, even in developing nations (USRDS, 2014). Some reasons for HD being more predominant include higher perceived susceptibility to technique failure in PD, with peritonitis being an important cause of infection complications (Aslam et al., 2006). Additionally, PD requires greater patient autonomy that may preclude elderly patients (Sinnakirouchenan & Holley, 2011). Another study suggested that the cheaper labor costs involved in having nurses perform hemodialysis compared to the more expensive use of imported dialysate solution might also result in the lower uptake of PD (Anand et al., 2014).

The following figure presents a select few countries in illustrating the global prevalence of HD.

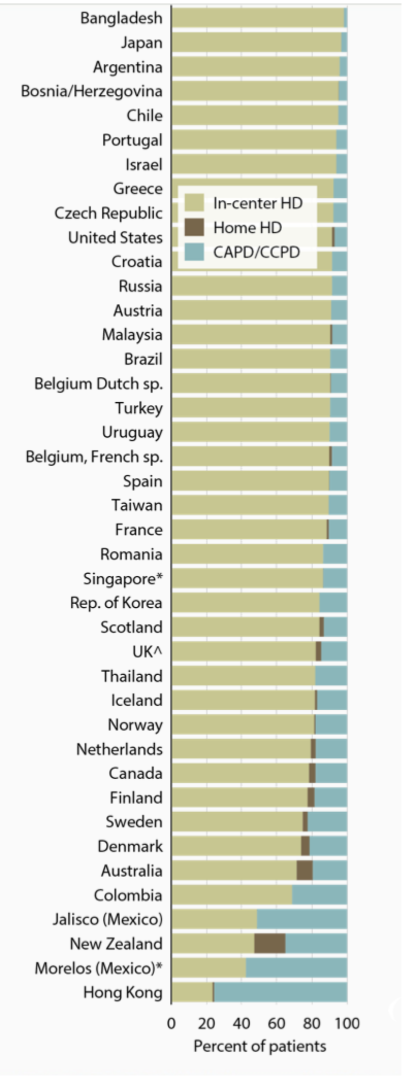


Figure 1. *International Epidemiology of Hemodialysis vis-à-vis Peritoneal Dialysis (USRDS, 2014)*

The mechanism of HD is similar to PD, in that it involves the diffusion of solutes across a membrane. Unlike PD, HD is performed thrice weekly, usually in hospitals or dialysis centers (in the case of Singapore, community dialysis centers) (Griva et al., 2011). In

HD, a dialysis machine and a special filter (called a dialyzer) are used to clean blood. Access to the blood is done through an intravenous catheter, an arteriovenous fistula or a synthetic graft, which is in turn influenced by factors such as prognosis and condition of vasculature.

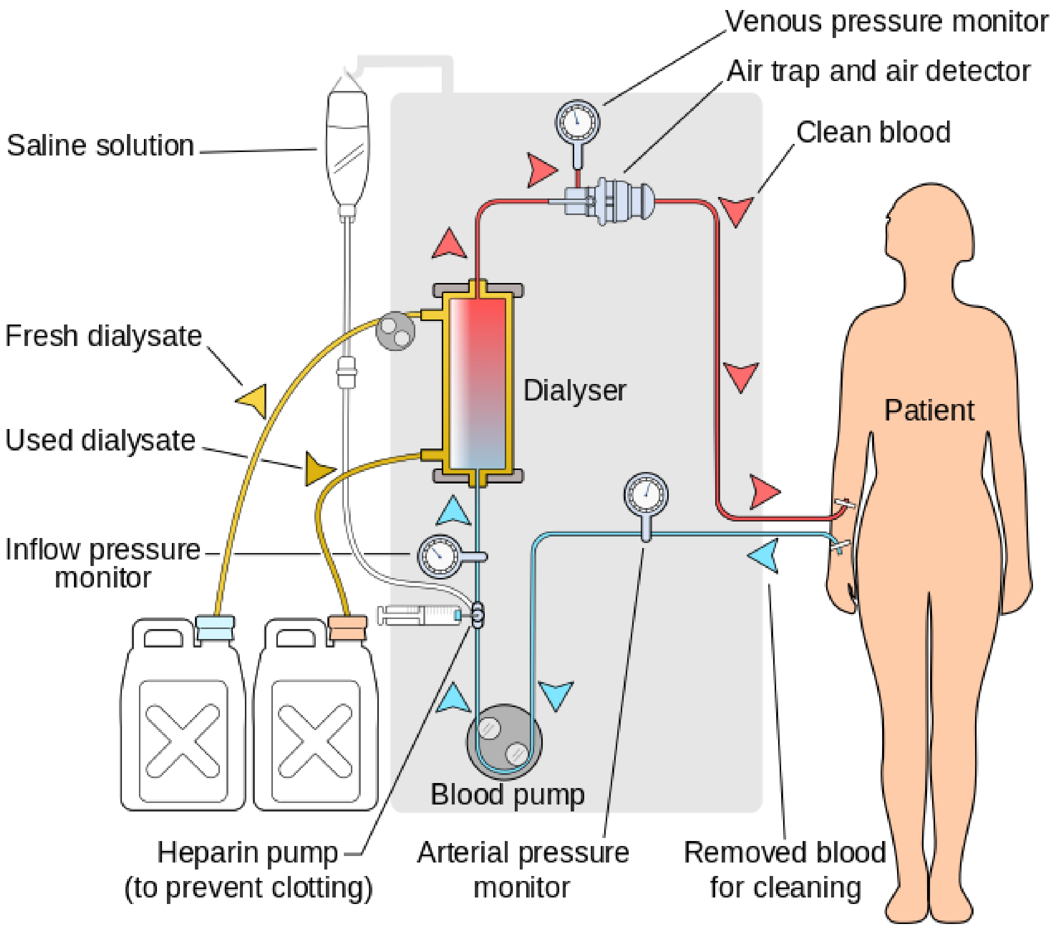


Figure 2. *Illustrating the Hemodialysis procedure*

Comparing PD with HD. Studies comparing clinical outcomes (e.g. mortality, morbidity and hospitalization rates) between PD and HD see mixed findings. Some studies suggest general comparability (e.g. Harris et al., 2002; Griva et al., 2014); another documented that PD patients seem to have lower mortality rates (Fenton et al., 1997), while others suggest that HD patients have lower mortality rates (Bloembergen et al., 1995).

A study examining modality selection found that the choice of dialysis modality is driven by patient preferences rather than clinical outcomes (Wuerth et al., 2002). Cited reasons for choosing HD is primarily the desire for having a set schedule and leaving the management of the dialysis procedure to Health Care Professionals (HCP) and nurses. Cited reasons for choosing PD is primarily due to the desire for flexibility of schedule and a convenience for performing dialysis at home (Wuerth et al., 2002). Demographically, HD patients tend to be older and less educated (Little et al., 2001).

Diabetes Mellitus

Diabetes Mellitus (DM), or commonly known as Diabetes, is a global epidemic projected to be the 7th leading cause of death by 2030 (Mathers & Loncar, 2006). The World Health Organization (WHO) reports the global prevalence of DM to be 9% in 2014, and an estimated 1.5 million deaths in 2012 were directly caused by DM (WHO, 2015). In Singapore, the prevalence of DM rose from 9% in 1998 to 11.3% in 2010, and constituted 10% of the cause of death within the Singapore population in 2010 (Ministry of Health Singapore, 2015). Additionally, DM is also associated with a 3-fold increase in mortality in Singapore (MOH, 2015).

Clinically, DM is a group of metabolic diseases characterized by hyperglycemia (excess of glucose in the bloodstream) resulting from defects in insulin secretion, insulin action, or both. Clinical diagnosis of DM is made when fasting blood glucose is above 7mmol/I or if a 2-hour plasma glucose during an oral glucose intolerance test is above 11.1mmol/I. Long-term hyperglycemia is associated with both short and long-term damage and dysfunction of several organs in the body, including the eyes, heart and kidneys (American Diabetes Association, 2015). If untreated, these complications could be fatal. The plethora of DM complications include:

- Polyuria (abnormally large volumes of diluted urine),
- Polydipsia (abnormally increased thirst),

- Susceptibility to infections,
- Retinopathy (disease of the retina resulting in impaired vision),
- Peripheral neuropathy (damage to peripheral nerves),
- Cardiovascular dysfunction. A study found that 50% of diabetic patients died of cardiovascular complications (Morrish et al., 2002), and
- Nephropathy leading to renal failure. WHO reports that DM is amongst the leading causes of renal failure (WHO, 2015).

Majority of the DM cases fall into two broad etiopathogenetic (cause and development) categories: Type 1 and Type 2 DM. Type 1 DM is essentially a deficiency of insulin production in the pancreas. It is most common in children and young adults, and this group of DM patients requires injections of insulin to control levels of glucose in their blood. Type 1 DM accounts for 5-10% of all DM patients worldwide (WHO, 2015). The more prevalent (90-95% of all DM patients) Type 2 DM involves patients' resistance to insulin action and inadequate compensatory insulin secretory response (or Insulin Resistance). Type 2 DM is common in the elderly and the overweight. Usually, they can control their diabetic condition if food intake is controlled, coupled with weight loss and regular exercise. Therefore, patients with Type 2 DM produce insulin but do not use it as well as they should. Both Type 1 and Type 2 DM patients are required to adhere to a treatment regimen that involves strict diet, medication and exercise requirements (Griva et al., 2014).

Coexisting Conditions: Diabetes Mellitus and End Stage Renal Disease

Multimorbidity

Multimorbidity refers to the coexistence of multiple chronic conditions. Previous studies indicate that as much as 45% of the general population and 88% of the population aged 65 years and older have at least 2 chronic conditions (Wolff et al., 2002). With increased life expectancy, the prevalence of chronic conditions is expected to increase. By 2020, it is projected that at least half of the US population would have at least 1 chronic condition, with suggested reasons including advanced healthcare that prolongs life (Wu & Green, 2000). Singapore faces the problem of an ageing population, with the number of persons aged 65 years and above projected to increase from 9% of the population in 2010 to 19% of the population by 2030. Individuals with at least 1 chronic condition are also more likely to have other comorbid conditions (Guralnik et al., 1989). The presence of multiple chronic conditions presents greater disease burden and compounds the effect of the diseases, making it difficult to address the patients' clinical needs (Tong & Stevenson, 2007). Public health research has endeavored to identify patient outcomes, factors, needs and challenges of patients to devise disease management programs and patient education efforts to prevent and control the rising rates of chronic conditions (Bodenheimer, 1999). However, despite accumulating evidence of the tendency of chronic conditions to co-occur, most of these research efforts focus on handling a single chronic condition, leading to a dearth of similar research for multiple chronic conditions (Wolff et al., 2002; Mishra et al., 2011).

Coexisting Conditions of Diabetes Mellitus and ESRD

In addition to DM and ESRD being global epidemics in their own right, DM is amongst the leading causes of ESRD (Reutens et al., 2008). It is the primary cause of ESRD for 20% to 40% of patients beginning dialysis worldwide (National Institute of Health, 2007). Kidney disease occurs in about one third of people with either Type 1 or Type 2 DM (International Diabetic Foundation, 2014). Diabetic Nephropathy (as nomenclature for etiology leading to DM-ESRD) affects approximated 60 million people worldwide (IDF, 2014). In financial terms, 30% of the predicted 1.1 trillion dollar (USD) medical costs of dialysis worldwide would stem from Diabetic Nephropathy (Lysaght, 2002). DM- ESRD patients do not fare well in clinical outcomes – disconcerting evidence demonstrates that more than 50% of DM-ESRD dialysis patients die within 2 years of commencing dialysis (USRDS, 2014). In response to these critical findings, policy advocacy discussions have shifted towards finding ways to increase awareness of the severity of DM and kidney disease (Atkins & Zimmet, 2010).

Briefly, the mechanisms behind Diabetic Nephropathy are such that high blood glucose levels could damage vessels in the kidney, which in turn affects the filtering function of the kidney. Wastes then build up in in blood, and when kidney damage reaches the final stage of ESRD, built up waste in the blood can build to toxic levels and cause death.

Overall, the comorbid conditions of DM and ESRD lead to an adverse compounded effect on patients, with higher mortality rates and poorer quality of life presenting a mounting challenge to public healthcare. However, the lack of research on patient outcomes for comorbid conditions (Mishra et al., 2011) also extends to DM-ESRD patients (Williams et al., 2008).

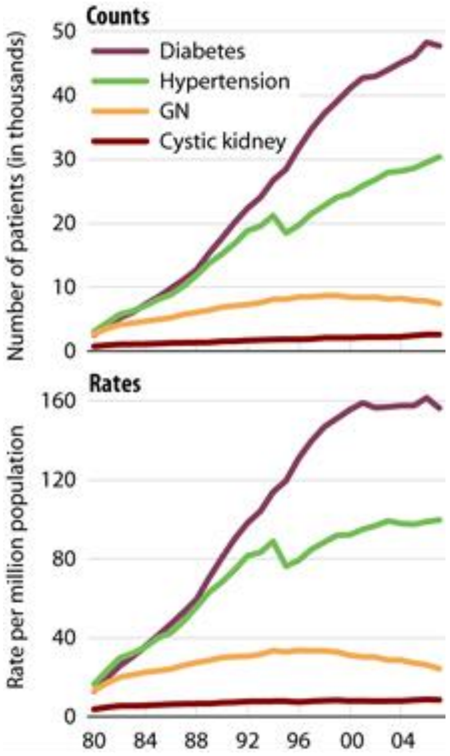


Figure 3. *Diabetes versus other Etiologies of ESRD in the United States (USRDS, 2015)*

Psychological Distress

Psychological distress is amongst the most common comorbid conditions in chronic disease patients, and is associated with diminished health status and significantly lower health-related quality of life (Chapman, Perry & Strine., 2005). Furthermore, a study also reported that psychological distress increases with multimorbidity (Fortin et al., 2006). Psychological distress can be key indicator of an individual's overall health status and can be thought of to refer primarily to a subjective experience that describes an individual's functional (or dysfunctional) adaptation to their environment (McDowell & Newell., 1996). In relation to patients with chronic diseases (e.g. DM and ESRD), psychological distress can intensify the effect of these diseases and lead to poorer health outcomes and increased risks of treatment complications (Anderson et al., 2002; Kruse, Schmitz & Thefeld., 2003). However, little is known about the relationship between psychological distress and multimorbidity despite epidemiological prevalence of multimorbid conditions (Huntley et al., 2006).

Considering that ESRD is a chronic and life-threatening condition, psychological distress is documented to be highly prevalent (Kimmel et al., 2003; Cukor, Cohen, Peterson & Kimmel, 2007; Ramirez & Macedo, 2012; Griva et al., 2014). A broad spectrum of challenges is associated with a diagnosis of ESRD, which may in turn increase psychological distress of a patient (Martin et al., 2004). Some evidence has suggested that psychological distress contributes to greater morbidity and even earlier mortality (Gilbar et al., 2005). A dialysis patient must cope with the constant threat of death and reduced life expectancy. Thus, a maladaptive form of coping can contribute to psychological distress as well (Wright et al., 1999).

Despite DM being one of the leading causes of ESRD, the documentation of psychological distress in DM-ESRD patients is largely lacking (William et al., 2008). Existing studies mostly focus on either DM or ESRD singly and evidence on how these patients manage multiple conditions with psychological distress is largely unknown. In comparison to other chronic medical conditions, including other etiopathologies of ESRD (e.g. Hypertension & Glomerulonephritis), DM-ESRD patients face a wider spectrum of demands from their treatment regimen (e.g. very strict diet, more medication, glucose monitoring and exercise requirements). Managing just a single dimension of the treatment regimen would be ineffective – for example, medication without dietary modification would not result in optimal treatment outcomes such as good glycemic, potassium and phosphate control in DM. Thus, it is expected that these additional demands impact the psychological well-being of DM-ESRD patients.

There is no question that DM-ESRD is a complex condition driven by many factors. While medical outcomes (e.g. dialysis adequacy) serve as objective markers of treatment status, understanding psychological distress in DM-ESRD patients promotes policy advocacy discussions to find ways of improving mortality rates and overall quality of life. In fact, some research has emphasized that subjective psychological distress may have a more direct impact on patients’ lives than medical outcomes since the experience of negative emotions are more visceral and immediate (Petrie et al., 1996). Hence, the lack of studies examining psychological distress in DM-ESRD patients thus drives the goal for a deeper understanding of this high-risk population.

Depression

As one of the more common manifestations of psychological distress (Sartorius et al., 1996; Ibrahim & El Salamony., 2008), depression is a state of low mood and aversion to activity that can affect a person’s thoughts, behavior, feelings and sense of well-being (Diagnostic and Statistical Manual of Mental Disorders Fifth Edition, 2014). Typical depressive symptoms include “depressed mood, anhedonia, appetite or weight change, sleep disturbance, fatigue, psychomotor disturbances, feelings of worthlessness or guilt, impaired concentration and suicidal thoughts” (Koenig et al., 1997).

Several studies documenting prevalence rates of depression in HD patients estimates the figure to be between 28% to 40% (Fukunishi et al., 2002; Drayer et al., 2006; Park et al., 2010). A Singaporean study examining depression levels between HD and PD patients reported 16% and 32% prevalence rates respectively (Griva et al., 2014). To further compound the problem of high depression rates, many studies indicate that depression is related to higher morbidity and mortality rates in HD patients (Israel, 1986; Craven et al., 1988; Cukor et al., 2007; Hedayati et al., 2009; Park et al., 2010). Depression is projected to be a leading future cause of mortality, surpassed only by cardiovascular disease in terms of the number of years of productive life diminished by disability (Kimmel et al., 2010).

Previous studies examining the association between depression and survival rates suggest that ESRD patients who live longer report more depressive symptoms (Kimmel et al., 2000). A concrete link between depression and mortality in ESRD patients has yet to be established, but suggested reasons include impaired nutrition status, self-care activities and immune functioning (Kimmel, Weihs & Peterson, 1993).

Studies examining the effects of depression in ESRD patients found that depression increases the likelihood of nonadherence with medical treatment, resulting in unfavorable treatment outcomes (Griva et al., 2014). Another study also found that depression may be associated with ESRD patients' ideation about withdrawing from dialysis treatment, a concept linked with hopelessness (to be discussed subsequently) (Christensen & Ehlers, 2002). Studies examining the effects of depression in diabetic patients found associations with poor self-management in diabetic self-care (e.g. blood glucose monitoring, dietary adherence and medication adherence) (Katon, 2008). Conversely, both DM and ESRD, as chronic diseases, have been reported to worsen symptoms of depression primarily through a heavy disease burden (Katon, 2008). Despite evidence of adverse effects of depression, the construct is still largely under-recognized, misdiagnosed and undertreated in the ESRD population (Young et al., 2010). Of clinical relevance, symptoms of depression such as loss of appetite and lack of concentration may also be a manifestation of ESRD. Thus, Healthcare Providers (HCP) may not notice the presence of depressive symptoms in patients.

Past studies identifying predictors of depression in ESRD patients suggest that an older age, being female, having a high number of comorbidities and poor nutrition status as indicated by serum albumin to be useful in predicting depression (Carton & Schweitzer, 1996; Friend et al., 1997; Kimmel, 2002).

In the context of DM and ESRD as comorbid conditions, research on depression in DM-ESRD patients has been generally lacking. Of the limited evidence available in current literature, one study documented a 20% prevalence rate of depression in DM-ESRD patients, and also reported that depression was associated with a 2.95-fold greater risk of death, a number significantly greater than those found for the general DM population but equivocal to the general ESRD population (Young et al., 2010). More research is necessary for exploring depression in the DM-ESRD population, particularly its prevalence rate and associated factors.

Anxiety

Anxiety is an emotion characterized by an unpleasant state of inner turmoil and dread over anticipated events, and includes a feeling of imminent death. Feelings of uncertainty, tension, inadequacy, difficulty in concentration, feeling flushed, helplessness, irregular breathing and quick heartbeat are common symptoms of anxiety. Several studies have identified anxiety to be associated with poorer quality of life (Vazquez et al., 2005; Vasilieva, 2006).

Similar to depression, anxiety has been cited as a common manifestation of psychological distress (e.g. Segrin et al., 2007). In comparison to depression, the attention given by research to anxiety in ESRD patients is in stark contrast and is largely lacking. Of the limited evidence available, one study documented the prevalence rates of anxiety in ESRD patients to be 24.7% (Patridge & Robertson, 2011), while another documented 57% prevalence rates of anxiety in HD patients (Martin, Tweed & Metcalfe, 2004). The authors further reported that anxiety adversely affects adherence to dialysis regimes. A Singaporean study examining anxiety levels between HD and PD patients reported 22% and 14% prevalence rates respectively (Griva et al., 2014). The mechanisms in which anxiety affects treatment outcomes in the ESRD population is suggested to be that symptom severity, employment difficulties (and associated financial difficulties), and strict treatment compliance may lead to a situation where the patient feels uncertainty about the future in terms of disease management and treatment outcomes (Martin & Thompson, 2000). Little is known about the relationship between DM and anxiety (Li et al., 2008). Some available evidence suggests that complications from DM are associated with higher levels of anxiety (Peyrot & Rubin, 1997). A study by Li and colleagues (2008) found that older age was associated with lower prevalence of anxiety diagnosis, although the authors have stated that underlying mechanisms between age and anxiety remain unclear.

There is a paucity of research examining anxiety in DM-ESRD patients. It is thus necessary to further strengthen literature examining prevalence rates and associated factors in the DM-ESRD population.

Loneliness

There is no current consensus on the proper definition of loneliness (Karnick, 2005). Individuals may experience and describe loneliness in subjective ways. An early study into the construct suggested for the definition to be “the extent that a person’s network of social relationships is smaller or less satisfying than the person desires” (Peplau & Perlman, 1979). A more recent operationalization of the term describes loneliness as “a continual, painful companion that causes people to regard their affliction as a personal defect or deficiency” (Thesen, 2001). Loneliness is considered to be a multidimensional psychological construct, and represents a personal and subjective experience related to the individual’s gender, age, marital status and social relations amidst a cultural context (Nilsson et al., 2006). Overall, sufferers of loneliness describe the experience to be emotionally and socially excluding, and is a significant portion in the experience of psychological distress (Lindgren et al., 2014).

It is suggested that poor physical and psychological states resultant from the experience of chronic diseases creates barriers to social networks and close relations (Victor & Yang, 2012). Chronic conditions such as ESRD are postulated to have a significant effect on other healthy members of the family, especially for the spouse of the ill person (Asti et al., 2006). This in turn may promote a sense of helplessness in dealing with the illnesses and elicit psychological responses including loneliness. Furthermore, it has been suggested that the complex treatment regime that ESRD patients face may restrict patients' social activities and lead to feelings of isolation (Asti et al., 2006). Additionally, a cognitive bias may cause persons suffering from chronic debilitating illnesses to see themselves differently from healthy persons, resulting in attitudes facilitating social withdrawal (Weillitz & Sciver, 1996). Miller (1983) suggests that friends of patients with chronic diseases may withdraw from the patient because of their reaction to unpleasant symptoms or a discomfort over being healthy in the presence of somebody ill, although there is insufficient evidence to support this claim. Overall, loneliness is assessed to be an important theme in patients' experience with ESRD (Herlin & Wann-Hanson, 2010).

In terms of research on loneliness in diabetic patients, reports have been mixed. A longitudinal study examining social relationships in young adults with Type 1 DM reported that diabetic patients experienced less trust and a sense of intimate friendship compared to controls, but did not differ in the experience of loneliness (Jacobson et al., 1997). Another cross-sectional study on the differences in loneliness between healthy subjects and different chronic conditions reported that diabetic patients scored poorer on loneliness scores, but receive better instrumental support (e.g. given help with chores, meals and transportation) compared to other chronic conditions (Penninx et al., 1999).

In the last few decades, the prevalence of loneliness has been studied in different clinical populations, and generally, the findings usually document that loneliness is a condition that is widely distributed and severely distressing (Weiss, 1973; Prince, Harwood & Blizard, 1997; Russell et al., 1997; Victor et al., 2002;). However, loneliness remains less studied in the diabetic and ESRD population. Overall, epidemiological studies point out the importance of social networks and social inclusion for morbidity and mortality (Berkman & Syme, 1979; Penninx et al., 1999).

Overall, research into loneliness has been disparate in the sense that it is studied exclusively in either the ESRD or the diabetic population. Loneliness as a construct in DM-ESRD patients is relatively unexplored, despite the collective evidence for documented loneliness in chronic diseases.

Hopelessness

Hopelessness is defined by Aaron T. Beck as pessimism or "a system of negative expectancies" concerning oneself and one's future life (Beck et al., 1974). Hopelessness is identified as one of the core characteristics of depression (Beck, 1967), and is also reported as an aggravating factor for depression (Abramson & Metalsky, 1989). Additionally, hopelessness is also associated with a wide spectrum of other psychological disorders. Of note, longitudinal studies have identified hopelessness to be predictive of suicide ideation even after controlling for history of attempts (e.g. Klonsky et al., 2012).

It is necessary to distinguish hopelessness as a distinct construct from depression. While hopelessness is reported to be a symptom of depression and thus it may be challenging to disentangle these two psychological constructs, hopelessness is found to have both somatic and psychological effects that are distinct from depression. For example, a longitudinal study examining the relationship between hopelessness and heart disease found that the effect of hopelessness was stronger than the effect of depression on incidence of fatal ischemic heart disease and hypertension in general (Everson et al., 2000). In addition, hopelessness has been found to correlate weakly with standard depression measurement scales (Everson et al., 1996). The different psychological effects rest primarily in the basis of the operational definitions:

that is, depression refers to a loss of *pleasure* (a form of mood) while hopelessness refers to a loss of *meaning* (a form of cognition). Hopelessness is suggested to be primarily linked to a "Demoralization Syndrome", where a sense of pessimism, helplessness, loss of hope for improvement or recovery along with associated alienation and lack of social support would pose as a significant barrier to effective care (Kissane, 2009). Therefore, hopelessness may deserve studying in its own right.

Hopelessness has been associated with discontinuation of life-prolonging treatments (e.g. Dialysis) (Jones et al., 2003). A study also reported that hopelessness predicts a wish for hastened death (Breitbart et al., 2000), which has significant implications for dialysis as a life-sustaining treatment. A study examining hopelessness (using the Beck Hopelessness Scale) in an ESRD population found that reported hopelessness rates were greater than population norms by more than 2 standard deviations, and these rates may also be related to treatment withdrawal ideation (Kim et al., 2002). The authors suggested that the primary reasons for hopelessness in the study population were due to treatment and disease burden. Several other studies of ESRD patients also document the presence of hopelessness (White & Grenyer., 1999; Lew & Piraino, 2005).

Studies of hopelessness in the diabetic population have been limited, although a recent first-of-its-kind study documented the prevalence of hopelessness in a diabetic population to be around 40%. However, the reported mean hopelessness score in the study were below the clinical cut-off score (Pompili et al., 2009), signaling the need for greater examination of hopelessness in the DM population.

Considering that studies of hopelessness in combined DM-ESRD patients have been very limited, the urgent impetus to examine hopelessness in DM-ESRD patients is clear. Implications for the documentation of hopelessness are especially important in shaping the conception of intervention programs necessary for addressing hopelessness and if necessary, the accompanying construct of suicide ideation. Studies examining hopelessness usually do so in the context of examining it as a symptom of depression, but the reasons for distinguishing these two psychological dimensions and examining them separately have been discussed. Overall, the study of hopelessness as a separate construct in this study would set precedence for future research in distinguishing these two psychological dimensions.

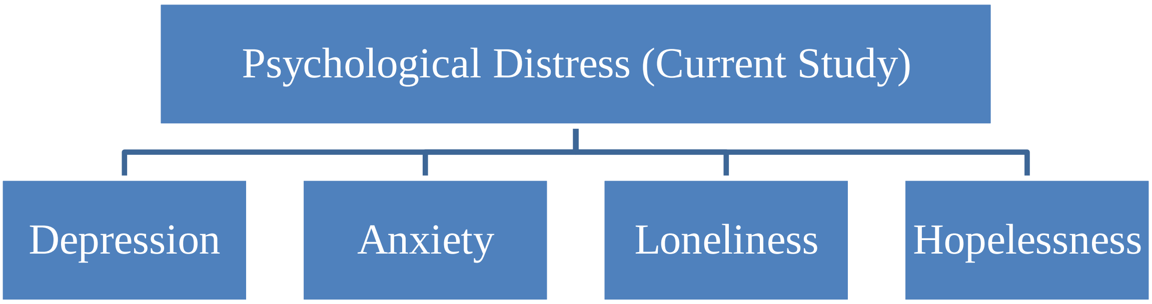


Figure 4. Psychological Distress Dimensions Explored in the Current Study

Psychosocial Dimensions of Importance to Psychological Distress

Four important psychosocial dimensions have been identified in the present study. The overarching theme to these constructs is that some evidence exists suggesting their relationship with some (or all) of the dimensions of psychological distress (in the present study) that in turn affects treatment outcomes, but these four constructs are relatively unexplored in the context of the DM-ESRD patient population. The four psychosocial constructs include:

i. Health Literacy,

ii. Nutritional Quality of Life,

iii. Illness Perception, and

iv. Adherence.

Health Literacy

The WHO describes health literacy as "*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*" (WHO, 1998). Broadly, health literacy refers to a set of skills that individuals need to function effectively in the health care environment (Berkman et al., 2011). Some of these skills include the individual ability to read and interpret health-related information, use quantitative information for tasks (e.g. interpreting caloric and other nutrition information on a food label or measuring and understanding blood glucose levels in a meaningful way), adhering to treatment regimens and the ability to establish good communication with Health Care Providers (Berkman et al., 2011). Poor health literacy has been linked with poor treatment outcomes, increased mortality, lower physical functioning, lower use of preventive healthcare services and elevated risks for medication errors (Osborne et al., 2013). It is important to examine health literacy in patient populations as poor health literacy may lead to difficulties in understanding basic medication instructions, health documents, education information or even provide informed consent with regard to their treatment. These patients may subsequently become disadvantaged in the proper management of their conditions (Kalichman & Rompa, 2000). Health literacy has been described as a key factor of a patient's ability to better manage their conditions and of a particular health system's ability to ensure equitable access to health services (Nielson-Bohlman et al., 2004).

In the United States, a report suggests that 80 million U.S. adults have limited health literacy, and further projects poor health literacy to increase national annual healthcare expenditure by US$73 billion, thus presenting a major public health problem (USA National Academy on an Aging Society, 2013). In response, policy and advocacy organizations have rallied for initiatives to improve health literacy. For example, the Institute of Medicine's

(IOM) published a comprehensive report "*Health Literacy: A Prescription to End Confusion*" (IOM, 2004) to rally nationwide efforts to improve health literacy in both general and clinical populations.

Poor health literacy is reported to be most pronounced amongst patients with chronic medical conditions (Osborne et al., 2013). As 2 chronic conditions, co-existing DM and ESRD have complex treatment requirements and therefore health literacy research should be extended to examining health literacy needs in the DM-ESRD population, as managing DM together with ESRD may present a significantly higher requirement for good health literacy as compared to unidimensional illnesses. In addition to the competing needs and demands of DM-ESRD, the added complexity of treatment regimens require DM-ESRD patients to make complex decisions and even reconcile contradictory treatment guidelines (Lai et al., 2013). For example, dietary recommendations for the management of DM include the consumption of fruits high in potassium (e.g. avocadoes and bananas), but dietary recommendations for ESRD paradoxically recommends against the consumption of such foods as it may cause hyperkalaemia and side effects such as nausea, weakness and slow pulse (Kopple, 2001). A study suggested that the complexity of DM and ESRD treatment increases the chance for misinformation about medication, which in turn reduces confidence and increases the chance of non-adherence to the medication regimen (Williams, Manias & Walker, 2009). In addition and of interest to the present study, several studies report that ESRD patients may be predisposed to choose HD as a dialysis modality when certain deficiency in health literacy is documented and patients are not given adequate information regarding both modalities (Little et al., 2001; Marron et al., 2005). Furthermore, it has been reported that when patients have access to information about the differences between PD and HD as treatment modalities, as much as 50% of pre-dialysis patients who were suitable for both modalities chose PD (Prichard, 1996). This is contrasted with the reality of the dominance of HD as the utilized dialysis modality worldwide. Thus, there is some evidence to suggest that between the PD and HD modalities, health literacy in HD patients may be less-than-ideal. This provides an additional impetus for examining health literacy in a HD population.

However, considering that health literacy is a relatively new concept in public health, there is a shortage of studies examining health literacy across various populations in Singapore. One such study examining the relationship between health literacy and self-care management with regard to behaviours such as dietary adherence and blood glucose testing indicated that some aspects of health literacy were associated with better diabetic self-care management in ESRD patients, but found no relationships between functional health literacy (defined as basic literacy skills of reading and writing) and self-care management (Lai et al., 2013).

Overall, there is a need for greater effort to identify and address health literacy needs in the DM-ESRD population to improve disease self-management.

Nutritional Quality of Life

Nutritional QOL in HD

Proper nutrition is essential for chronic disease patients to maintain general well-being and optimal treatment outcomes. Malnutrition is defined as “a condition that results from eating a diet in which nutrient are ***either not enough*** **or are** ***too much*** such that the diet causes health problems” (Chung et al., 2003). It is important to note that malnutrition refers to both “over-nutrition” and “under-nutrition”, as opposed to a common misunderstanding of malnutrition to be limited to “under-nutrition” (National Institute of Health, 2014). Malnutrition has serious consequences for any individual and sub-optimal nutritional may not be clinically identified until a later time. With increased malnutrition, altered biological functions in the body may amplify clinical symptoms that lead to morbidity and in untreated cases, death. Even malnutrition of a less severe degree may have a substantial negative impact. For example, protein nutritional deficiency may result in an impaired immune response, which in turn increases the risk of infections, while excess of protein is related to metabolic changes (Grundy et al., 2005).

For HD patients, the documented sensory, hedonic, physical and psychosocial problems are found to decrease nutritional status (Han et al., 2012). The prevalence of malnutrition is frequently documented in HD patients (e.g. Wolfson et al., 1984; Han et al., 2012; Sedhain et al., 2015). Signs of malnutrition in dialysis in HD patients include low concentrations of albumin and low soluble protein in the muscles. A more convenient method of examining nutrition is Body Mass Index (BMI). A recent study indicated a significantly lower BMI difference between HD patients and controls (Montazerifar, Karajibani, Gorgij & Akbari, 2014). Multiple medications (which may lead to certain side effects) and socioeconomic constraints (e.g. stemming from the perception that healthy food costs more) may also further contribute to decreased dietary intake (Diaz-Buxo et al., 2000).

Mounting evidence suggests that Type 2 DM is strongly related to malnutrition (Rosenbloom, Joe, Young & Winter, 1999; Pastors et al., 2002). Type 2 DM usually occurs in the context of obesity, which is found to be related to malnutrition in the sense that an overabundance of calories results in impaired biochemical processes that confuses metabolism (Prentice, 2006). The collective evidence for malnutrition in DM-ESRD warrants a closer examination into the subject matter for DM-ESRD patients, but few studies have directly examined nutrition in DM-ESRD patients.

Nutritional status is related to health-related Quality of Life (QOL). QOL can be broadly defined as “a state of complete physical, mental and social wellbeing” (WHO, 1995). Measurements of QOL typically target physical and mental components, such as general health, physical functioning, social functioning and mental health (Yeh et al., 1999; Kalantar-

Zadeh et al., 2001). Many studies have identified poor nutritional status in HD patients to be associated with poorer QOL in both physical and mental components (Diaz-Buxo et al., 2000; Laws, Tapsell & Kelly., 2000; Kalantar-Zadeh et al., 2001). Poor QOL is also thought to precede declines in nutrition status (Han et al., 2012). Overall, poor nutrition is found to be closely associated with poor QOL in HD patients and decreased QOL is generally found to be associated with increased morbidity and mortality rates (Dwyer et al., 2005). Thus, it may be worthwhile to study nutritional status and QOL collectively. In fact, a recent pioneering study developed an instrument to assess nutritional QOL (an instrument used in the present study) and the authors report the instrument to have strong correlation with health-related QOL (Han et al., 2012).

It is important to examine nutritional QOL in DM-ESRD patients, considering the scarcity of research examining nutritional status in this segment of the patient population.

Illness Perception

Theoretical developments of illness perceptions are based on the Common-Sense Model (CSM) (Leventhal et al., 1997). The CSM describes a parallel response model in which individuals process emotional responses to illness and make cognitive representations of the illnesses independently. These cognitive representations subsequently motivate certain behaviors to regulate their emotions as well as seek ways to improve the outcome of their illness. These behaviors then further lead to an appraisal of the effects on the illness and result in a feedback loop. As research into the concept developed, illness perception became associated with reference to mental representations and personal ideas about an illness.

Self-regulatory theory is also used to illustrate the concept of illness perception. Broadly, the theory suggests that illness outcomes are influenced by how patients perceive their illnesses because individuals with poorer illness perception may have lower impulse control and may be prone to acting on immediate desires, leading to situations such as treatment nonadherence (Leventhal et al., 1984). Petrie and Weinman (2012) suggests that patients' mental representations and ideas tend to fall along at least five dimensions: *identity of the illness* (name and symptoms), *cause of the illness*, *consequences* (impact on quality of life and different life domains), *timeline* (course of illness) and lastly, *control* (how the illness can be controlled). Illness perception is found to have a direct relationship with illness outcomes in several studies (Hagger & Orbell, 2003; Petrie et al., 2007). In a meta-analysis of illness perceptions and treatment outcomes, it was demonstrated that negative illness perceptions were associated with poorer overall well-being (Hagger & Orbell, 2003).

In the HD population, studies have examined the impact of illness perceptions on clinical and psychological outcomes such as treatment adherence, self-management behavior and psychological distress (Chilcot, Wellsted & Farrington, 2011). Illness perceptions involve cognitions surrounding illness identity, treatment control, illness comprehensibility, treatment burden and consequences (Broadbent et al., 2006). In multimorbidity studies, illness perception is also thought to involve the degree to which patients may face conflicting requirements in prioritizing one condition over another (Gibbons et al., 2013). Importantly, illness perception has been found to predict survival rates in the ESRD population (van Dijk et al., 2009).

In diabetic populations, illness perception has been mainly used to study adherence to treatment (e.g. Broadbent, Donkin & Stroh, 2011). Adherence is mostly associated with lower perceived consequences of DM, higher personal control and specific beliefs about the usefulness of treatment.

Multimorbidity presents a significant challenge to patients that may significantly affect illness perception but overall, there is a scarcity of studies examining illness perception in DM-ESRD patients (or multimorbid conditions in general). Existing studies on multimorbid conditions in general indicate that the presence of multimorbidity impacts patient illness representations in relation to dimensions of identity, perceived cause and consequences (Bower et al., 2012). In addition, illness perceptions may also be critical to the patient experience of multimorbidity, as illness perception is suggested to be an enabler of the ability to make sense of conditions appropriately (Kenning et al., 2015).

Adherence

A widely used definition of adherence in health research is “the extent to which a person’s behavior, such as taking medication, following a diet, and/or executing lifestyle changes…that corresponds with agreed recommendations from a Health Care Provider” (Sabate, 2003). Nonadherence to treatment recommendations (in terms of diet, medication and dialysis) is predictive of higher mortality rates in ESRD patients and is postulated to be in the same order of importance as clinical indicators (such as outcomes of patient care) (Bander & Walters, 1998). As previously mentioned, the treatment requirement for dialysis is complicated, demanding and time-consuming. Regular dialysis sessions at community HD centers, taking a plethora of medications and fluid/diet restrictions contribute to treatment complexity that is often cited as a cause of nonadherence in ESRD patients (Donovan, 1995).

In the case of DM, Diabetic patients are instructed to perform insulin injections, conduct multiple urine or blood glucose tests, follow a diet low in saturated fat and other safety precautions relating to the body (such as foot care). Behavioral researchers have consistently given adherence in DM considerable attention (Glasgow et al., 1986; Ho et al., 2006). A systematic review of adherence to medication for diabetic patients found the rates to be range from 36% to 93%, with higher adherence rates documented for patients who use electronic monitoring systems (Cramer, 2004). Cross-sectional studies of dietary adherence in diabetic patients mostly report a high degree of nonadherence to diet despite their diagnosis (Schafer et al., 1986; Lin et al., 2004).

Adherence is not a one-dimensional concept as DM-ESRD patients may not give the same level of importance across all aspects of the treatment regimen (e.g. dialysis, medication and diet/fluid). Few studies have attempted to document adherence rates in the DM-ESRD patient population. In HD adherence research however, many studies demonstrate that dialysis sees reasonably high adherence rates (e.g. Block, Hulbert-Shearon, Levin & Port, 1998; Taskapan et al., 2005), but the evidence for medication and diet/fluid adherence has been mixed (Lin & Liang, 1997; Curtin, Svarstad & Keller, 1999; Griva et al., 2014). A suggested reason for the disparity in adherence to different aspects is because somatic symptoms are relieved by dialysis, and skipping even a single dialysis session would have significant impact on the patient's health (Khalil et al., 2011). Thus, it may be useful to direct focus towards an in-depth examination of medication and diet/fluid adherence in ESRD patients. Of note to the present study, adherence in the DM-ESRD population may be more problematic compared to other etiopathologies because these patients developed kidney disease due to nonadherence to diabetic treatment in the first place.

Psychological Distress and Health Literacy, Illness Perception, Nutritional QOL and Adherence in DM-ESRD Patients

There are limited studies on DM-ESRD patients in general and there are even fewer studies examining psychological distress and the four identified psychosocial dimensions (Health Literacy, Illness Perception, Nutritional QOL and Adherence) in DM-ESRD patients. This study is a pioneering effort in this research area. Nonetheless, it is necessary to review the available evidence on factors associated with the four dimensions of psychological distress for ESRD patients in general. Overall, the literature review of this area affirms the need to compare the four dimensions of psychological distress with the four identified psychosocial dimensions.

Health Literacy and the Four Dimensions of Psychological Distress

The available evidence for the relationship between health literacy and depression in ESRD patients is very limited. One available study found that health literacy has no association with depression in patients on HD (Green et al., 2011). However, the sample size was relatively small (n = 41) and the study had excluded patients on transplant lists or those of whom who are considering a switch to PD, which may at the same time exclude subjects with higher health literacy.

A literature search did not find any available studies examining anxiety and health literacy in ESRD. One study examining health literacy self-management in patients with Type 2 DM and stage 3 CKD found that feelings of anxiety may alter the ability to perceive and receive health information, and could also possibly compound information confusion (Sakraida & Robinson, 2009). It is likely that DM-ESRD patients may report similar tendencies.

No existing studies have explored the relationship between health literacy, loneliness and hopelessness in DM-ESRD patients.

Illness Perception and the Four Dimensions of Psychological Distress

Studies examining the relationship between illness perception and depression in ESRD patients are also limited. An epidemiological survey of depression, perception of illness and mortality in ESRD patients report that illness perception is associated with depression and were both predictive of higher mortality (Peterson et al., 1991). Another study also found that a greater perception of illness burden was associated with reporting more depressive symptoms (Devins et al., 1990).

There is a general lack of studies examining the relationship between illness perception and anxiety in DM-ESRD patients. One study examining illness intrusiveness and quality of life in ESRD patients found that in both PD and HD patients, higher levels of perceived illness intrusiveness (treatment burden) was associated with greater negative affect, including anxiety (Devins et al., 1990).

A search in the literature reveals that no current studies have explored the relationship between illness perceptions, loneliness and hopelessness in DM-ESRD patients.

Nutritional QOL and the Four Dimensions of Psychological Distress

As nutritional QOL is a relatively new concept on its own, the review of literature in this area will focus on reviewing the closely related construct of nutritional status (as discussed previously in this chapter) with psychological distress.

Research has generally shown significant associations between depression and nutritional status (Koo et al., 2003; Bilgic et al., 2007). The severity of depression is predictive of the degree of malnutrition in HD patients, but it remains unclear as to whether depression may be the cause or the end result of poor nutrition (Bilgic et al., 2007). Some suggestions for the underlying mechanisms include a clinical explanation that proinflammatory cytokine-induced chronic inflammation that could cause both depression and malnutrition in HD patients, in addition to depression usually having accompanying symptoms of loss of appetite, in turn affecting nutrition (Bilgic et al., 2007).

Research on nutritional status, anxiety and loneliness are limited and unclear, although it is likely that these psychological distress constructs would influence nutrition status in similar ways to depression. Hopelessness has been found to lead to poor intake of food and poor nutrition in general (Kalender et al., 2006; Lew et al., 2005), although these studies usually examine hopelessness as an extension and symptom of depression.

Adherence and the Four Dimensions of Psychological Distress

The relationship between nonadherence and depression is well documented. For example, Cukor and colleagues (2007) reported that depression was a significant predictor of nonadherence to treatment for HD patients and argue for routine screening of depression to promote adherence. The proposed mechanism underlying the relationship is still unclear, although some suggestions include poor health education and high dosage frequencies that increase depressive symptoms (e.g. rumination) (Stein-Shvachman, Karpas, Werner, 2013). Additionally, a study reported that depression affects adherence mainly through perceived side effects, general barriers and low self-efficacy (Chao et al., 2005).

In the study of adherence in ESRD patients, depression, anxiety and hopelessness have usually been lumped together under the ambit of a broader term – Emotional Distress (e.g. Brownbridge & Fielding, 1994; DeOreo, 1997). However, the present study attempts to distinguish these three dimensions.

Loneliness and social isolation have been shown to be associated with low adherence in ESRD patients, but evidence is also limited. One study found that social support is an important psychosocial factor related to fluid control adherence in patients on dialysis (Heaney & Israel, 2002; Yokoyama et al., 2009). The proposed mechanisms include the idea that social support can enhance an individual’s ability to access information and diminish negative effects of the complexity of treatment, thus improving motivations and beliefs for adherence to treatment (Yokoyama et al., 2009).

Limitations of Previous Studies

The present paper has presented a case for the scarcity of studies examining the DM-ESRD patient population in general. The four psychological dimensions (depression, anxiety, loneliness and hopelessness) are distinct constructs, but in general previous studies do not give accordance to the distinction and usually examines them collectively, especially in terms of depression and hopelessness. In addition, studies examining the four psychosocial dimensions (health literacy, illness perception, nutritional QOL and adherence) in the context of co-existing chronic conditions are limited as well.

Study Hypotheses

Hypothesis 1: The study population will report psychological distress. In addition, Health Literacy, Illness Perception, Nutritional QOL and Adherence is expected to differ between the respective distressed vs. non-distressed subgroups.

Hypothesis 2: Health Literacy, Illness Perception, Nutritional QOL and Adherence are expected to make significant contributions to the prediction of each of the four psychological distress subgroups.

CHAPTER TWO

Methodology

Design Rationale

This was a mixed methods study. By combining qualitative and quantitative methodologies, mixed methods research has been argued to increase the meaningfulness of research compared to either qualitative or quantitative methods on their own (Creswell & Clark, 2007). In addition, mixed methodology is suitable for addressing the research aims of this study. Firstly, the lack of studies examining psychosocial outcomes in DM-ESRD patients permit an explorative qualitative component (in-depth interviews with patients) to examine a unique population that faces unique and complex treatment challenges relative to other chronic disease populations (including other segments of ESRD population). A quantitative approach allows the identification of significant relationships between psychological distress and the other psychosocial variables (i.e. illness perception, health literacy, adherence and nutritional QOL), as well as identifying determinants of psychological distress using regression-based methods (i.e. hierarchical stepwise logistic regression). Hence, the use of mixed methods in this study allows for a critical exploration of new lines of enquiry of DM-ESRD population needs, as well as test for significant relationships between psychological distress and the 4 relevant psychosocial constructs identified for the purposes of this study.

Qualitative Methodology

As part of a broader study exploring multi-morbidity, (DM & ESRD) (Griva et al., 2015), a total of thirty-one (31) DM-ESRD patients were recruited for the qualitative component of this study between June 2014 to October 2014.

In consultation with NKF Health Care Professionals, the study identified eligible DM-ESRD participants and these patients were approached at several participating National Kidney Foundation community Dialysis Centers in Singapore (NKF DCs). Following informed consent, arrangements were made for a mutually agreeable date, time and venue for conducting a semi-structured interview. Participants were purposively sampled to ensure age, gender, and ethnic diversity.

Inclusion Criteria

Patients were recruited if they met the following criteria:

1. Cause of renal failure was Diabetes Mellitus;
2. Aged 21 years or over;
3. Received dialysis for a minimum of 3 months;
4. Able to provide informed consent; and
5. Able to communicate with research assistants using English, Malay or Mandarin.

Procedure

The semi-structured interviews averaged 45 minutes each and were conducted by research assistants with experience in interviewing in either English, Mandarin or Malay. It may be useful to note that although English is the *lingua franca* in Singapore, there is a more predominant use of mother tongue (e.g. Mandarin or Malay) in older Singaporeans and as such a multilingual approach is necessary in this study as ESRD patients tended to be in the older population segment (Cavallero & Ng, 2014). The interviews were audio-recorded and transcribed verbatim to promote accuracy of data and allow for in-depth analysis.

Interview questions (See Appendix A were informed by topic guides developed in light of the literature, study aims and inputs from an advisory group of nephrologists and patient representatives. Through emerging findings following analyses of early interviews, a topic guide was devised and includes the following categories of questions:

i. Patient perspectives on multimorbidity (e.g. "*How do you feel about having to be on dialysis as well as managing diabetes? Have you ever felt that being on dialysis affects your diabetes? Or, conversely, that diabetes affects how well you do on dialysis? In what ways and why?").*

ii. Challenges in managing aspects of treatment, including Diet, Fluid and Medication (e.g. "*What are the main reasons for failing to achieve treatment goals (specifically, in relation to either your diabetes/kidney condition(s))? Any other reasons? What are the main challenges for people who have to follow diet for both diabetes and dialysis and why?*).

iii. Health services and interactions (e.g. *Thinking of your health condition and all aspects of your treatment for both diabetes and kidney condition which do you think you could use the most help with? In what way could you use help?).*

Data Analysis

An inductive thematic analytical approach was used in which transcripts were cross-compared (e.g. De Chesnay, 2015) to examine potential issues and experiences that cut across different patients' accounts and underlying reasons for similarities and differences in their experiences and views. The thirty-one interviews were evaluated, discussed, coded and compared between the Principal Investigator (also the thesis supervisor to the present study) and two research assistants, including the current author. Coding and constant comparative analysis continued until saturation occurred (reiteration of items in themes identified, with no new information forthcoming).

Quantitative Methodology

Participants

Participants were recruited from various NKF community DCs across Singapore between October 2014 to February 2015 (upon completion of qualitative interviews). The DCs are geographically distributed across Singapore. They include centers in the East (Bedok DC), West (Clementi & Ghim Moh DCs), Central (Ang Mo Kio & Kim Keat DCs) and North (2 Woodlands DCs) districts of Singapore. There are no NKF community dialysis centers in southern Singapore due to it being primarily a business district. Patients who undergo dialysis in NKF community dialysis centers are supported by some degree of government funding. 63% of all HD patients in Singapore are treated at these community dialysis centers, while the remaining patients are treated at privatized dialysis centers (SRR, 2014).

Picture A: Hemodialysis at Community Dialysis Centers in Singapore (Source: http://www.nkfs.org/)

Inclusion Criteria

Similar to the qualitative component requirements patients were recruited if they met the following criteria:

1. Cause of renal failure was Diabetes Mellitus;
2. Aged 21 years or over;

3. Received dialysis for a minimum of 3 months;
4. Able to provide informed consent; and
5. Able to communicate with research assistants using English, Malay or Mandarin.

Recruitment Process

DC staff nurses identified patients whose etiology of ESRD was DM and research assistants subsequently approached these patients while they were undergoing hemodialysis. All approached patients were given a short introduction about the purpose and procedure of the study. Patients that expressed discomfort with participating in the questionnaire survey were immediately excused. Patients failing to meet the inclusion criteria were excluded from participation. Eligible participants were read a participant information sheet that lists out details of the study (Appendix B). Written consent was acquired prior to study administration (Appendix B). The recruitment process is illustrated in Figure 5.

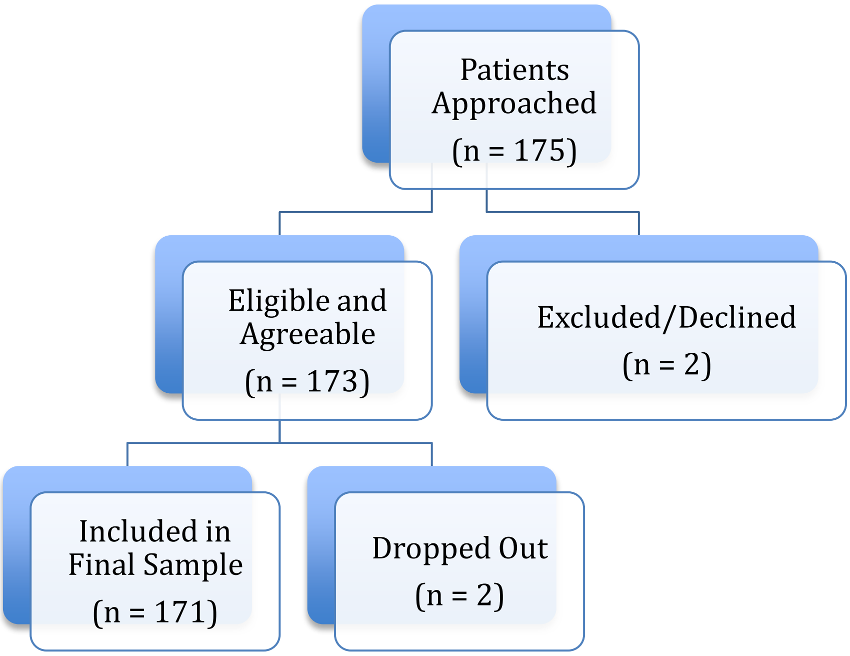


Figure 5: Flowchart of the recruitment process

One hundred and seventy-five patients were approached at the various community HD DCs while they were undergoing Hemodialysis. Considering that the process of initiating HD is complex and requires some setup time, research assistants did not administer the study instruments in early period when HD was being initiated. Of the 175 patients approached, 1 patient was misidentified for having DM as cause of ESRD, and 1 patient declined to participate in the study. The low exclusion rate (1%) may be due to DC staff nurses selecting more cooperative and/or cognitively-able participants for the Research Assistants to approach. Of the 173 eligible patients who agreed to participate in the study, $n = 2$ patients dropped out, citing reason of fatigue.

Study Instruments

Demographics

Demographics (gender, age, language spoken, ethnicity, education level, income, employment, relationship status, housing conditions) were collected using a self-designed questionnaire (Appendix C).

Medical Information

Medical information (time on dialysis, comorbidities, medication prescription, potassium, creatinine, phosphate, hemoglobin, HbA1C, Kt/V) were extracted from medical records by research assistants in the community dialysis centers. HbA1C is a term commonly referred to in diabetes, and refers to glycated hemoglobin, which is use to obtain an overall picture of blood sugar levels. Kt/V is a number used to quantify hemodialysis and peritoneal dialysis treatment adequacy (K = dialyzer clearance of urea, t = dialysis time and V = volume of distribution of urea).

Charlson Comorbidity Index (CCI)

In addition to being an indicator of comorbidity severity, CCI is used to estimate the prognosis of ESRD patients, and is calculated using an empirically validated methodology by Di Lorio et al. (2004). Comorbid conditions included in the calculation of CCI, and their respective score weightages are:

1 Point: Myocardial Infarction, Congestive Heart Failure, Peripheral Disease, Diabetes without end-organ damage, Dementia, Cerebrovascular Disease, Chronic Pulmonary Disease, Connective Tissue Disease, Peptic Ulcer Disease, Mild Liver Disease;

2 Points: Hemiplegia, Moderate/Severe Renal Disease, Tumor without metastasis, Leukemia, Lymphoma, Diabetes with end-organ damage (retinopathy, neuropathy, nephropathy or brittle diabetes);

3 Points: Moderate to Severe Liver Disease; and

6 Points: Metastatic Solid Tumor and Acquired Immune Deficiency Syndrome (AIDS).

An additional point was added to the total CCI score for each decade of ≥ 40 years of age.

Psychological Distress Measures – Anxiety and Depression

Hospital Anxiety and Depression Scale (HADS). Symptoms of depression and anxiety were assessed using HADS (Zigmond & Snaith, 1983). HADS is a popular instrument that consists of a Depression subscale (7 items) and an Anxiety Subscale (7 items). Participants rate their degree of depression and anxiety in the past 2 weeks on a 4-point Likert scale, ranging from zero (0; yes, definitely) to three (3; no, not at all). Aggregate scores for the subscales are calculated and the final score ranges from zero to twenty one (0 to 21). A higher score represents a higher level of depression or anxiety. Scores are classified into normal (0-7), borderline (8-10) and abnormal (11-21) (Martin, Thompson & Chan, 2004). Both subscales demonstrated moderate to high levels of reliability, as determined by a Cronbach's alpha of .58 for the anxiety subscale and .82 for the depression subscale. In addition, HADS is chosen over other depression and anxiety instruments because it precludes somatic symptoms such as fatigue and weight loss, which may be confounded with symptoms related to renal conditions and uremia (Mykletun, Stordal & Dahl, 2001). Furthermore, HADS is consistently applied and validated in measuring depression and anxiety amongst ESRD patients (Martin et al., 2004; Loosman et al., 2010; Johansson, Hickson & Brown., 2013; Turkistani et al., 2014; Griva et al., 2014). To facilitate between-group comparisons, patients with scores of 8 and above for each subscale (qualifying for "borderline" and "abnormal") will be classified as either Depressed or Anxious (coded as "1"), while scores below 8 will be classified as either Non-depressed or Non-Anxious (coded as "0"). This classification process is illustrated in Figure 6.

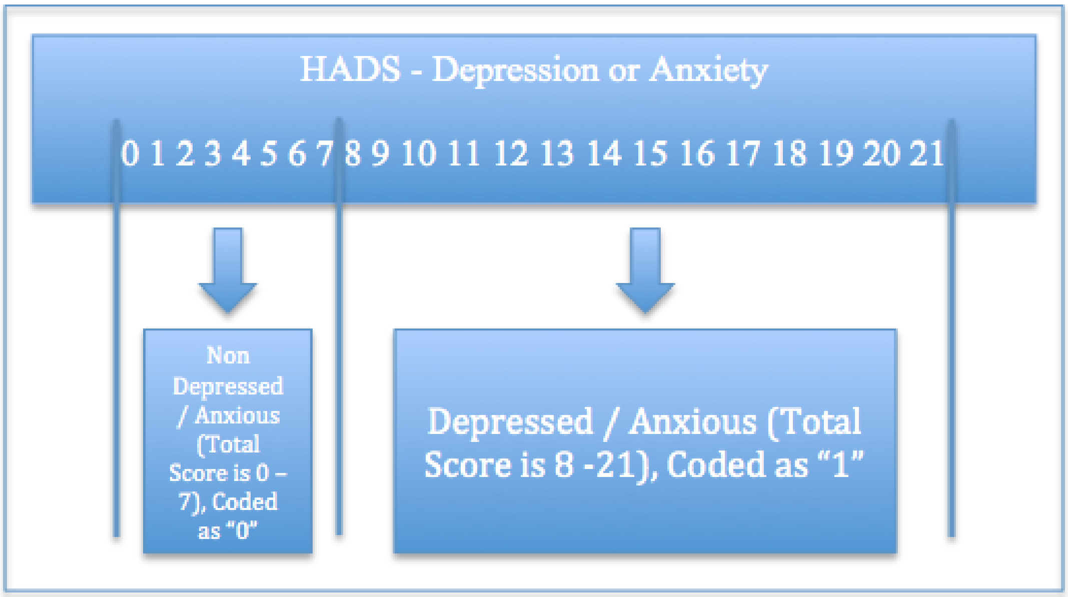


Figure 6: HADS Score Classification

Psychological Distress Measures – Loneliness

An alternative short-form of the widely used revised UCLA Loneliness Scale (ULS-20) was devised by Hays & DiMatteo (1987). Termed the UCLA Loneliness Scale-8 (ULS-8), the scale is found to be a short yet reliable and valid substitute for the ULS-20. The 8 items (Appendix C) are scored on a 4-point Likert scale. The aggregate score (range = 8 to 36) was calculated, with a higher score indicating a higher degree of loneliness. This scale had moderate reliability in this study, Cronbach's alpha = .60. In the original ULS-20, aggregate score range was 20 to 80, and the combined score may be classified into low (20-34), moderate (35-49), moderately high (50-64) and high (65-80). There are currently no guidelines for the classification of the scores for the ULS-8. Thus, for the purposes of this study, the categorizations have been extrapolated from the ULS-20. Figure 7 illustrates the extrapolation process used in the current study. Goossens et al. (2014) recommend that scores above 15 ("moderate" level category) be used as a cutoff and to facilitate between-group comparisons, patients with scores of 15 and above (qualifying for "moderate" and above) will be classified as Lonely (coded as 1), while scores below 15 will be classified as non-Lonely (coded as 0).

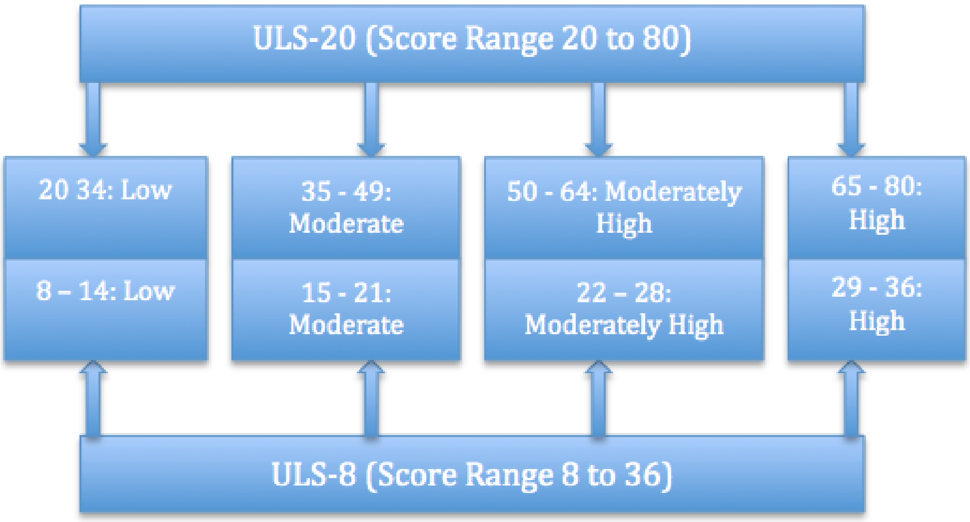


Figure 7: ULS-8 Scores Classification

Psychological Distress Measures – Hopelessness

The Beck Hopelessness Inventory (BHI) – Short Version was used to assess Hopelessness, as an indicator of suicide risk. In the present study, instead of using the original 20-item Beck Hopelessness Scale (Beck et al., 1974), the 4-item BHI was chosen (Appendix C) as it was found to have good psychometric properties with internal consistency (Forintos et al., 2013). The 4-item BHI is used in the current study to also reduce the burden of completion for respondents. In addition, the creators of BHI report that the scale is a good predictor of suicidal thoughts and behavior. The items are rated on a 4-point Likert scale (0 to 3) with higher scores indicating higher hopelessness. The BHI had high reliability in this study, Cronbach's alpha = .82. The clinical cutoff score for suicidal risk in the BHI is proposed by the creators to be >5 (Forintos et al., 2013). To facilitate between-group comparisons, scores >5 will be classified as Hopeless (coded as 1), while scores ≤5 will be classified as non-Hopeless (coded as 0). This classification process is illustrated in Figure *8*.

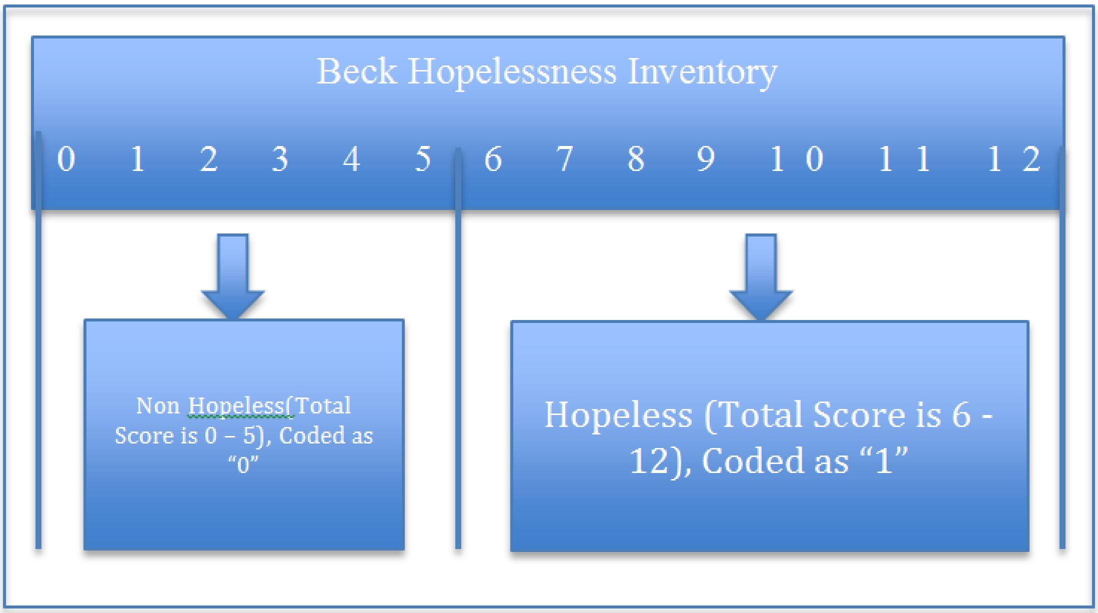


Figure *8*: BHI Score Classification

Health Literacy

The Health Literacy Questionnaire (HLQ). HLQ is a comprehensive measure of health literacy developed to assess nine different dimensions of health literacy needs and challenges (Osborne et al., 2013). Despite its youth, the HLQ has been validated on chronic diseases populations (e.g. Beauchamp et al., 2015). The first five of the nine dimensions are scored on a range of 1 to 4 (“*How strongly you disagree or agree with the following statements: strongly disagree/disagree/agree/strongly agree”*), and these five dimensions are:

- “Feeling Understood and Supported by Healthcare Providers”,
- “Having Sufficient Information to Manage My Health”,
- “Actively Managing my Health”,
- “Social Support for Health”, and
- “Appraisal of Health Information”.

The rest of the four dimensions are scored on a range of 1 to 5 (“*How easy or difficult are the following tasks for you to do now: cannot do/very difficult/quite difficult/quite easy/very easy”*), and these remaining dimensions include:

- “Ability to Actively Engage with Healthcare Providers”,
- “Navigating the Healthcare System”,
- “Ability to Find Good Health Information”, and
- “Understanding Health Information Well Enough to Know What to Do”.

The HLQ is appended in Appendix D. The nine dimensions and their reliability coefficients are displayed in Table *1*. As observed from the table, all HLQ dimension subscales show a high level of reliability (all Cronbach’s alpha > .78, range = .78 to .93). There are no cutoff or classification of scores in the HLQ.

Table 1

Number of Items, Reliability Coefficients and Concepts Measured by HLQ

Dimension	No. of items	Cronbach's alpha	Explanation[1]
Feeling Understood and Supported by Healthcare Providers	4	.78	This dimension examines the extent of relationship and trust with at least one healthcare provider as a source of information and provider of advice about health.
Having Sufficient Information to Manage my Health	4	.82	Examines the extent of confidence in having information necessary to live, manage their conditions and to make decision.
Actively Managing my Health	5	.88	Examines how patients may recognize the importance of, and the ability to take responsibility for their own heath. They proactively engage in their own care and make their own decision about their health.
Social Support for Health	5	.84	Examines the extent to which a person's social system provides them with all the support they want or need.
Appraisal of Health Information	5	.83	Examines the extent of the ability to identify good information and reliable sources of health information, including ability to resolve conflicting information by themselves or with help from others.
Ability to Actively Engage with Healthcare Providers	5	.89	Examines the extent to which patients are proactive about their health and feel in control in relationships with HCPs. Additionally, examines if patients are able to seek advice from additional HCPs when necessary.
Navigating the Healthcare System	6	.92	Examines the ability to find out about services and supports to meet individual needs. Additionally, examines ability to advocate on their own behalf at the system and service level.
Ability to Find Good Health Information	5	.93	Examines if patient is an "information explorer", and if they use a diverse range of sources to find information and is up to date.
Understanding Health Information Well Enough to Know What to Do	5	.87	Examines if patient is able to understand all written information (including numerical information) in relation to their health and fill up medical forms where required.

Note. HLQ = Health Literacy Questionnaire. [1]Cited from "The grounded psychometric development and initial validation of the Health Literacy Questionnaire," by Osborne, R.H., Batterham, R.W., Elsworth, G.R., Hawkins, M. & Buchbinder, R, 2013, *BMC Public Health*, 13, p. 658 – 675.

Illness Perception

Brief Illness Perception Questionnaire (BIPQ). A subset of six items that were deemed relevant for the purposes of this study was chosen from the original 9-item BIPQ. The six items assess “Consequences”, “Personal Control”, “Treatment Control”, “Identity”, “Concern” and “Illness Comprehensibility” (Broadbent et al., 2006). These six items were also created separately for DM and kidney disease (Appendix C). This presents an opportunity to compare the overall scores on BIPQ between the two conditions. Each item is rated on an 11-point Likert scale and an overall score was calculated to examine the degree to which the illness was perceived as threatening or benign. Higher scores indicate a more threatening perception of the measured illness. Both BIPQ-Diabetes and BIPQ-Kidney Disease scales demonstrated satisfactory reliability. BIPQ-Diabetes scale Cronbach’s alpha = .72, BIPQ-Kidney Disease scale Cronbach’s alpha = .74. The original 9-item BIPQ has been validated and applied successfully in measuring illness perception among Diabetic HD patients (Petrie & Weinman, 2012; Pula, 2012). Relevant score items that were required to be reverse-coded were performed appropriately.

Multimorbidity Illness Perceptions Scale (MULTIPleS). The MULTIPleS scale is divided into five discrete domains, namely, “Treatment Burden”, “Prioritization”, “Causal Relationships”, “Emotional Representations” and “Activity restriction” (Gibbons et al., 2013). To reduce the burden of study completion and to scrutinize the exact psychological parameters in the interest of the present study, only the Treatment Burden and Prioritization subscales are be employed (Appendix C). The MULTIPleS scale has been utilized in several studies examining the impact of multimorbidity on illness perceptions in chronic disease populations (Coventry et al., 2015; Kenning et al., 2015). Each item is rated on a 6-point Likert scale ranging from zero (Strongly Disagree) to five (Strongly Agree) and an overall score was calculated to examine the degree of patients’ illness perceptions of their multimorbidity. Both subscales displayed satisfactory reliability in this study. Treatment burden subscale Cronbach’s alpha = .69, Prioritization scale Cronbach’s alpha = .67.

Adherence

Adherence is commonly measured via self-report measures and is considered a more cost-effective approach compared to using biological/biochemical markers or monitoring of dialysis records. Although some studies have shown that self-reports may not be as accurate because of responder bias and an overestimation of compliance (Vlaminck et al., 2001), it has been suggested that the benefits of self-report in a larger sample size may offset responder bias (Domino & Domino, 2006). The following figure illustrates the various self-report instruments that are employed in measuring various dimensions of adherence.

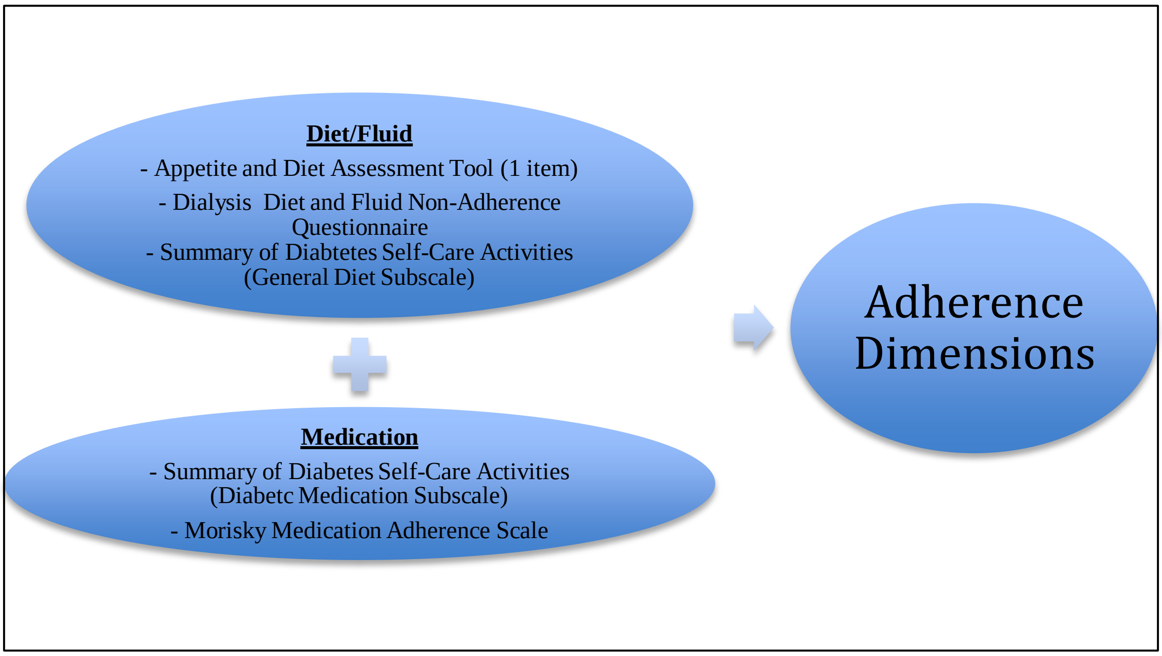


Figure 9: Adherence Dimensions examined in this study.

Appetite and Diet Assessment Tool (ADAT). The original 44-item ADAT (Burrowes et al., 1996) evaluates appetite and factors affecting dietary intake in hemodialysis patients. To reduce the burden of completion, this study employs only one of the key items in the ADAT – "*Do you have difficulty following your diet?"* (0 = no, 1 = yes). The subscale was found to have good reliability in this study (Cronbach's alpha = .88).

Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ). A tool to measure nonadherence to diet and fluid guidelines, the DDFQ is widely used for the collection of nonadherence data (e.g. Vlamick et al., 2001; Kugler et al., 2011; Clark et al., 2014). The 4-item instrument captures frequency of nonadherence behavior with diet and fluid restrictions by asking the participants "*How many times in the last 14 days did you not follow your diet or fluid guidelines?*" of which the responses range from zero to 14 days. Degrees of deviation are examined by asking "*To what degree did you deviate from your diet or fluid guidelines*?" and deviation is rated on a five point Likert scale from zero ("no deviation") to five ("very severe deviation"). The scale has good reliability in this study (Cronbach's alpha = .85).

Summary of Diabetes Self-Care Activities (SDSCA). The SDSCA-revised version is a well-validated measure of diabetes self-care (Toobert et al., 2000), and has been used by studies examining diabetic patients (e.g. Piette et al., 2003; Bains et al., 2011). It measures various domains of self-care behaviors and includes general diet and medication. The authors of the scale have recommended for each domain to be assessed separately rather than to combine scores across domains (Toobert et al., 2000). For the domain of general diet, the two questions are "*How many of the last SEVEN days have you followed a healthful eating plan?"* and *"On average, over the past month, how many days per week have you followed your eating plan?"* to which participants would be asked to respond from zero to seven days. A total score is calculated from calculating the mean number of days for these two questions.

For the domain of medication, participants are asked to tick all that apply in relation to the following medications for DM that are prescribed:

a. *"An Insulin shot 1 or 2 times a day",*

b. *"An Insulin shot 3 or more times a day",*

c. *"Diabetes pills to control my blood sugar level",*

d. *"Others (Specify)",* and

e. "*I have not been prescribed either insulin or pills for my diabetes".*

If the participants answered either (a), (b), (c) or (d), they would answer the follow-up question "*On how many of the last SEVEN Days did you take your recommended diabetes medication?"* to which participants would be asked to respond from zero to seven days. A score is calculated based on the total number of days from the follow-up question. The two subscales see moderate reliability in this study, general diet subscale Cronbach's alpha = .61, medication subscale Cronbach's alpha = .65.

Morisky Medication Adherence Scale (MMAS-8). While the SDSCA is an indication of medication self-care (Toobert et al., 2000), the MMAS-8 (8 items) provides an indication to the severity of medication nonadherence and is a reliable measurement tool examining the circumstances surrounding adherence behavior (Appendix C). The MMAS-8's questions are phrased to avoid a "yes-saying" bias by reversing the wording of the questions about the way patients might experience failure in adhering to their medication regimen, as there is evidence for a tendency for positive responder bias to health care providers (Morisky et al., 2008). Each item measures a specific medication-taking behavior rather than a determinant of adherence behavior. Response categories are yes or no for items one through seven and on a 5-point Likert scale for item eight. The scores are then further categorized in high level of adherence (total score = 0), medium level of adherence (total score = 1 or 2), and low level of adherence (total score = >2). The MMAS-8 has good reliability in this study, Cronbach's alpha = .87.

Nutritional Quality of Life

Nutrition-Specific Quality of Life (NSQOL). The NSQOL is a 15-item questionnaire providing specific information about hemodialysis-related food intake issues and is developed based on a combination of items from the Appetite and Diet Assessment Tool and Food Enjoyment in Dialysis tool (Appendix C) (Han et al., 2012). It is a rapid self-administered tool that can be used to assess appetite-related quality of life in patients receiving hemodialysis and is well correlated with other Health-related Quality of Life (HRQOL) indices in hemodialysis patients (Han et al., 2012). A total combined score is used to indicate quality of nutritional status. The NSQOL had good reliability in this study, Cronbach's alpha = .88.

Summary of Study Instruments Used in Present Study

The following table presents a summary of the instruments used in the present study.

Table 2
Summary of instruments employed in present study

Dimension/Concept	Instrument	Cronbach's alpha
Psychological Distress		
Anxiety	Hospital Anxiety and Depression Scale (HADS)	.58
Depression	Hospital Anxiety and Depression Scale (HADS)	.82
Loneliness	UCLA Loneliness Scale 8 (ULS-8)	.60
Hopelessness	Beck Hopelessness Inventory (BHI)	.82
Health Literacy	Health Literacy Questionnaire (HLQ)	.78 to .93
Illness Perception		
General Illness Perception	Brief Illness Perception Questionnaire (BIPQ) – Diabetes	.72
	Brief Illness Perception Questionnaire (BIPQ) – Dialysis	.74
Prioritization	Multimorbidity Illness Perception Scale (MULTIPleS)-Prioritization	.69
Treatment Burden	Multimorbidity Illness Perception Scale (MULTIPleS)-Treatment Burden	.67
Adherence		
Dialysis Diet	Appetite and Diet Assessment Tool (ADAT); Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ)	.88
Diabetic Diet	Summary of Diabetes Self Care Activities (SDSCA)	.61
Medication (Indication/Frequency of Adherence)	Summary of Diabetes Self Care Activities (SDSCA)	.65
Medication (Severity of Non-Adherence)	Morisky Medication Adherence Scale (MMAS-8)	.87
Nutrition Status	Nutrition-Specific Quality of Life (NSQOL)	.88

Data Analysis

Missing Data

Table *3* shows the distributions of missing items. The number of missing items was minimal in nature and the distribution was random. Thus, mean imputations were used if at least 50% of the participants responded in the particular dimension.

Table 3
Distribution of Missing Values

	Frequency	%
MMAS-8	1	0.01
HLQ	1	0.01
BIPQ-Diabetes	2	0.01
HbA1C	5	0.03
Urea	5	0.03
Kt/V	3	0.02
Creatinine, Hemoglobin, Potassium, Phosphate, Albumin	3	0.01

Note. MMAS-8 = Morisky Medication Adherence Scale – 8. HLQ = Health Literacy Questionnaire.

Statistical Analysis

Descriptives. Descriptive statistics included medians, means and standard deviations for continuous variables and frequencies and percentages for categorical variables.

Univariate analyses. Kolmogorov-Smirnov tests were used to assess the normality of variable distribution. Means were compared with independent *t* tests, paired *t* tests, ANOVA or ANCOVA and percentages were compared with χ^2 tests. When data were not normally distributed, non-parametric tests (Mann-Whitney tests) are used instead and annotated accordingly). In addition, results reporting will replace ($p < .001$) with ($p = 0+$).

Multivariate analyses. One-way Multiple Analysis of Variance (MANOVA) were used to determine the effect of the respective dimensions of psychological distress (i.e. Depressed vs. Non-Depressed, Anxious vs. Non-Anxious, Lonely vs. Non-Lonely & Hopeless vs. Non-Hopeless) on the nine dimensions of Health Literacy as measured by the HLQ (nine continuous dependent variables). Key assumptions involving multicollinearity, univariate or multivariate outliers, having multivariate normality, homogeneity of variance-covariance matrices are checked through to ensure compliance. $p = .05$ was used as the entry or removal criteria.

In addition, hierarchical stepwise logistic regressions were used to identify important predictors of the 4 dimensions of psychological distress. In the context of the current study, the large amount of variables would increase the risk of Type 1 error and thus univariate tests of association would be used to identify the demographic, clinical and psychosocial variables associated with psychological distress. $p = .05$ and $p = .10$ were used as entry and removal criteria. Forward stepwise procedure was deployed to select variables that were significant at .05 at univariate screening.

Statistical significance level was set at .05 for all procedures. Bonferroni α-adjustment was applied for post-hoc comparisons. All analyses were performed using the Statistical Package for Social Sciences (SPSS) version 23.0 for Macintosh (IBM Corp, Armonk, NY, USA).

Ethics

The National University of Singapore Institutional Review Board approved this study, under the aegis of larger study called “Combined Diabetes and Renal Control Trial (C-DIRECT) (Griva et al., 2015).

CHAPTER THREE

Results

Part I. Qualitative Component Results

Part I presents results with respect to study aim **1**.

Qualitative Study Sample

Out of 32 patients approached, 1 patient declined and the 31 others accepted the offer to participate in the study. The demographics of the participants for the qualitative component of the study are listed in Table *4*.

Thirty one (31) DM-ESRD patients participated in the qualitative component of the study. The mean age of the participants was 57.68 (*SD* = 7.48) and the median age was 57 years, relatively close to the median age of 61 years for Singapore prevalent HD patients (Singapore Renal Registry, 2014). Sixty five percent (65%) of the qualitative study sample are male. Fifty five percent (55%) of the sample are ethnic Malay and thirty nine percent (39%) are Chinese. Of note, the ethnic proportion in the present study sees a lower proportion of Chinese patients and a larger proportion of Malay patients compared to the prevalent HD patients (67% and 25% respectively) (SRR, 2014). Sixty five percent (65%) of the qualitative study sample are married, sixty eight percent (68%) are unable to be gainfully employed due to their medical condition and seventy four percent (74%) lived in subsidized public housing.

Table 4

Demographics of Qualitative Sample

	Total Sample (n = 31)
Age	57.68 ± 7.48
Gender	
Male	20 (65)
Female	11 (35)
Ethnicity	
Chinese	12 (39)
Malay	17 (55)
Indian/Others	2 (6)
Education Level	
No Education/Primary	12 (39)
Secondary	15 (48)
Tertiary	4 (13)
Marital Status	
Married	20 (65)
Not Married	11 (35)
Family Income	
<$2000	22 (71)
≥$2000	9 (29)
Employment	
Employed (Full or Part time)	10 (32)
Unemployed	21 (68)
Housing	
1 to 4 months	23 (74)
5 months/Private Housing	8 (26)

Note. Data expressed as *M* ± *SD* or n (%)

Key Themes

The following themes were identified through appropriate coding schema and thematic analysis. The key themes voiced by the patients were mainly related to:

i. Emotional Difficulties,

ii. Dietary and Fluid Intake Issues,

iii. Health Literacy and

iv. Interpersonal Relationships

Theme (i): Emotional Difficulties

In general, patients report experiencing general negative affect and/or mood changes often as a result of their kidney conditions. Most of the time, the patients are unable to articulate the reasons behind their negative affect and mood changes. In addition, feelings of negative affect are reported to influence motivation to adhere to treatment.

> *"I feel sad…Everyday, I have all the illnesses – diabetes, the heart problems, there's this and that…daily, there's dialysis. If I want to go anywhere, I have to think, oh no, dialysis again tomorrow. I've been forced to…what else can I do*." - **P12.**

> *"They even they referred me to psychiatrist, just to give me a kind of motivation and inspiration…yah.. of course very sad.. a lot of things in my mind.. a bit mentally disturbed. And my mind, my emotion also a bit change. Because last time I was an active man..you know.. We used to work. Happy happy then suddenly like become like this la… now its already 4 years 4 months…but sometimes I feel down also lah but I try to control myself.* - **P13**.

In discussing their treatment goals, patients generally express depression and a kind of hopelessness about any form of progress.

> *“Patient: I’m so old…im just waiting to die.*
>
> *Interviewer: No you’re not...you still have some time.*
>
> *Patient: I only have a few years left.*” – **P26.**

> “*Nothing to achieve anymore because if no dialysis you will not be strong…the dialysis is forever until you close your eyes that’s all” –* **P8.**

Patients recounted a high perception of treatment burden and a high “workload” of health care that patients must perform, which is in turn associated with feelings of hopelessness.

> *“What else do I have to say? That’s all I have to say. Diabetes…I have to look after my diet. Last time, without the kidney problems, I don't look after my diet, it’s still okay to eat a little bit because there’s medication. The kidneys can work the medication. Now, the kidneys can’t work the medication, although eating just a little bit, there will be a flare up. Eat a little bit and it will flare up, eat a little bit and it will flare up. I am always in and out of hospital”. –* **P4**

Patients also recounted how managing multiple coexisting conditions lead to a lack of confidence in managing their condition. Additionally, patients also report temper issues related to “frustration” and “anger” with their conditions. It is important to note that frustration and anger are qualitatively different constructs from the four psychological distress dimensions measured in the present study. Several patients also discussed how they were also emotionally affected by the chronicity of their illness. These reasons have been linked to a decrease in motivation to adhere to treatment.

> *"I feel very tired trying to manage both illnessess…I would put a 5/10 in confidence in managing my illness. I actually don't feel like I have to change the way I eat, except for the fact that I feel extremely tired…after dialysis. I have also felt my tempers soaring at times, I even feel lazy to come for dialysis. My temper flares about once a week, and my moodiness affects how willing I am to come for dialysis. At the end of the day however, I still come for dialysis*" – **P1**

> *"I feel…I do feel sad…I have to come for dialysis three times a week, so I feel like…sad because unitl when do I have to undergo dialysis? If possile, I would like to be cured from my illness"*- **P7.**

Patients also shared that they experienced an intensification of negative affect following the initial period of being diagnosed with ESRD.

> *"That was beginning…in the year of 2008 when I got to know I'm (have)a kidney failure…so I really frustrated and I thought I want to give up my life".*- **P15**

Not only are the requirements of dialysis rigid, but many patients also describe the high costs of treatment to be problematic. Patients frequently express that financial aid may possibly be one of the more important types of assistance they can receive.

> *"Now you cannot earn money whatever, you also control a bit la. Not necessary you don't buy la, just buy some food, some every day want to pass on the thing. That's a problem. Every time tell doctor, just money only, other thing okay, all perfect."* – **P2**

> *"The most important help, finance...this is important. Finance right. Finance…other than that, I don't think (there is anything else)"* - **P20.**

Theme (ii): Dietary and Fluid Intake Issues

One of the key challenges was patients' lack of restraint in following dietary recommendations. Challenges in lack of restraint may be related to the diabetic diet to control sugar intake and foods with high Glycemic Index (GI). In addition, patients also report have poorer restraint in social situations.

> **"***The sugar part is the hardest. Because, for example, when drinking beverages, some sugar makes it better. It has to become a habit. I find it also, very hard to abstain totally*" – **P27.**

> *"Interviewer: Why is that so? Why is that you think sometimes you can't control the diet?*
>
> *Patient: Maybe the food is really nice? Tempting me so I… because actually to be frank I don't like to take rice. Ok. Totally no. But I love*

> *to eat yellow noodle (a type of high GI food)s. But since I got this dialysis, I'm a kidney failure, so the dietician from Tan Tock Seng advised me to take beehoon (rice vermicelli) instead of yellow noodles. So I try my best, but actually bee hoon all I don't like…I love the yellow mee."* **P15.**

> *"Interviewer: When you go out to meet your friends, you know, gatherings…do you try to control what you eat?*
> *Patient: Sometimes I try…but the thing is that there are ten kinds of food. Foods ah, everything you (will) try some, add up…still the same what…correct or not?...How small portion still at the end you hit the target. Like that how ah…so it is very difficult to control"*- **P17.**

In similar veins as the reported lack of restraint in dietary intake, some patients report that coexisting conditions of DM and ESRD lead to conflicting dietary requirements. A commonly recounted situation where such a conflict might occur is that post-dialysis appetite may be greater (as patients feel weaker and require energy/carbohydrate rich foods), but this lies in conflict with the diabetic diet (that forbids quick energy, simple carbohydrates).

> "*If I were to eat like what the dietician say (diabetic diet), I will faint. Not enough. Not enough and then nevermind ah. As a dialysis patient you cannot eat that little."* – **P17.**

> "*I can't eat too much after dialysis but I can't help it. After dialysis, I kind of put my knowledge of diabetes(dietary adherence) aside and just go ahead to eat whatever I want*". – **P1.**

Patients also reported a disturbance to their appetite. Most of the patients report that appetite and dietary patterns deteriorate when they experience negative affect (e.g. upset, troubled or distressed).

> "*Sometimes, the lunch time…I don't know. Sometimes when I eat the gravy, certain time I like it, certain time I don't like it, I feel like throw out. And that's where I don't take anymore. I just stop it. Like yesterday the other time I know, they cook for me bean sprout, it was nice, I can eat. But yesterday I don't know why, I just for moment I take one spoon of bean sprout, I cannot eat go in anymore. I just eat the rice with my fish, bean sprout left it alone. After that I go and throw out…it all depends on my body. Sometimes I can, sometimes I cannot. So I was telling to my maid, I say, it's not your this one, sometimes it depends on me nowadays. I say this three months, I said it's not good for me."* – **P22.**

However, some patients conversely reported a general lack of appetite.

> "*Sometimes…it's not certain. Sometimes, I don't have the appetite. Sometimes, it's difficult. Sometimes, I eat only once a day."*- **P7.**

Lastly, the lack of restraint also extends to fluid intake. Patients usually recount that living in a hot tropical weather increases their thirst. Although they do understand the need for fluid restriction, they commonly state that they are still unable to control their thirst.

> *"Fluid…for me, I never follow…just ownself manage my cup…this (following strict fluid guidelines) creates suffering for me. You see, like a normal person drink one cup of water and feels happy, but I feel sad (that I cannot do the same)"* – **P2.**

Theme (iii): Health Literacy

Patients recount having difficulties understanding health information (i.e. feeling like they do not have the information they need to manage their health concerns) and report that they may be unable to act on own behalf to use the healthcare system to address their health needs (e.g. navigate the healthcare system). Even when HCPs discuss aspects of their treatment with them, their understand of their conditions remain limited.

> *"Doctors give me examples of what to eat and what not to eat. They teach me how to control my diet in that sense. They also tell me what effects dialysis has on my body but for the most part I forget about that easily. I don't really know what dialysis does to my body except that it "washes" my blood"* – **P1**

> *"I know briefly the kinds of food that I can or cannot eat. Beyond that, not really. I don't know much else about what to eat or what not to eat. I also not sure if something is good for me or not"* – **P10**

The analysis also revealed that there may be a lack of explanation given to patients in addressing their misperception with regard to their treatment as well (e.g. not having to be on medication since they are already on dialysis). Patients also reported tensions in their engagement with HCPs (e.g. unable to ask questions to get information or to clarify what they do not understand), recounting unhappiness with the lack of explanation by HCPs with regard to providing sufficient information to their queries. In addition, patients also reported that they are not involved in the decision making process surrounding their treatment, and state some unhappiness with the lack of attention given to them by HCPs.

> *"They put me (on) insulin…I told the doctor, if I put on insulin, I very weak. Sometimes I can get knocked down. Then he asked me to monitor myself. I said, you're the doctor, you don't know why you put me insulin then I find myself that I weak…after my dialysis ah…I say doctor, I got dialysis, no need medicine now is it? Still have to take medicine? Then what is the purpose of having dialysis? Doctor cannot answer me like that"* – **P3**

> *"I learnt that I had diabetes... and then at first they ask me to go for my check-up, they say my blood creatinine is high, eh what protein. I was very scared, I said, why want to go? Because I didn't want to go. For about two-three months, I didn't want to go. I was so scared. I say,*

> *what's really happen to me? Why do I have to go for my blood test? What shows.. then I sitting there.. and they mentioned kidney. I get more worried when the doctor mention. So I went to the kidney centre. The doctor told me that you're having a kidney problem, now we have to go give you a medication you go.. So he give me the urine medication. Don't know what's the name, forgot the name…then just recently, two years ago, doctor say your creatinine level all of a sudden is very high, you have to go for dialysis. I was very very sad when I went for my dialysis… So I said, why is it like that? She said it could be 'cause sometimes you carry heavy thing? Or a infection? So I wonder what happened to me. How come got infection? So I wondering after how maybe I could have ask more details to the nurse, how to prevent it.* – **P22.**

> **"***I think the doctors could be paying slightly more attention to us, especially those in the hospital. Service in the hospital is not great either."* **– P6**

Conversely, some patients also report that health information is readily available, and that HCP support and advice are good.

> *"I manage it…by the advice of the nurses and doctors here. Good advice – not to take this, not to take that…it helped me through.* " **P19**.

> *"My doctor…she will inform me what to do…the doctor is very supportive…so I already happy lah. When she have you know…what you got problem, what problem, then she will ask you. "how? Everything ok? Finance ok?""* – **P20.**

Theme (iv): Interpersonal Relationships

Patients also report having a lack of support as a result of their demanding chronic conditions. Considering that an individual's social system provides them with support that they need for health, the possibility of poor social support can also impair their motivation for treatment.

> *"I manage all of these (treatment aspects) by myself. My children do not care anymore about anything. If I want to be well and avoid frequent hospitalization, I have to watch what I eat and drink. That's all on me. My children, they don't care. All that they know is…waking up in the morning and going to work and back home again*". - **P4.**

> "*Yeah. Angry sometimes…suddenly come. You cannot know why…suddenly…suddenly you get angry. So, I don't know…I don't… Sometimes I think I don't understand why. Why? Maybe my wife do something wrong a little bit wrong also I can get angry."* – **P20.**

Despite not receiving social support, some patients report bolstering their resiliency by aligning themselves with the cognition that they should strive to adhere to their treatment regime as strictly as possible to reduce burden on their friends and family. This observation may be a culturally-bound phenomenon.

> *"I don't want to be a burden to others. I want to manage myself and then should be less problematic to others… Regular medication, regular diet and little exercise will make us live. I mean, lead a healthy life."* **P12.**

A summary of the themes and subthemes are illustrated in Table *5* for ease of reference.

Table 5
Summary of Themes and Subthemes in Qualitative Component

Theme	Subtheme
Emotional Difficulties	1. General negative affect and/or mood changes as a result of kidney conditions. 2. Managing coexisting conditions lead to lack of confidence and temper issues such as frustration. 3. Intensification of negative affect following the initial period of ESRD diagnosis. 4. Depression and hopelessness when discussing treatment goals and progress. 5. Financial concerns are commonly explained to cause some distress. 6. Feelings of hopelessness associated with treatment burden.
Dietary and Fluid Intake Issues	1. Lack of restraint in following dietary recommendations. 2. Conflicting dietary requirements arising from coexisting conditions. 3. Disturbances to appetite with deteriorating mood. 4. Lack of appetite. 5. Social settings may decrease restraint. 6. Deviation from fluid guidelines.
Health Literacy	1. Difficulty understanding health information 2. Lack of given health information and unhappiness and inability to actively engage with HCPs. 3. Some evidence for good HCP support and advice
Interpersonal Relationships	1. Some evidence of strained social relationships and subsequent poor social support. 2. Striving to reduce burden to others.

Part II. Quantitative Component Results

Aspects of Psychological Distress and Biopsychosocial Differences

Part II presents results with respect to study aims **2a** and **2b**.

Demographics/clinical characteristics of the study sample, documented rates of the 4 dimensions of psychological distress (Depression, Anxiety, Loneliness and Hopelessness), followed by their respective subgroup (e.g. depressed vs non-depressed) comparison on dimensions of health literacy, nutritional QOL, illness perception and adherence will be presented. Following which, biopsychosocial determinants of psychological distress will be discussed.

1. Demographics and Clinical Characteristics

One hundred and seventy-one (171) DM-ESRD patients participated in the quantitative component of the study. Table *6* summarizes the patients' demographic characteristics. The mean age of all participants was 58.84 years (*SD* = 9.43) and the median age was 58 years, relatively close to the median age of 61 years for Singapore prevalent HD patients (Singapore Renal Registry, 2014). Sixty-two percent (62%) of the study sample are male. Fifty-one percent (51%) of the sample are ethnic Chinese and thirty-five percent (35%) are Malay. Of note, the present study population sees a slightly lower proportion of Chinese patients and a larger proportion of Malay patients compared to prevalent HD patients (67% and 25% respectively) (SRR, 2014). Sixty-three percent (63%) of the study sample are married, eighty percent (80%) of the sample are unable to be gainfully employed and eighty-eight percent (88%) lived in government-subsidized public housing.

Table 6

Demographics of Total Sample (Quantitative)

	Total Sample (n = 171)
Age	57.97 ± 6.94
Gender	
Male	65 (38)
Female	106 (62)
Ethnicity	
Chinese	87 (51)
Malay	60 (35)
Indian/Others	24 (14)
Education Level	
No Education/Primary	85 (47)
Secondary	66 (39)
Tertiary	24 (14)
Marital Status	
Married	108 (63)
Not Married	63 (37)
Family Income	
<$2000	89 (52)
≥$2000	82 (48)
Employment	
Employed (Full or Part time)	37 (20)
Unemployed	134 (80)
Housing	
1 to 4 months	150 (88)
5 months/Private Housing	21 (12)

Note. Data expressed as *M* ± *SD* or n (%).

Table *7* displays the study samples’ clinical characteristics. Overall, the patients are observed to have high mean comorbidities, with sixty-three percent (63%) of the study sample scoring in the “high” category and sixteen percent (16%) scoring in the “very high” category in the Charlson Comorbidity Index. Seventy-four percent (74%) of the study sample have been on dialysis for more than two years.

Table 7

Clinical Characteristics of the Total Sample

	Total Sample (n = 171)
CCI	6.67 ± 2.15
Low (<3)	0 (0)
Moderate (4 to 5)	37 (21)
High (6 to 8)	108 (63)
Very High (>8)	26 (16)
Time on Dialysis	
< 1 Year	24 (14)
1 to 2 Years	20 (12)
> 2 Years	127 (74)
Biochemistry (n = 168)	
Potassium (mmol/I)	4.84 ± 0.66
Creatinine (mmol/I)	8.68 ± 2.13
Phosphate (mmol/I)	4.71 ± 1.22
Hemoglobin (g/dl)	11.04 ± 1.19
HbA1C (%)	8.05 ± 1.68
Kt/V	1.55 ± 0.20

Note. Data expressed as *M* ± *SD* or n (%).

2. Psychological Distress

A broad summary of descriptive mental health results are first presented in the following table.

Table 8

Summary of Mental Health Results in Total Sample

	Total (*n* = 171)
HADS Depression	7.46 ± 4.17
HADS Anxiety	8.23 ± 3.56
Beck Hopelessness Inventory	4.48 ± 3.27
UCLA Loneliness Scale	18.68 ± 3.98

Note. Data expressed as *M* ± *SD*. Higher value indicates more anxiety, depression, hopelessness and/or loneliness. HADS = Hospital Anxiety and Depression Scale.

Depression and Anxiety

Distribution of HADS scores are illustrated in Figures *10* and *11*. Mean depression score of 7.46 (*SD* = 4.17) was in the borderline range (8-10) and mean anxiety score of 8.23 (*SD* = 3.56) was also in the borderline range (8-10).

Based on clinical cut-offs (≥ 8; Bjelland et al., 2002), depression was documented in 46% of the sample (*n* = 79). Anxiety was documented in 53% of the sample (n = 90).

Figure 10 : Degree of Depression for All Patients (n = 171)

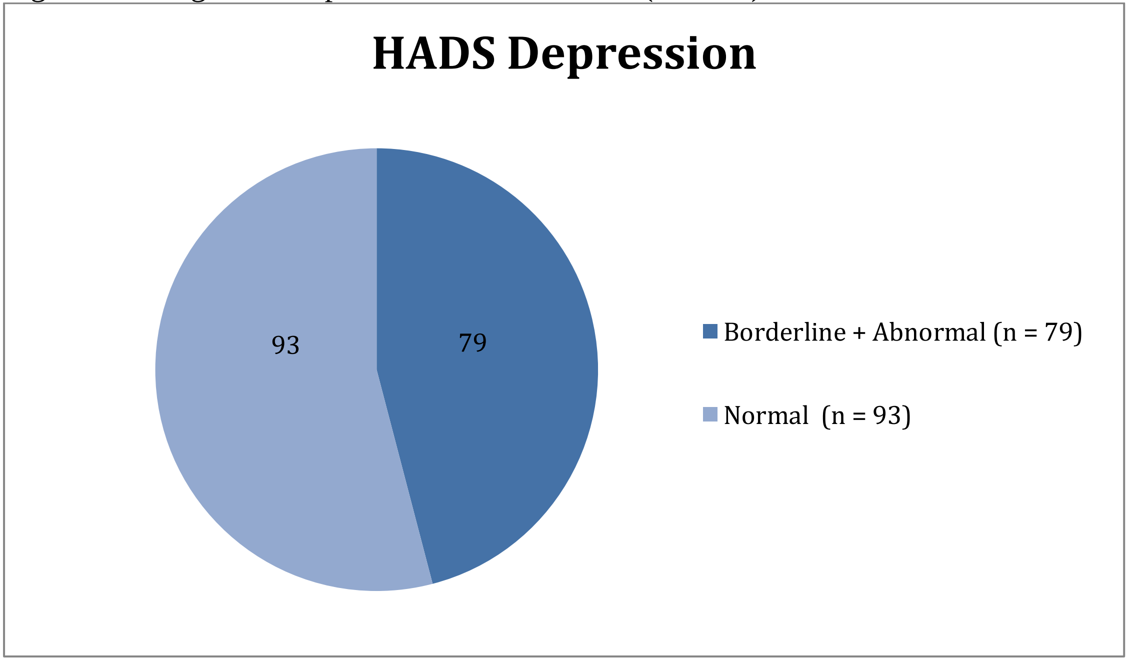
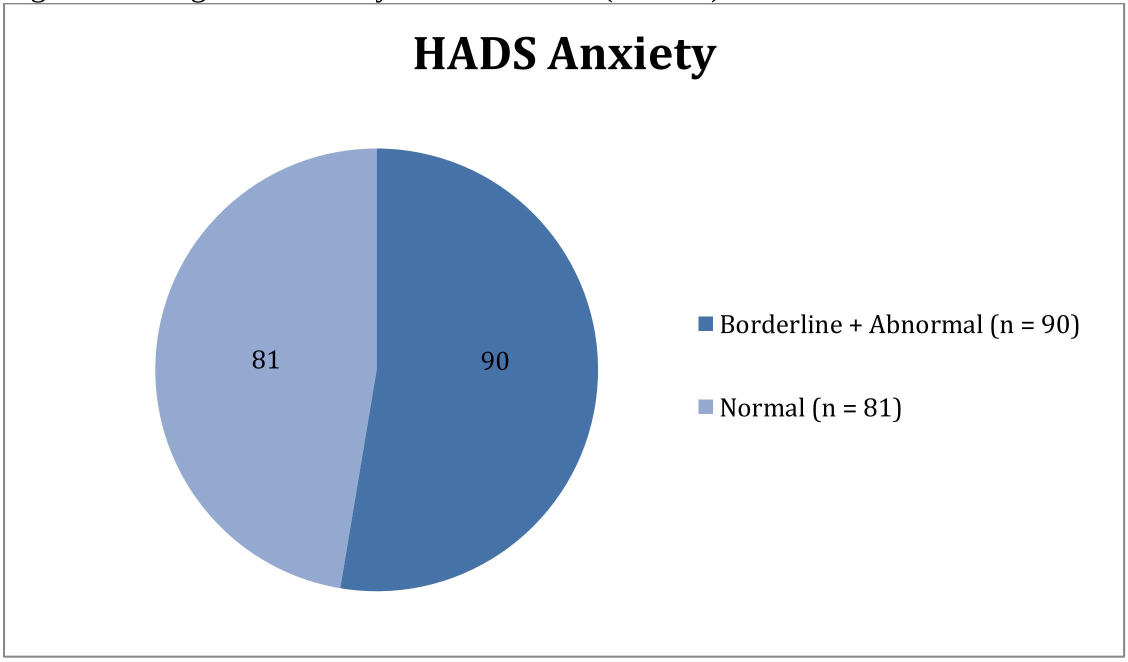


Figure 11 : Degree of Anxiety for All Patients (n = 171)



Loneliness

Distribution of loneliness scores is illustrated in Table *8* and Figures *12* and *13*. Mean loneliness score was 18.68 (*SD* = 3.98). There are currently no recommended loneliness clinical cutoffs for the ULS-8. For the purposes of this study, cutoff levels for the ULS-8 are mirrored and extrapolated from the scoring system of the *Revised UCLA Loneliness* Scale (ULS-20). The scores may be classified into low (8-14), moderate (15-21), moderately high (22-28) and high (29-36). Additionally, by classifying scores above the "moderate" threshold as recommended by Goossens et al., 2014, loneliness was documented in 79 % of the sample (*n* =135).

Figure 12: Distribution of Loneliness for all Patients (n = 171)

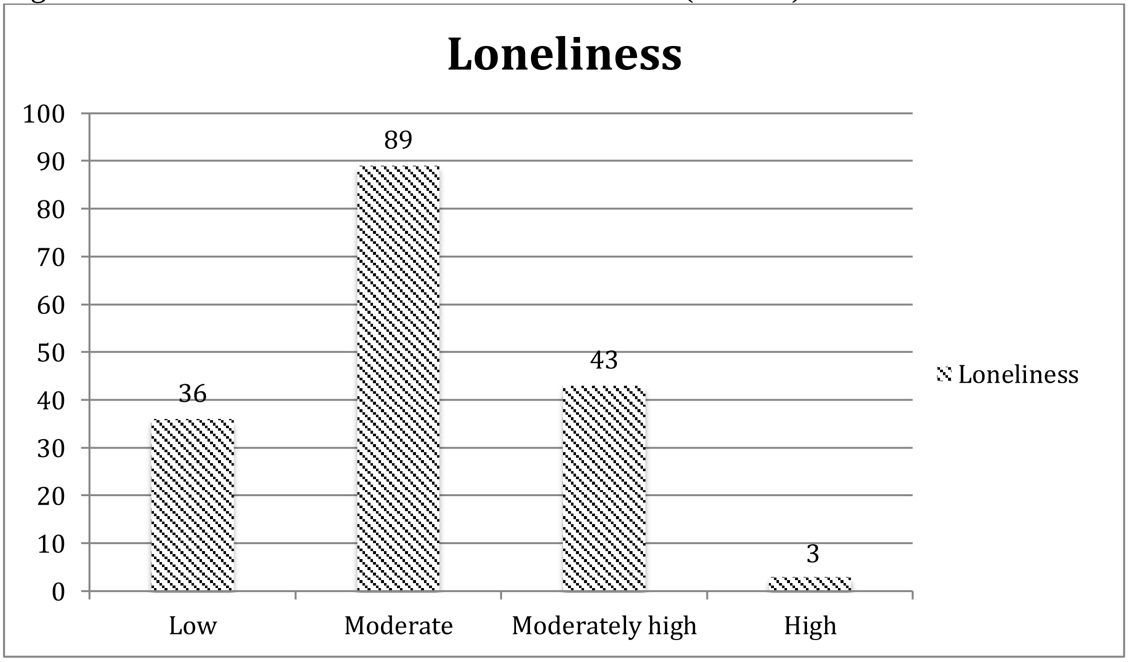
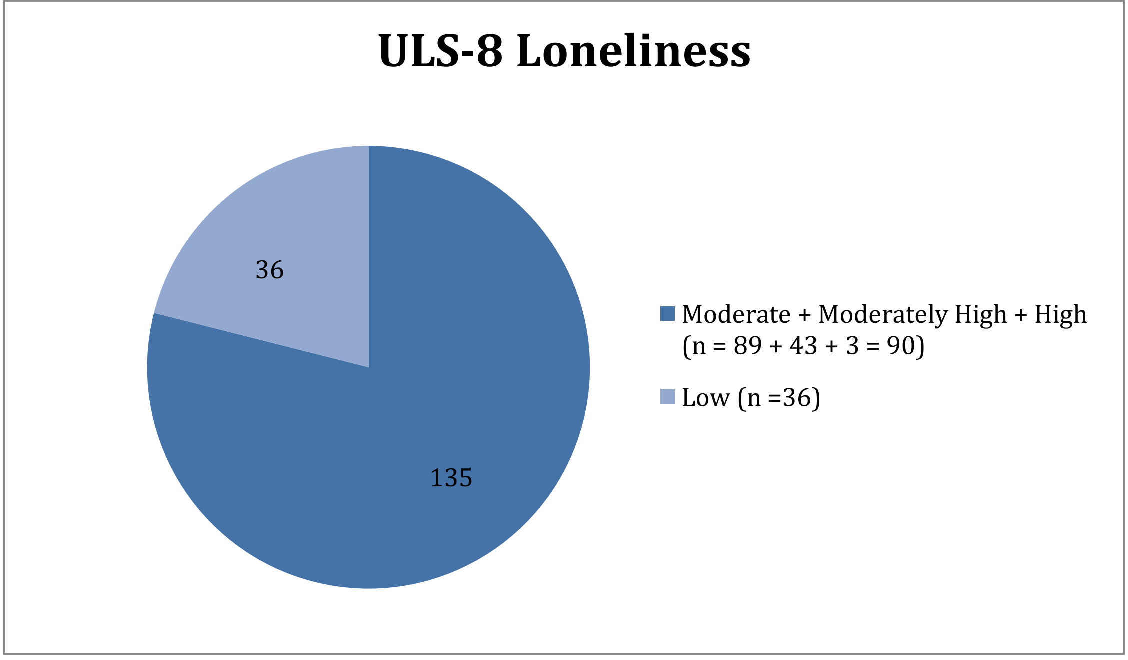


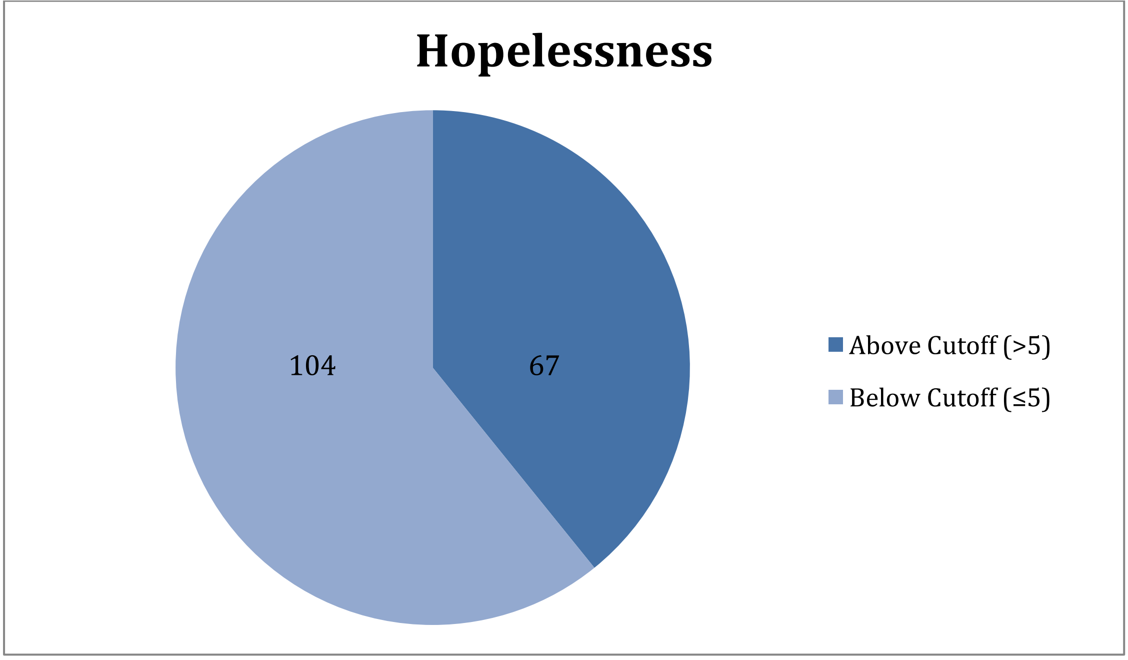
Figure 13 : Degree of Loneliness for All Patients (n = 171)



Hopelessness

Distribution of hopelessness scores is illustrated in Table *8* and Figure *14*. Mean hopelessness score of 4.48 (*SD* = 3.27) is slightly below the recommended clinical cutoff (>5; Forintos et al., 2013). Hopelessness was documented in 39% of the sample (*n* = 67).

Figure 14: Degree of Hopelessness for All Patients (n = 171)



2.1. Psychological Distress Subgroups – Demographics

Between the depression subgroups, comparisons indicate that non-depressed patients were significantly more likely to be ethnically Malay and Indian, while depressed patients were significantly more likely to be Chinese, χ^2 (2, N = 171) = 17.95, $p < .01$. No other differences were documented for other demographic variables between depressed and non-depressed patients.

Between the anxiety subgroups, comparisons indicate that non anxious patients were significantly more likely to be female than male, χ^2 (1, N = 171) = 6.04, $p = .01$. No other differences were documented for other demographic variables.

Between the loneliness subgroups, comparisons indicate that lonely patients were significantly more likely to be Chinese, χ^2 (2, N = 171) = 10.51, $p = .02$. No other differences were documented for other demographic variables.

Between the hopelessness subgroups, comparisons indicate that hopeless patients were significantly more likely to be Chinese, χ^2 (2, N = 171) = 11.12, $p = .01$. No other differences were documented for other demographic variables.

All casemix differences were subsequently controlled for in further analyses between the respective Psychological Distress subgroups. Where applicable, Levene's test of homogeneity of variances yielded equal variance (e.g. for “Age”, F= 2.80, p = .09).
The following table provides a broad overview of the demographic differences between the various psychological distress subgroups.

Table 9: Demographics of Total Sample and Psychological Distress Subgroup Comparison

	Total Sample	**Non-Depressed**	**Depressed**	***p***	**Non-Anxious**	**Anxious**	***p***	**Non-Lonely**	**Lonely**	***p***	**Non-Hopeless**	**Hopeless**	***p***
	(N=171)	(N=92)	(N=79)		(N=81)	(N=90)		(n = 36)	(n = 135)		(n = 104)	(n = 67)	
Age (Years)	58.84± 9.43	57.97±6.94	59.85 ±11.63	0.19	58.74±7.90	58.97±10.67	0.8	58.81 ± 7.0	58.84±9.89	0.98	58.37±8.37	59.57±10.88	0.41
Gender				0.55			.01**			0.07			0.25
Female	65 (38)	35 (38)	30 (38)		58 (71)	48 (53)		27 (75)	79 (59)		36 (35)	29 (43)	
Male	106 (62)	57 (62)	49 (62)		23 (29)	42 (47)		9 (25)	56 (41)		68 (65)	38 (57)	
Ethnicity				0+**			0.27			0.02*			.014*
Chinese	87 (51)	33 (36)	54 (69)		35 (42)	52 (57)		11 (31)	76 (56)		43 (41)	44 (65)	
Malay	60 (35)	42 (45)	18 (23)		33 (41)	27 (30)		16 (44)	44 (32)		46 (44)	14 (20)	
Indians/Others	24 (14)	17 (16)	6 (8)		13 (17)	11 (13)		9 (25)	15 (12)		15 (15)	9 (15)	
Education Level				0.94			0.55			0.57			0.78
No Education/Primary	85 (47)	42 (46)	39 (49)		41 (47)	40 (44)		14 (38)	67 (49)		46 (44)	35 (52)	
Secondary	66 (39)	36 (39)	30 (38)		28 (38)	38 (42)		15 (41)	51 (37)		43 (41)	23 (34)	
Tertiary	24 (14)	14 (15)	10 (12)		12 (15)	12 (14)		7 (21)	17 (14)		15 (15)	9 (14)	
Marital Status				0.49			0.42			0.09			0.59
Married	108 (63)	62 (67)	46 (58)		55 (68)	53 (58)		30 (83)	78 (57)		69 (66)	39 (58)	
Not Married	63 (37)	30 (33)	33 (42)		26 (32)	37 (42)		6 (17)	57 (43)		35 (34)	28 (42)	
Family Income													
				0.18			0.41			0.74			0.26
<S$2000	89 (52)	43 (47)	46 (58)		43 (53)	46 (51)		16 (44)	73 (54)		51 (49)	38 (57)	
≥S$2000	82 (48)	49 (53)	33 (42)		38 (47)	44 (49)		20 (56)	62 (46)		53 (51)	29 (43)	
Employment				0.31			0.76			0.14			0.41
Employed(full or part time)	37 (20)	24 (27)	13 (20)		19 (23)	18 (20)		12 (33)	25 (19)		26 (25)	11 (16)	
Unemployed	134 (80)	68 (73)	66 (80)		62 (77)	72 (80)		24 (67)	110 (81)		78 (75)	56 (84)	
Housing[1]				0.08			0.41			0.86			0.58
1 to 4 rooms	150 (88)	77 (84)	72 (91)		69 (85)	80 (88)		31 (86)	118 (87)		90 (86)	59 (88)	
5 rooms/Private	21(12)	15 (16)	7 (9)		12 (15)	9 (11)		5 (14)	26 (13)		14 (14)	7 (12)	

Data expressed as M ± SD or n (%),* $p \leq 0.05$, ** $p \leq 0.01$

1Public apartments developed by the Housing and Development Board (HDB) in Singapore that are available to Singaporeans with subsidy rates and housing loans .

2.2. Psychological Distress Subgroups - Clinical Characteristics

Mann-Whitney tests indicated that mean Kt/V levels were higher in non-anxious patients (Median = 1.60) patients than anxious patients (Median = 1.52), U = 4204.0, *p* = .03. This factor is controlled for in further analyses.

There were no significant differences between the depression, hopelessness and loneliness subgroups in the clinical parameters.

The following table provides a broad overview of the clinical characteristics difference between the various psychological distress subgroups.

Table 10: Clinical Characteristics of Total Sample and Psychological Distress Subgroup Comparison

	Total Sample	**Non-Depressed**	**Depressed**	***p***	**Non-Anxious**	**Anxious**	***p***	**Non-Lonely**	**Lonely**	***p***	**Non-Hopeless**	**Hopeless**	***p***
	(N=171)	(N=92)	(N=79)		(N=81)	(N=90)		(N = 36)	(N = 135)		(N = 104)	(N = 67)	
CCI	6.67 ± 2.15	6.36 ± 2.36	6.97 ± 1.92	0.07	6.67 ± 2.20	6.68 ± 2.12	0.96	6.94 ± 1.49	6.91 ± 1.84	0.92	6.88 ± 1.72	6.92 ± 1.84	0.75
Low (<3)	0 (0)	0 (0)	0 (0)		0 (0)	0 (0)		0 (0)	0 (0)		0 (0)	0 (0)	
Moderate (4-5)	37 (21)	23 (23)	17 (21)		14 (16)	23 (25)		5 (14)	32 (23)		22 (21)	13 (19)	
High (6-8)	108 (63)	57 (64)	49 (62)		57 (72)	52 (58)		25 (69)	82 (60)		66 (63)	44 (65)	
Very High (>8)	26 (16)	12 (13)	13 (17)		10 (12)	15 (17)		6 (17)	21 (17)		16 (16)	10 (16)	
Time on Dialysis				0.09			0.54			0.77			0.14
< 1 Year	24 (14)	17 (19)	7 (8)		13 (16)	10 (11)		5 (14)	19 (14)		19 (18)	5 (7)	
1 to 2 Years	20 (12)	8(9)	12 (15)		8 (10)	12 (13)		3 (8)	17 (13)		12 (11)	8 (12)	
> 2 Years	127 (74)	67 (72)	60 (77)		59 (74)	68 (76)		28 (78)	99 (73)		73 (71)	54 (81)	
Biochemistry (n = 168)													
Potassium (mmol/l)	4.84 ± 0.66	4.82 ± 0.61	4.84 ± 0.70	0.78	4.88 ± 0.59	4.80 ± 0.72	0.42	4.88 ± 0.51	4.83 ± 0.70	0.73	4.87 ± 0.64	4.81 ± 0.70	0.42
Creatinine (mmol/l)	8.68 ± 2.13	8.74 ± 2.16	8.53 ± 2.11	0.53	8.72 ± 2.06	8.62 ± 2.21	0.76	9.18 ± 2.55	8.54 ± 1.99	0.11	8.87 ± 2.17	8.37 ± 2.04	0.14
Phosphate (mmol/l)	4.71 ± 1.22	4.62 ± 1.22	4.82 ± 1.85	0.3	4.69 ± 1.25	4.71 ± 1.20	0.88	4.68 ± 1.30	4.78 ± 1.20	0.89	4.69 ± 1.25	4.74 ± 1.18	0.8
Hemoglobin (g/dl)	11.04 ±1.19	11.03 ± 1.15	10.98±1.25	0.75	11.15 ±1.28	10.91 ± 1.09	0.18	11.38 ± 1.18	10.95 ± 1.18	0.06	11.05 ± 1.24	11.02 ± 1.13	0.89
HbA1C (%)	8.05 ± 1.68	8.01 ± 1.93	8.09 ± 1.43	0.77	7.86 ± 1.47	8.21 ± 1.89	0.19	7.91 ± 1.20	8.09 ± 1.78	0.56	7.97 ± 1.51	8.19 ± 1.91	0.42
Kt/V	1.55 ± 0.20	1.57 ± 0.20	1.54 ± 0.21	0.48	1.52 ± 0.21	1.59 ± 0.19	.03*	1.54 ± 0.20	1.56 ± 0.21	0.63	1.56 ± 0.21	1.55 ± 2.05	0.78

Note. Data expressed as M ± SD or n (%). CCI = Charlson Comorbidity Index.*Mann-Whitney Test.

3. Health Literacy

3.1. Depression and Health Literacy

A one-way Multivariate Analysis of Variance (MANOVA) was run to determine the effect of depression on the nine dimensions of Health Literacy Questionnaire (HLQ) scores. Preliminary assumption checking revealed that there were no univariate outliers, as assessed by inspection of boxplots. All nine HLQ dimensions scores were normally distributed, as assessed by Shapiro-Wilks test ($p < .05$). There were no multicollinearity, as assessed by Pearson's Correlation (lowest $r = .19$; highest $r = .80$, all p values $<.05$). Scatterplots suggest that there were linear relationships between the nine HLQ dimension scores. There were no multivariate outliers in the data, as determined by Mahalanobis distance ($p > .001$).

There was homogeneity of variance-covariance matrices, as assessed by Box's test of equality of covariance matrices ($p < .01$). There were homogeneity of variances, as assessed by Levene's Test of Homogeneity of Variance ($p > .05$).

There was a statistically significant difference between the depression subgroups on the combined dependent variables, $F(9, 156) = 7.35$, $p = 0+$; Wilks' $\lambda = .702$; partial $h^2 = .298$. Follow-up univariate ANOVAs showed that all but one ("Having Sufficient Information") of the nine HLQ dimension scores were statistically significantly higher for non-depressed compared to depressed patients, using a Bonferroni adjusted α level of .025. These differences and their descriptives are displayed in Table 11.

Table 11: Health Literacy Scores of the Depression Subgroups, with Total Sample for Reference

Health Literacy Dimension	**Total Sample** (N=171)	**Non-Depressed** (N=92)	**Depressed** (N=79)	***p***
Feeling Understood and Supported by Healthcare Providers	3.02 ± 0.48	3.12 ± 0.42	2.87 ± 0.52	0+*
Having Sufficient Information	3.02 ± 0.44	3.06 ± 0.48	2.95 ± 0.38	.09
Actively Managing My Health	2.84 ± 0.45	2.91 ± 0.47	2.75 ± 0.41	.02*
Social Support for Health	2.98 ± 0.60	3.20 ± 0.55	2.71 ± 0.55	0+*
Appraisal of Health Information	2.66 ± 0.58	2.75 ± 0.63	2.53 ± 0.49	.02*
Ability to Actively Engage with Healthcare Providers	3.76 ± 0.77	4.05 ± 0.65	3.39 ± 0.74	0+*
Navigating the Healthcare System	3.66 ± 0.62	3.85 ± 0.62	3.41 ± 0.51	0+*
Ability to Find Good Health Information	3.53 ± 0.74	3.71 ± 0.77	3.28 ± 6.07	0+*
Understanding Health Information Enough to Know what to Do	3.57 ± 0.83	3.71 ± 0.89	3.35 ± 0.71	.02*

Note. Data expressed as *M* ± *SD.*

3.2. *Anxiety and Health Literacy*

One-way MANOVA was run to determine the effect of anxiety on the nine dimensions of HLQ scores. There was homogeneity of variance-covariance matrices, as assessed by Box's test of equality of covariance matrices ($p = .01$). There were homogeneity of variances, as assessed by Levene's Test of Homogeneity of Variance ($p > .05$).

There was a statistically significant difference between the anxiety subgroups on the combined dependent variables, $F(9, 156) = 6.18$, $p = 0+$; Wilks' $\lambda = .737$; partial $h^2 = .263$. Follow-up univariate ANOVAs showed that of the nine HLQ dimensions, five dimension scores ("Healthcare Provider Support", "Social Support", "Ability to Actively Engage with Healthcare Providers", "Navigating Healthcare System" and "Ability to Find Good Health information") were statistically significantly higher for non-anxious compared to anxious patients, using a Bonferroni adjusted α level of .025. These differences and their descriptives are displayed in Table 12.

Table 12: Health Literacy Scores of the Anxiety Subgroups, with Total Sample for Reference

Health Literacy Dimension	**Total Sample** (N=171)	**Non-Anxious** (N=81)	**Anxious** (N=90)	***p***
Feeling Understood and Supported by Healthcare Providers	3.02 ± 0.48	3.08 ± 0.46	2.93 ± 0.48	0+*
Having Sufficient Information	3.02 ± 0.44	3.07 ± 0.40	2.97± 0.44	.16
Actively Managing My Health	2.84 ± 0.45	2.87 ± 0.47	2.82 ± 0.42	.44
Social Support for Health	2.98 ± 0.60	3.15 ± 0.62	2.81 ± 0.54	0+*
Appraisal of Health Information	2.66 ± 0.58	2.74 ± 0.59	2.60 ± 0.54	.11
Ability to Actively Engage with Healthcare Providers	3.76 ± 0.77	4.10 ± 0.69	3.43 ± 0.71	0+*
Navigating the Healthcare System	3.66 ± 0.62	3.90 ± 0.60	3.44 ± 0.56	0+*
Ability to find Good Health Information	3.53 ± 0.74	3.78 ± 0.73	3.33 ± 0.68	0+*
Understanding Health information Enough to Know what to Do	3.57 ± 0.83	3.69 ± 0.92	3.50 ± 0.71	.13

Note. Data expressed as $M \pm SD$.

3.3. *Loneliness and Health Literacy*

One-way MANOVA was run to determine the effect of loneliness on the nine dimensions of HLQ scores. There was homogeneity of variance-covariance matrices, as assessed by Box's test of equality of covariance matrices ($p = .0+$). There were homogeneity of variances, as assessed by Levene's Test of Homogeneity of Variance ($p > .05$). However, the HLQ dimension of "Navigating the Healthcare System" did not test for homogeneity of variance, F (1, 164) = 10.99, ($p = .01$) even after transforming for the skewness. Hence, the level of statistical significance (a) for "Navigating the Healthcare System" was set at $p \leq .01$ instead of $\leq .05$ in univariate analysis.

There was a statistically significant difference between the loneliness subgroups on the combined dependent variables, $F(9, 156) = 2.19$, $p = 03$; Wilks' $\lambda = .888$; partial $h^2 = .112$. Follow-up univariate ANOVAs showed that of the nine HLQ dimensions, all but one of the dimension scores ("Actively Managing My Health") were significantly higher for non-lonely compared to lonely patients, using a Bonferroni adjusted α level of .025. These differences are displayed in Table 13.

Table 13: Health Literacy Scores of the Loneliness Subgroups, with Total Sample for Reference

Health Literacy Dimension	**Total Sample** (N=171)	**Non-Lonely** (N=36)	**Lonely** (N=135)	***p***
Feeling Understood and Supported by Healthcare Providers	3.02 ± 0.48	3.18 ± 0.44	2.96 ± 0.48	.02
Having Sufficient Information	3.02 ± 0.44	3.17 ± 0.38	2.98 ± 0.43	.02
Actively Managing My Health	2.84 ± 0.45	3.21 ± 0.55	2.91 ± 0.60	.30
Social Support for Health	2.98 ± 0.60	3.22 ± 0.62	2.91 ± 0.60	.01
Appraisal of Health Information	2.66 ± 0.58	2.90 ± 0.54	2.60 ± 0.56	.01
Ability to Actively Engage with Healthcare Providers	3.76 ± 0.77	4.14 ± 0.59	3.65 ± 0.79	0+
Navigating the Healthcare System*	3.66 ± 0.62	4.01 ± 0.43	3.57 ± 0.63	0+
Ability to find Good Health Information	3.53 ± 0.74	3.78 ± 0.73	3.33 ± 0.68	0+
Understanding Health Information Enough to Know what to Do	3.57 ± 0.83	3.69 ± 0.92	3.50 ± 0.71	0+

Note. Data expressed as *M* ± *SD*. * a level set at .01

3.4. Hopelessness and Health Literacy

One-way MANOVA was run to determine the effect of hopelessness on the nine dimensions of HLQ scores. There was homogeneity of variance-covariance matrices, as assessed by Box's test of equality of covariance matrices ($p = .02$). There were homogeneity of variances, as assessed by Levene's Test of Homogeneity of Variance ($p > .05$).

There was a statistically significant difference between the hopelessness subgroups on the combined dependent variables, $F(9, 156) = 2.19$, $p = 0+$; Wilks' $\lambda = .762$; partial $\eta^2 = .238$.

Follow-up univariate ANOVAs showed that of the nine HLQ dimensions, all but three of the dimension scores ("Having Sufficient Information", "Actively Managing My Health" and "Appraisal of Health Information") were significantly higher for non-hopeless compared to hopeless patients, using a Bonferroni adjusted α level of .025. These differences are displayed in Table 14.

Table 14: Health Literacy Scores of the Hopelessness Subgroup, with Total Sample for Reference

Health Literacy Dimension	**Total Sample** (N=171)	**Non-Hopeless** (N=104)	**Hopeless** (N=67)	***p***
Feeling Understood and Supported by Healthcare Providers	3.02 ± 0.48	3.04 ± 0.46	2.94 ± 0.48	.18
Having Sufficient Information	3.02 ± 0.44	3.03 ± 0.44	3.00 ± 0.40	.68
Actively Managing My Health	2.84 ± 0.45	2.88 ± 0.47	2.79 ± 0.41	.21
Social Support for Health	2.98 ± 0.60	3.13 ± 0.51	2.73 ± 0.64	0+
Appraisal of Health Information	2.66 ± 0.58	2.75 ± 0.62	2.55 ± 0.47	.03
Ability to Actively Engage with Healthcare Providers	3.76 ± 0.77	3.98 ± 0.72	3.38 ± 0.73	0+
Navigating the Healthcare System*	3.66 ± 0.62	3.81 ± 0.63	3.43 ± 0.53	0+
Ability to find Good Health Information	3.53 ± 0.74	3.72 ± 0.77	3.328± 0.61	0+
Understanding Health Information Enough to Know What to Do	3.57 ± 0.83	3.74 ± 0.85	3.35 ± 0.72	0+

Note. Data expressed as *M* ± *SD*

3.5. Summary of Health Literacy vs. Psychological Distress

For ease of reference, Table 15 illustrates all statistically significant differences between the Psychological Distress subgroups.

Table 15. Summary of Significant Differences: Health Literacy Scores vs. Psychological Distress

Health Literacy Dimension	**Depression**	**Anxiety**	**Loneliness**	**Hopelessness**
Feeling Understood and Supported by Healthcare Providers	✓	✓	✓	
Having Sufficient Information			✓	
Actively Managing My Health	✓			
Social Support for Health	✓	✓	✓	✓
Appraisal of Health Information	✓		✓	✓
Ability to Actively Engage with Healthcare Providers	✓	✓	✓	✓
Navigating the Healthcare System	✓	✓	✓	✓
Ability to Find Good Health Information	✓	✓	✓	✓
Understanding Health Information Enough to Know what to Do	✓		✓	✓

Note. ✓ = Univariate statistically significant difference. All differences are uni-directional (i.e. distressed subgroup scored lower on all HLQ Dimensions).

4. Nutritional Quality of Life

The mean NSQOL score of the study sample was 9.52 (SD = 1.86). Population means are unavailable as the use of NSQOL has been used primarily in clinical populations. However, this mean NSQOL score in the present study is comparable to other studies performed on similar cohorts (e.g. Han et al., 2012).

Table *16* illustrates the results of a one-way ANOVA indicated that NSQOL scores were statistically different for the depression subgroup, *F* (1,169) = 11.77, *p* < .01 and the anxiety subgroup, *F* (1,169) = 15.36, *p* < .01. ANCOVA tests controlling the influence of Kt/V levels (for Anxiety subgroup), gender and ethnicity yielded similar results.

Table *17* illustrates the ANOVA results for Loneliness and Hopelessness subgroups. Results indicate that NSQOL scores were statistically different for the Loneliness subgroup, *F* (1,169) = 16.38, *p* < .01 and the hopeless subgroup *F* (1,169) = 8.63, *p* < .01. ANCOVA tests controlling the influence of gender and ethnicity yielded similar results.

Table 16
Nutritional QOL Results in Total Sample and HADS Subgroups

	Total (*n* =171)	Non-Depressed (*n* = 92)	Depressed (*n* = 79)	*p*	Non-Anxious (n – 81)	Anxious (n = 90)	*p*
NSQOL	9.52 ± 1.86	10.19 ± 3.48	8.59 ±3.08	0+	10.51 ±3.46	8.60 ±3.06	0+

Note. Data expressed as *M* ± *SD*. NSQOL = Nutrition-Specific Quality of Life.

Table 17
Nutritional QOL Results in Total Sample, Loneliness and Hopelessness Subgroups

	Total (*n* =171)	Non-Lonely (*n* = 36)	Lonely (*n* = 135)	*p*	Non-Hopeless (n – 104)	Hopeless (n = 67)	*p*
NSQOL	9.52 ± 1.86	10.19 ± 3.48	8.59 ±3.08	0+	10.12 ±3.42	8.59 ±3.13	0+

Note. Data expressed as *M* ± *SD*. NSQOL = Nutrition-Specific Quality of Life.

5. Illness Perception

The mean score for BIPQ-Diabetes was 38.89 (out of a maximum score of 60) (SD = 7.26) and the mean score for BIPQ-Dialysis is 41.23 (out of a maximum score of 60) (SD = 7.74), indicating a degree of negative illness perception. One-way ANOVA comparison between scores on BIPQ-Diabetes and BIPQ-Dialysis revealed that patients had greater negative illness perception of dialysis, *F* (1, 339) = 7.83, *p* = .01 (see superscript “[1]” in table 18).

The mean MULTIPleS – Prioritization score was 12.46 (out of a maximum score of 24) (SD = 7.09) and mean MULTIPleS-Treatment Burden Score was 12.19 (out of a maximum score of 36) (SD = 5.62). No cutoff or categorizations are available. The item with the highest mean score, out of 6 in the prioritization scale was “One *of my conditions has more of an impact on my life”* (M = 3.76). The item with the highest mean score, out of 6, in the treatment burden scale was “*I feel so overwhelmed by the treatment for one condition that it is hard to manage any others”*(M = 3.88).

Anxiety and Depression

Table 18 illustrates the results of a one-way ANOVA indicated that BIPQ-Dialysis scores were significantly higher for the depressed subgroup compared to the non-depressed subgroup, *F* (1,169) = 6.37, *p* = .01. No other differences are documented in other BIPQ scores within the depression and anxiety subgroups.

One-way ANOVA results indicate that MULTIPleS-Treatment Burden scores were significantly higher for the depressed subgroup, *F* (1, 169) = 13.57, *p* = 0+. Both MULTIPleS-Treatment Burden, *F* (1,169) = 11.48, *p* = 0+, and MULTIPleS-Prioritization scores *F* (1,169) = 4.10, *p* = 05 are significantly higher for the anxious subgroup. ANCOVA tests controlling the influence of ethnicity yielded similar results.

Table 18

Illness Perception Results in Total Sample and HADS Subgroups

	Total (*n* =171)	Non-Depressed (*n* = 92)	Depressed (*n* = 79)	*p*	Non-Anxious (n = 81)	Anxious (n = 90)	*p*
BIPQ[1]							
Diabetes	38.89 ± 7.26	38.28 ± 6.33	39.53 ± 8.05	.27	38.63 ± 6.53	39.37 ± 7.91	.51
Dialysis	41.23 ± 7.74	39.64 ± 7.01	42.61 ± 7.98	.01*	40.44 ± 7.32	42.29 ± 8.03	.12
MULTIPleS							
Prioritization	12.46 ± 7.09	11.59 ± 6.29	12.87 ± 4.79	0.14	11.28 ± 5.95	13.01 ± 5.25	.05*
Treatment Burden	12.19 ± 5.62	10.93 ± 7.78	14.54 ± 5.57	0+*	10.63 ± 7.78	14.15 ± 6.01	0+*

Note. Data expressed as *M* ± *SD*. Higher value indicates greater negative illness perception and/or treatment burden. [1]Significant difference found for BIPQ-Diabetes and BIPQ-Dialysis.

Loneliness and Hopelessness

Table 19 illustrates the ANOVA results for Loneliness and Hopelessness subgroups. Results indicate that BIPQ scores were significantly higher in the Hopeless subgroup, *F* (1,169) = 4.39, *p* = .04. In addition, one-way ANOVA results indicate that MULTIPleS-Treatment Burden scores were significantly higher in the lonely subgroup, *F* (1,169) = 12.74, *p* = 0+ and for the hopeless subgroup, *F* (1,169) = 8.74, *p* = 0+. ANCOVA tests controlling the influence of ethnicity and gender yielded similar results. No other differences are documented in other Illness perception scores within the lonely and hopeless subgroups.

Table 19

Illness Perception Results in Total Sample, Loneliness and Hopelessness Subgroups

	Total (*n* =171)	Non-Lonely (*n* = 36)	Lonely (*n* = 135)	*p*	Non-Hopeless (n = 104)	Hopeless (n = 67)	*p*
BIPQ							
Diabetes	38.89 ± 7.26	40.60 ± 7.26	43.58 ± 9.08	.08	39.70 ± 7.34	42.322 ± 7.91	.04*
Dialysis	41.23 ± 7.74	38.62 ± 6.92	39.88 ± 8.42	.08	38.46 ± 6.42	39.70 ± 7.34	.55
MULTIPLES							
Prioritization	12.46 ± 7.09	11.38 ± 6.56	12.40 ± 5.35	0.34	11.86 ± 6.06	12.70 ± 4.88	.34
Treatment Burden	12.19 ± 5.62	8.83 ± 7.72	13.42 ± 6.62	0+*	11.20 ± 7.44	14.41 ± 6.08	0+*

Note. Data expressed as *M* ± *SD*. Higher value indicates greater negative illness perception and/or treatment burden.

6. Adherence

A summary of the patients' self-reported adherence results is included in Table *20.* Forty-seven percent (47%), twenty-six percent (26%) and twenty-seven percent (27%) of the study sample reported high, medium and low adherence to medication in the MMAS respectively.

Thirty-eight percent (38%) reported some difficulty in following their prescribed diet in the ADAT.

In SDSCA, study participants reported that out of the last seven days, a mean of 5.08 (SD=2.01) days was spent following their diet plans and a mean of 6.99 (SD = 0.58) days was spent following their recommended diabetic medication.

In DDFQ-diet, participants reported that the frequency of deviation from their dietary guidelines within the recent 2 weeks to be M = 3.48 (SD = 1.48) days, median = 2 days, with the mean degree of deviation from dietary guidelines to be 1.09 (SD = 0.96) days out of a maximum possible of 14 days. In DDFQ-fluid, participants reported that the frequency of deviation from their fluid guidelines within the recent 2 weeks to be M = 3.56 (SD = 1.09) days, median = 2 days, with the mean reported degree of deviation from fluid guidelines to be 1.13 (SD = 1.09) days out of a maximum possible of 14 days.

Anxiety and Depression

Table *20* illustrates the self-reported adherence outcomes in the Depression and Anxiety subgroups. Between the depression subgroups, comparisons indicate that non-depressed patients were significantly more likely to report no difficulty in following their diet on the ADAT, χ^2 (2, N = 171) = 13.95, p = .01. No other differences were documented for other adherence variables between depressed and non-depressed patients. ANCOVA tests controlling the influence of ethnicity and Kt/V levels yielded a similar result.

Between the anxiety subgroups, comparisons indicate that non-anxious patients were significantly more likely to report no difficulty in following their diet on the ADAT, χ^2 (2, *N* = 171) = 15.22, *p* = .0. No other differences were documented for other adherence variables between anxious and non-anxious patients. ANCOVA tests controlling the influence of gender yielded a similar result.

Table 20

Self-Reported Adherence Results in the HADS Subgroups

	Total (*n* =171)	Non-Depressed (*n* = 92)	Depressed (*n* = 79)	*p*	Non-Anxious (n = 81)	Anxious (n = 90)	*p*
MMAS				.69			.06
High (0)	80 (47)	45 (49)	35 (45)		44 (54)	37 (41)	
Medium (1,2)	45 (26)	21 (23)	24 (30)		15 (19)	30 (33)	
Low (>2)	46 (27)	25 (28)	20 (25)		22 (27)	23 (26)	
ADAT				.01*			0+*
Difficulty Following Diet	65 (38)	27 (29)	38 (48)		22 (27)	43 (48)	
No Difficulty Following Diet	106 (62)	65 (71)	41 (52)		59 (73)	47 (52)	
SDSCA							
General Diet	5.08 ± 0.41	5.11 ± 0.41	5.05 ± 0.40	.85	5.23 ± 0.39	4.94 ± 0.44	.34
Diabetic Medication	6.99 ± 0.01	6.87 ± 0.03	6.88 ± 0.01	.91	6.90 ± 0.01	6.86 ± 0.03	.70
DDFQ- Diet							
Frequency of Deviations	3.48 ± 1.48 (Median = 2)	3.63 ± 4.33	3.32 ± 4.01	.63	3.37 ± 0.48	4.01 ± 0.43	.44
Degree of Deviation	1.09 ± 0.96	1.01 ± 0.91	1.18 ± 0.90	.23	0.93 ± 0.82	1.23 ± 0.96	.03*
DDFQ-Fluid							
Frequency of Deviations	3.56 ± 4.39 (Median = 2)	3.62 ± 4.38	3.29 ± 4.41	.47	3.41 ± 0.49	3.68 ± 0.46	.43
Degree of Deviation	1.13 ± 1.09	1.18 ± 1.05	1.06 ± 1.08	.46	0.92 ± 0.10	1.17 ± 0.12	.17

Note. Data expressed as *M* ± *SD.* Scores of reversed items are recorded.
MMAS = Morisky Medication Adherence Scale. SDSCA = Summary of Diabetes Self-Care Activities revised version. DDFQ = Dialysis Diet and Fluid Non-Adherence Questionnaire.

Loneliness and Hopelessness

Table *21* illustrates the self-reported adherence outcomes in the loneliness and hopelessness subgroups. No differences in any of the adherence dimensions were documented for any of the adherence variables in the loneliness subgroup. ANCOVA tests controlling the influence of ethnicity yielded similar results.

Between the hopelessness subgroups, comparisons indicate that hopeless patients were significantly more likely to report difficulty in following their diet on the ADAT, χ^2 (2, N = 171) = 13.12, p = .0+. No other differences were documented for other adherence variables. ANCOVA tests controlling the influence of ethnicity yielded similar results.

Table 21

Self-Reported Adherence Results in the Loneliness and Hopelessness Subgroups

	Total (*n* =171)	Non-Lonely (*n* = 36)	Lonely (*n* = 135)	*p*	Non-Hopeless (n = 104)	Hopeless (n = 67)	*p*
MMAS[1]				.55			.21
High (0)	80 (47)	19 (53)	61 (45)		47 (45)	27 (40)	
Medium (1,2)	45 (26)	10 (27)	35 (36)		28 (27)	26 (38)	
Low (>2)	4627)	7 (20)	38 (19)		29 (28)	14 (22)	
ADAT				.12			0+*
Difficulty Following Diet	65 (38)	27 (75)	102 (76)		33 (32)	39 (58)	
No Difficulty Following Diet	106 (62)	9 (25)	33 (24)		71 (68)	28 (42)	
SDSCA							
General Diet	5.08 ± 0.41	5.16 ± 0.39	5.05 ± 0.43	.78	5.14 ± 0.35	4.98 ± 0.46	.34
Diabetic Medication	6.99 ± 0.01	6.99 ± 0.01	6.97 ± 0.01	.93	6.97 ± 0.01	6.99 ± 0.01	.32
DDFQ- Diet							
Frequency of Deviations	3.48 ± 1.48 (Median = 2)	3.52 ± 4.13	3.42 ± 3.82	.71	3.33 ± 0.41	3.64 ± 0.44	.44
Degree of Deviation	1.09 ± 0.96	1.04 ± 0.95	1.19 ± 0.92	.14	1.03 ± 0.82	1.14 ± 0.96	.24
DDFQ-Fluid							
Frequency of Deviations	3.56 ± 4.39 (Median = 2)	3.59 ± 4.38	3.52 ± 4.31	.43	3.45 ± 0.29	3.62 ± 0.39	.43
Degree of Deviation	1.13 ± 1.09	1.14 ± 1.15	1.10 ± 1.02	.55	0.92 ± 0.10	1.17 ± 0.12	.17

Note. Data expressed as *M* ± *SD.* Scores of reversed items are recorded.[1]Mann-Whitney U test
MMAS = Morisky Medication Adherence Scale. SDSCA = Summary of Diabetes Self-Care Activities revised version. DDFQ = Dialysis Diet and Fluid Non-Adherence.

Part III.

Biopsychosocial Determinants of Psychological Distress

Part III presents results with respect to study aim **3.** Hierarchical stepwise logistic regression models for (1) Depression, (2) Anxiety, (3) Loneliness and (4) Hopelessness will be presented in the respective order.

Depression

Univariate analyses. Results indicating univariate association between demographics, clinical and psychosocial variables with depression that were performed in Part II of the present study are summarized in Table *22A*. Significant associations were mainly found for demographic and psychological variables. In consideration of results from previous univariate comparisons, Malays and Indians/Others have been combined into an independent variable level (Non-Chinese) to increase the predictive power of ethnicity.

Table 22A

Factors Affecting Depression Based on Biopsychosocial factors in Univariate Analyses

	Non-Depressed (n = 79)	Depressed (n = 92)	*p*
Ethnicity			0+
Chinese	33 (51)	54 (69)	
Non-Chinese	59 (49)	24 (31)	
HLQ			
Feeling Understood and Supported by Healthcare Providers	3.12 ± 0.42	2.87 ± 0.52	0+
Actively Managing My Health	2.91 ± 0.47	2.75 ± 0.41	.02
Social Support for Health	3.20 ± 0.55	2.71 ± 0.55	0+
Appraisal of Health Information	2.75 ± 0.63	2.53 ± 0.49	.02
Ability to Actively Engage with Healthcare Providers	4.05 ± 0.65	3.39 ± 0.74	0+
Navigating the Healthcare System	3.85 ± 0.62	3.41 ± 0.51	0+
Ability to find Good Health Information	3.71 ± 0.77	3.28 ± 6.07	0+
Understanding Health Information Enough to Know what to Do	3.71 ± 0.89	3.35 ± 0.71	.02
NSQOL	10.19 ± 3.48	8.59 ±3.08	0+
BIPQ - Dialysis	39.64 ± 7.01	42.61 ± 7.98	.01
MULTIPLES – Treatment Burden	10.93 ± 7.78	14.54 ± 5.57	0+
ADAT			.01
Difficulty following diet	27 (29)	38 (48)	
No difficulty following diet	65 (71)	41 (52)	

Note. Data expressed as *M* ± *SD* or *n* (%). HLQ = Health Literacy Questionnaire. NSQOL = Nutrition-Specific Quality of Life. BIPQ = Brief Illness Perception Questionnaire. MULTIPLES = Multimorbidity Illness Perception Scale. ADAT = Appetite and Diet Assessment Tool.

Multivariate Analysis. Depression (as a binary variable) was regressed to ethnicity and psychosocial variables in two separate logistic regression models. Only variables associated with depression were entered as potential predictors (See Table *22A*). Demographic variables were entered on the first step, followed by psychosocial variables on the second step. Nagelkerke's R^2 was used to assess how much variance in depression could be explained by the regression models. Forward: Likelihood Ratio was used to select each variable. Table *22B* presents the final regression models for depression.

The final logistic regression model included four variables: ethnicity, HLQ-Ability to Actively Engage with HCP, HLQ Social Support and NSQOL (Omnibus $\chi^2 = (4, n = 171) = 63.64$, $p = 0+$, Nagelkerke $R^2 = .43$. Chinese had 2.48 times *more* likelihood to exhibit depression (scoring ≥ 8 on the HADS-Depression) than the non-Chinese ($\beta = 0.91$, OR =

2.48, CI [2.33, 2.54], *p* = 0+). An increase in one point of score on “HLQ-Ability to actively engage with HCP” was associated with 1.47 times (or 47%) *less* likelihood of exhibiting depression (β = -1.09, OR = 0.68, CI [0.21, 0.42] *p* = 0+.). An increase in one point of score on “HLQ – Social Support” was associated with a 1.49 times (or 49%) *less* likelihood of exhibiting depression (β = -1.21, OR = 0.67, CI [0.28, 0.36], *p* = .05). Additionally, an increase in one point of score on NSQOL was associated with 1.07 times 7% *less* likelihood of exhibiting depression (β = -0.50, OR = 0.93, CI [0.87,0.98], *p* = .05). The final model was able to explain 43% (Nagelkerke R^2) of the variance in depression and correctly classified 78% of the cases.

Table 22B
Predictors of Depression in Stepwise Logistic Regression

Dependent variable: HADS-Depression (0 = Non-depressed, 1 = Depressed)

Step	Predictor	β	OR	Nagelkerke R^2	χ^2	*p*
1	Chinese (vs Non-Chinese)	0.91**	2.48	.27	38.02	0+**
2	HLQ – Actively Engage with HCP	−1.09**	1.47	.43	63.64	0+**
	HLQ – Social Support	- 1.21*	1.49			
	NSQOL	- 0.50*	1.07			

Note. Hierarchical stepwise logistic regressions were used. OR = Odds Ratio. HLQ = Health Literacy Questionnaire. NSQOL = Nutrition Specific Quality of Life.
$^{*}p < .05$. $^{**}p < .01$.

Anxiety

Univariate Analyses. Results examining the demographical, clinical and psychosocial associated with anxiety with observed significant results are summarized in Table 23A.

Table 23A

Factors Affecting Anxiety Based on Biopsychosocial factors in Univariate Analyses

	Non-Anxious (n = 81)	Anxious (n = 90)	*p*
Gender			.01
Male	58 (71)	48 (53)	
Female	23 (29)	42 (47)	
Kt/V	1.53 ± 0.21	1.59 ± 0.19	.01
HLQ			
Feeling Understood and Supported by Healthcare Providers	3.08 ± 0.46	2.93 ± 0.48	0+
Social Support for Health	3.15 ± 0.62	2.81 ± 0.54	0+
Ability to Actively Engage with Healthcare Providers	4.10 ± 0.69	3.43 ± 0.71	0+
Navigating the Healthcare System	3.90 ± 0.60	3.44 ± 0.56	0+
Ability to Find Good Health Information	3.78 ± 0.73	3.33 ± 0.68	0+
NSQOL	10.51 ±3.46	8.60 ±3.06	0+
MULTIPLES - Prioritization	11.28 ± 5.95	13.01 ± 5.25	.05
MULTIPLES – Treatment Burden	10.63 ± 7.78	14.15 ± 6.01	0+
ADAT			0+
Difficulty following diet	22 (27)	43 (48)	
No difficulty following diet	59 (73)	47 (52)	
DDFQ – Degree of Deviation	0.93 ± 0.82	1.23 ± 0.96	.03

Note. Data expressed as *M* ± *SD* or *n* (%). HLQ = Health Literacy Questionnaire. NSQOL = Nutrition-Specific Quality of Life. BIPQ = Brief Illness Perception Questionnaire. MULTIPLES = Multimorbidity Illness Perception Scale. ADAT = Appetite and Diet Assessment Tool. DDFQ = Diabetic Diet and Fluid Non-adherence Questionnaire.

Multivariate Analysis. Anxiety (as a binary variable) was regressed to gender, Kt/V levels and psychosocial variables in three separate logistic regression models. Only variables associated with anxiety were entered as potential predictors. Demographic variables (gender) were entered on the first step; clinical variables (Kt/V levels) were entered on the second step, followed by psychosocial variables on the third step. Nagelkerke's R^2 was used to assess how much variance in anxiety could be explained by the regression models. Forward: Likelihood Ratio was used to select each variable. Table 23B presents the final regression models for anxiety.

The final logistic regression model included four variables: gender, Kt/V, HLQ-Actively Managing my Health, and NSQOL (Omnibus χ^2 = (4, n = 171) = 38.67, *p* = 0+, Nagelkerke R^2 = .28. Males had 1.11 times (or 11%) *less* likelihood to report anxiety (scoring ≥ 8 on the HADS-Anxiety) than females (β = -0.11, OR = 1.11, CI [0.92, 1.18], *p* = .02). A decrease in 0.1 mL of Kt/V was associated with a 4.46 times *more* likelihood of reporting Anxiety (β = -1.82, OR = 4.46, CI [4.13, 4.66], *p* = .04). An increase in one point of score on "HLQ-Actively Managing my Health" was associated with 1.75 (or 75%) times *less* likelihood of reporting anxiety (β = -1.11, OR = 1.75, CI [1.43, 2.03] *p* = 0+.). Additionally, an increase in one point of score on NSQOL was associated with 4.94 times *less* likelihood of reporting anxiety (β = -0.12, OR = 4.94, CI [4.35, 5.44], *p* = .0+). The final model was able to explain 28% (Nagelkerke R^2) of the variance in anxiety and correctly classified 79% of the cases.

Table 23B
Predictors of Anxiety in Stepwise Logistic Regression

Dependent variable: HADS-Anxiety (0 = Non-Anxious, 1 = Anxious)

Step	Predictor	*β*	OR	Nagelkerke R^2	χ^2	*p*
1	Male (vs Female)	-0.11*	1.11	.21	28.59	.02
2	Kt/V	-1.82*	4.46	.25	34.08	.04
3	HLQ – Actively Managing my Health	- 1.11**	1.75	.28	38.67	0+
	NSQOL	- 0.12**	4.93			

Note. Hierarchical stepwise logistic regressions were used. OR = Odds Ratio. HLQ = Health Literacy Questionnaire. NSQOL = Nutrition Specific Quality of Life.
$^{*}p < .05$. $^{**}p < .01$.

Loneliness

Univariate Analyses. Results examining the demographical, clinical and psychosocial associated with loneliness with observed significant results are summarized in Table 24A.

Table 24A

Factors Affecting Loneliness Based on Biopsychosocial factors in Univariate Analyses

	Non-Lonely (n = 36)	Lonely (n = 135)	*p*
Gender			.02
Chinese	11 (31)	76 (56)	
Non-Chinese	25 (69)	59 (44)	
HLQ			
Feeling Understood and Supported by Healthcare Providers	3.18 ± 0.44	2.96 ± 0.48	.02
Having Sufficient Information	3.17 ± 0.38	2.98 ± 0.43	.02
Social Support for Health	3.22 ± 0.62	2.91 ± 0.60	.01
Appraisal of Health Information	2.90 ± 0.54	2.60 ± 0.56	.01
Ability to Actively Engage with Healthcare Providers	4.14 ± 0.59	3.65 ± 0.79	0+
Navigating the Healthcare System	4.01 ± 0.43	3.57 ± 0.63	0+
Ability to find Good Health Information	3.78 ± 0.73	3.33 ± 0.68	0+
Understanding Health Information Enough to Know what to Do	3.69 ± 0.92	3.50 ± 0.71	0+
NSQOL	10.19 ± 3.48	8.59 ±3.08	0+
MULTIPLES – Treatment Burden	8.83 ± 7.72	13.42 ± 6.62	0+

Note. Data expressed as *M* ± *SD* or *n* (%). HLQ = Health Literacy Questionnaire. NSQOL = Nutrition-Specific Quality of Life. BIPQ = Brief Illness Perception Questionnaire. MULTIPLES = Multimorbidity Illness Perception Scale.

Multivariate Analysis. Loneliness (as a binary variable) was regressed to ethnicity and psychosocial variables in two separate logistic regression models. Only variables associated with loneliness were entered as potential predictors. Ethnicity was entered on the first step followed by psychosocial variables on the second step. Nagelkerke's R^2 was used to assess how much variance in loneliness could be explained by the regression models. Forward: Likelihood Ratio was used to select each variable. Table 24B presents the final regression models for loneliness.

The final logistic regression model included four variables: HLQ - Social Support, HLQ – Navigating Healthcare, MULTIPleS Treatment Burden and NSQOL (Omnibus χ^2 = (4, n = 171) = 26.74, *p* = 0+, Nagelkerke R^2 = .23.

An increase in one point of score on HLQ – Social Support was associated with a 1.07 times (or 7%) *less* likelihood of reporting loneliness (β = -1.23, OR = 0.93, CI [0.81, 1.02], *p* = .0+). An increase in one point of score on "HLQ-Navigating Healthcare" was associated with a 1.02 times (or 2%) *less* likelihood of reporting loneliness (β = -0.81, OR = 0.98, CI [0.96, 0.99] *p* = .04.). An increase in one point of score on MULTIPleS-Treatment Burden was associated with 1.06 (or 6%) times *more* likelihood of reporting loneliness (β = 0.67, OR = 1.06, CI [1.03, 1.11], *p* = .03). Additionally, an increase in one point of score on the NSQOL was associated with 1.21 times (or 21%) less likelihood of reporting loneliness (β = -0.20, OR = 0.82, CI [0.69, 0.93] *p* = 0+). The final model was able to explain 23% (Nagelkerke R^2) of the variance in loneliness and correctly classified 64% of the cases.

Table 24B

Predictors of Loneliness in Stepwise Logistic Regression

Dependent variable: ULS-8 (0 = Non-Lonely, 1 = Lonely)

Step	Predictor	*β*	OR	Nagelkerke R^2	χ^2	*p*
2	HLQ - Social Support	- 1.23**	1.07	.23	26.74	0+
	HLQ – Navigating Healthcare	- 0.81*	1.02			
	MULTIPleS - Treatment Burden	0.67*	1.06			
	NSQOL	-0.20*	1.21			

Note. Hierarchical stepwise logistic regressions were used. OR = Odds Ratio. HLQ = Health Literacy Questionnaire. NSQOL = Nutrition Specific Quality of Life. MULTIPleS = Multimorbidity Illness Perception Scale.

$^{*}p < .05$. $^{**}p < .01$.

Hopelessness

Univariate analyses. Results examining the demographical, clinical and psychosocial associated with hopelessness with observed significant results are summarized in Table 25A.

Table 25A

Factors Affecting Hopelessness Based on Biopsychosocial factors in Univariate Analyses

	Non-Hopeless (n = 104)	Hopeless (n = 67)	*p*
Gender			.01
Chinese	43 (41)	44 (65)	
Non-Chinese	61 (59)	23 (35)	
HLQ			
Social Support for Health	3.13 ± 0.51	2.73 ± 0.64	0+
Appraisal of Health Information	2.75 ± 0.62	2.55 ± 0.47	.03
Ability to Actively Engage with Healthcare Providers	3.98 ± 0.72	3.38 ± 0.73	0+
Navigating the Healthcare System	3.81 ± 0.63	3.43 ± 0.53	0+
Ability to Find Good Health Information	3.72 ± 0.77	3.328± 0.61	0+
Understanding Health information enough to Know What to Do	3.74 ± 0.85	3.35 ± 0.72	0+
NSQOL	10.12 ±3.42	8.59 ±3.13	0+
BIPQ - Diabetes	42.322 ± 7.91	39.70 ± 7.34	.04
MULTIPLES – Treatment Burden	11.20 ± 7.44	14.41 ± 6.08	0+
ADAT			0+
Difficulty Following Diet	33 (32)	39 (58)	
No Difficulty Following Diet	71 (68)	28 (42)	

Note. Data expressed as *M* ± *SD* or *n* (%). HLQ = Health Literacy Questionnaire. NSQOL = Nutrition-Specific Quality of Life. BIPQ = Brief Illness Perception Questionnaire. MULTIPLES = Multimorbidity Illness Perception Scale.

Multivariate Analysis. Hopelessness (as a binary variable) was regressed to ethnicity and psychosocial variables in two separate logistic regression models. Only variables associated with loneliness were entered as potential predictors. Ethnicity was entered on the first step followed by psychosocial variables on the second step. Nagelkerke's R^2 was used to assess how much variance in hopelessness could be explained by the regression models. Forward: Likelihood Ratio was used to select each variable. Table 25B presents the final regression models for hopelessness.

The final logistic regression model included four variables: ethnicity, HLQ – Ability to actively engage with HCP, HLQ - Social Support and NSQOL (Omnibus χ^2 = (4, n = 171) = 44.39, *p* = 0+, Nagelkerke R^2 = .32.

Chinese had 1.04 (or 4%) times *more* likelihood to report hopelessness than other races ($\beta = 0.47$, OR = 1.04, CI [1.01, 1.10], $p = .03$). An increase in one point of score on HLQ – Social Support was associated with a 1.13 times (or 13%) *less* likelihood of reporting hopelessness ($\beta = -0.75$, OR = 0.88, CI [0.81, 0.92], p = .0+). An increase in one point of score on "HLQ-Ability to Actively Engage with HCP" was associated with a 1.11 times (or 11%) *less* likelihood of reporting hopelessness ($\beta = -0.66$, OR = 0.90, CI [0.83, 0.96] p = 0+). Additionally, an increase in one point of score on the NSQOL was associated with a 1.13 times (or 13%) *less* likelihood of reporting loneliness ($\beta = -1.24$, OR = 0.88, CI [0.77, 0.91] p = 0+). The final model was able to explain 32% (Nagelkerke R^2) of the variance in hopelessness and correctly classified 78% of the cases.

Table 25B

Predictors of Hopelessness in Stepwise Logistic Regression

Dependent variable: BHI (0 = Non-Hopeless, 1 = Hopeless)

Step	Predictor	*β*	OR	Nagelkerke R^2	χ^2	*p*
1	Chinese (vs Non-Chinese)	0.47*	1.04	.04	4.85	.03
2	HLQ - Social Support	- 0.75*	1.13	.32	44.39	0+
	HLQ – Actively Engage with HCP	- 0.66**	1.11			
	NSQOL	-1.24**	1.13			

Note. Hierarchical stepwise logistic regressions were used. OR = Odds Ratio. HLQ = Health Literacy Questionnaire. NSQOL = Nutrition Specific Quality of Life. MULTIPleS = Multimorbidity Illness Perception Scale.

$^{*}p < .05$. $^{**}p < .01$.

CHAPTER FOUR

Discussion

Overview

The present study is a pioneering effort in describing and examining the prevalence and predictors of psychological distress (Depression, Anxiety, Loneliness and Hopelessness) in DM-ESRD patients, as well as examining select psychosocial dimensions (Health Literacy, Illness Perception, Nutritional QOL and Adherence to Treatment) in the context of DM-ESRD.

There are several important findings in this study. Firstly, DM-ESRD patients experience a broad range of psychological distress symptoms. Secondly, psychologically distressed subgroups report poorer outcomes in each of the 4 psychosocial dimensions. Finally, the present study was able to identify several biopsychosocial factors that were predictive of the 4 different subgroups of psychological distress dimensions.

This chapter presents key findings and will be presented in the following sequential sections. Qualitative findings will be jointly discussed with quantitative results in each section.

1. Section one discusses the documented prevalence of psychological distress (*Research aims 1 and 2a.i*).
2. Section two discusses findings on the 4 psychosocial dimensions measured (Health Literacy, Illness Perception, Nutritional Quality of Life and Adherence) (*Research aims 1 and 2a.ii*).
3. Section three discusses the differences between psychological distress subgroups on the 4 psychosocial dimensions (*Research aims 1 and 2b*).
4. Section four discusses biopsychosocial determinants of psychological distress (*Research aims 1 and 3*).

5. Section five states the study strengths/limitations and future directions.

Section 1: Psychological Distress (Research Aims 1 and 2a.i)

Psychological distress is a common comorbidity following a chronic disease diagnosis, and the severity of psychological distress may increase with time (Jim et al., 2006). The present study was able to document rates of psychological distress in the DM-ESRD population.

At 46%, the prevalence rate of depression (HADS depression ≥ 8) in the study population was substantial. The prevalence rates were slightly higher compared to the rate of depression in the general ESRD population in other studies using the HADS (34% in Martin et al., 2004; 38% for Murtagh et al., 2007). With regard to DM-ESRD, little data is available on the prevalence of any form of psychological distress. It is pertinent to note that depression rates measured with different instruments may vary widely, with studies examining depression rates varying from 24% to 46% in HD patients (Brown et al., 2010; Conde et al., 2010; Hung et al., 2011). Qualitative analyses revealed that patients generally report negative affect and that having a chronic condition may possibly lead to a more depressed outlook of life and of their treatment goals. Through the study interviews, the presence of coexisting conditions has also been reported to have a negative influence on the wellbeing of patients.

The prevalence rate of anxiety (HADS anxiety ≥ 8) was also found to be substantial at 53%, a number slightly higher compared to other studies examining the general ESRD population using the HADS (45.6% in Martin et al., 2004; 27% in Murtagh et al., 2007). Qualitative findings suggest that patients report feeling anxious and worried about their health status, with several stating that coexisting conditions may make coping more difficult which further increases their anxiety about the future.

The documented depression and anxiety rates in the present study were comparable to that of other Asian populations (Kim et al., 2002; Ko et al., 2010). Some suggested reasons for this phenomenon are that Asian patients perceive their chronic disease as a burden not just to themselves, but to their families as well (Chen et al., 2010). This resonates with the documented qualitative subtheme of patients not wanting to be a burden to their families. Perceived burden has not only been postulated to be related to depression and anxiety, but suicide ideation as well (Brown et al., 2009).

The rates of depression and anxiety in the present study are generally comparable to other ESRD populations, but the rates are markedly high in comparison to studies examining depression and anxiety in a population with no chronic conditions (7.9% for depression and 2.6% for anxiety) (Broekman et al., 2008). A Singaporean study examining the prevalence of depression and anxiety in patients with chronic obstructive pulmonary disease using the HADS (with similar cutoff scores) reported the rates to be only 42% and 10% for depression and anxiety respectively (Cao, Ong, Eng, Tan & Ng, 2006). It is thus important to note that prevalence of depression and anxiety are high, even when compared to other chronic disease populations in Singapore.

A significant portion of the study population (79%) reported loneliness. These rates are comparatively higher compared to other studies examining loneliness in the HD population (e.g. 42.7% in Koc & Saglam, 2013). Qualitative analyses revealed that many patients report either feeling socially isolated or having a lack of social support. In examining individual item scores in the ULS-8, the item "*No one really knows me well"* is reported to be the top concern (highest mean score) reported by patients, which suggests that the patients do not feel like they are understood and supported from those around them. Moreover, social support has been reported to be an inverse correlate of loneliness (Kara & Mirici, 2004). When patients report that they are not well understood, it is difficult to ascertain the underlying reasons or directionality (i.e. whether the individuals close to the patient are unwilling to provide support or if the patients themselves are the barriers to poor social support), as a study reported that dialysis patients themselves may be embarrassed by the discussion of their treatment experiences with others and as a result, exhibit social withdrawal behaviour to avoid talking about their conditions (Herlin & Wann-Hannson, 2010).

Hopelessness was documented in 39% of the study sample. Studies examining hopelessness in the ESRD patient population are limited. A study using the parent version of the BHI (i.e. Beck Hopelessness Scale (BHS)) in PD patients found similar rates of hopelessness. Qualitative findings suggest that the chronicity of DM-ESRD, as well as their coexistence/comorbidity contributes to feelings of hopelessness about their conditions, which led to patients expressing bleak views about their future. In particular, the BHI item "*My future seems dark to me"* appears to be the top concern reported by patients. Of note, some studies have reported that hopelessness leads patients to feel that "enough is enough" and that remaining on dialysis represents a hopeless situation that may not improve (e.g. Ganzini et al., 1994). However, none of the patients interviewed in the qualitative component of the present study report any intention to withdraw from dialysis. In a previously listed example by *P1*, the quote "a*t the end of the day however, I still come for dialysis*" suggests that hope and hopelessness are a dialectically interacting construct. Oncology research examining hope and hopelessness in patients with terminal cancer suggests that the relationship between hope and hopelessness might be balanced on the subjective acceptance of their diagnosis (Sachs et al., 2013). However, while hopelessness may not be a strong indicator of treatment withdrawal in the present study, it remains important to highlight the documented prevalence of hopelessness in the DM-ESRD population as it has been found to affect overall well-being (Kim et al., 2002).

Depression, anxiety, loneliness and hopelessness, while measured as separate dimensions in this study, are nonetheless under the overarching construct of psychological distress. These four dimensions may all be responses to the demanding treatment requirements arising from coexisting conditions such as DM-ESRD (Abramson, Metalsky & Alloy, 1989).

It is also important to consider the sociocultural factors embedded within the present population that may contribute to the rates of psychological distress.

Firstly, qualitative analyses reveal that finances and the cost of treatment is a common problem that patients report to be a burden. Tan and colleagues (2005) reported that financial burden was the biggest stressor in Singaporean ESRD patients. In the Singapore healthcare framework, dialysis costs are not fully subsidized by the government (vis-à-vis the United Kingdom and the Netherlands) (Lai et al., 1999; Vanholder et al., 2012). In 2014, the average medical bill for HD per month in Voluntary Welfare Organizations (VWO) (which is also the cheapest option that HD patients have) amounted to S$2048.00 (Chowdhury, 2006). This problem may also be compounded with reported findings that ESRD patients are unable to be gainfully employed which in turn increases the financial burden on their family and/or caregivers (e.g. Tan et al., 2005). A study examining the annual cost for DM treatment in Singapore reported the number to be around S$700.00 per annum, but the actual cost may differ between individual needs and the medical facilities they attend (Ng et al., 2015). Beyond medication costs, the proper management of DM may require a strict adherence to a diabetic diet, which may require patients to deviate from cheaper, easier but less healthy alternatives from the plethora of food establishments in Singapore (Hankin et al., 2001). It may also be useful to compare the cost of treatment with the median monthly household income in Singapore for the year of 2014, which was about $7870.00 (Department of

Statistics Singapore, 2015), suggesting that DM-ESRD is likely to pose significant financial burden on most households in Singapore.

Relatedly, another sociocultural context that may act as a backdrop for the documented rates of psychological distress is that rising trends of dual-income households (which sees working children leaving their retired elderly parents at home during the day) may further contribute to feelings of depression, anxiety and loneliness in the typically elderly ESRD population (Ministry of Social and Family Development Singapore, 2011; Long & Martin, 2000). With dual-income households, it is common to hire domestic workers (commonly called maids in Singapore) to assist in household chores. However, it is also common for these domestic workers to also provide primary lay-caregiving to debilitated/chronically ill members present in the household (Yeoh et al., 2009). Several issues may surface with domestic workers providing caregiving. Firstly, considering that most of these domestic workers are not professionally trained to holistically manage patients (as compared to social workers or nurses), the low and/or poor level of care provided my them may instead lead to adverse mental health consequences, as reported by studies examining the effect of domestic workers' caregiving (Philips & Rempusheski, 1986). Secondly, turnover rates of domestic workers may be high, as employers are known to frequently re-hire new domestic workers whenever they feel dissatisfied with their domestic worker (Yeoh & Huang, 2000). This may create a barrier to forming a long-term, effective caregiving relationship.

Lastly, ESRD carries with it a stigma that patients have to manage (Bakewell et al., 2001). To exacerbate the situation for DM-ESRD patients, the diagnosis of DM has also been found to lead to guilt and shame (Nash, 2013). Considering that Asian cultures tend to embody the concept of *face*, defined as "*the positive social value that a person effectively claims for himself…face is an image of self-delineated in terms of approved social attributes*" (Kim & Nam, 1998), the present population may then wish to hide their chronic conditions from their friends and neighbours (thus further contributing to feelings of loneliness). DM-ESRD patients may hence experience an extra burden in this respect, even when compared to other ESRD subgroups.

Section 2: Rates of Health Literacy, Illness Perception, Nutritional QOL and Adherence (Research Aims 1 and 2a.ii)

Health Literacy

The present study is the first to utilize the HLQ to examine health literacy in the ESRD population. Comparisons with other studies examining health literacy in ESRD populations may not be meaningful because of the difference in health literacy instruments used, although reports suggest that ESRD populations generally have some health literacy deficiencies (Lai et al., 2013). Currently, only one other study has utilized the HLQ in examining health literacy, with the study sample examining the general population in Australia (Beauchamp et al., 2015). In comparison to the present study population, the overall trends in the nine health literacy dimensions on the HLQ are somewhat comparatively similar, although it can be observed that the current study sample scored poorer on most of these dimensions (except for "*Having Sufficient Information"*). Future studies examining the HLQ on general populations would be useful for population norms comparison. For ease of reference, the Beauchamp et al (2015) HLQ results are listed in the following table in comparison to the present study sample.

Table 26: Comparative Health Literacy Scores

Health Literacy Dimension	**Present Study Sample** (N=171)	**Comparative Sample (Beauchamp et al., 2015)** (N= 813)
Feeling Understood and Supported by Healthcare Providers	3.02 ± 0.48	3.21 ± 0.54
Having Sufficient Information	3.02 ± 0.44	2.98 ± 0.54
Actively Managing My Health	2.84 ± 0.45	3.02 ± 0.50
Social Support for Health	2.98 ± 0.60	3.03 ± 0.55
Appraisal of Health Information	2.66 ± 0.58	2.78 ± 0.54
Ability to Actively Engage with Healthcare Providers	3.76 ± 0.77	3.97 ± 0.69
Navigating the Healthcare System	3.66 ± 0.62	3.82 ± 0.67
Ability to Find Good Health Information	3.53 ± 0.74	3.65 ± 0.75
Understanding Health Information Enough to Know What to Do	3.57 ± 0.83	3.85 ± 0.74

Note. Data expressed as *M* ± *SD*.

In addition, Beauchamp et al (2015) in their study also reported that sub-populations with chronic conditions report (1) more difficulties navigating the healthcare system, (2) have insufficient information for health, and (3) having less social support for health. These three HLQ themes also resonate with the identified themes in the qualitative analysis results of the present study. Patients recount being unable to use the healthcare system to address their needs and have a limited understanding of what health services are available (Corresponding to "*Navigating the Healthcare System*"). In addition, patients also report having difficulties and gaps in their knowledge, and that they don't have the necessary information they need to live with and manage their health concerns (Corresponding to "*Having Sufficient Information to Manage my Health*"). Lastly, several patients have also expressed that they feel alone and unsupported for health (Corresponding to “*Social Support for Health”*). Some proposed reasons for chronic disease patients having difficulties in navigating the healthcare system and/or having enough information to manage health may be that patients with multimorbidity have been reported to be overwhelmed by the complexity of information and the number of different service providers to their health care (Manderson et al., 2012). This may be plausible in the context of DM-ESRD, as a typical patient in Singapore would be required to have monthly appointments with nephrologists, dieticians, resident physicians in dialysis centers as well as other medical specialists, subject to individual needs. Social support and loneliness are intimately related constructs (Jones & Moore, 1987), and thus it is expected that the observation of lack of social support follows the discussion of documented loneliness in the current study. The lack of social support has been associated with increased risk of mortality in several cohort studies among the general population, as individuals perceiving a non-supportive environment are more likely to be emotionally distressed, which in turn increases the likelihood of noncompliance with treatment (McClellan et al., 1993). Reasons for poor social support in the ESRD population has been suggested to be because ESRD patients require a broad range of forms of support, including anywhere from financial to emotional support. The long-term burden placed on patients’ closed ones may increase interpersonal stress, which may have adverse consequences for a healthy, supportive relationship (Eitel et al., 1995). A systematic review of social support in diabetic patients suggests that the lack of social support is related to poorer overall psychosocial functioning, but underlying mechanisms for this relationship remain unclear (van Dam et al., 2005). Therefore, DM-ESRD patients may be at increased risk for poor social support.

Illness Perception

The present study utilized a subset of items from the Brief Illness Perception Questionnaire (B-IPQ) to measure ESRD and DM separately as two conditions. Quantitative results revealed that patients have greater negative illness perception of ESRD compared to DM. This is also supported by the Multimorbidity Illness Perceptions Scale (MULTIPleS) findings that the highest mean score belonged to the prioritization subscale item, "*One of my conditions has more of an impact on my life".* While no current studies in the literature have compared differences in illness perception between DM and ESRD, several reasons may explain this finding. Firstly, studies examining the relationship between illness perceptions and quality of life in dialysis patients found that ESRD patients consistently report strong illness identity (an aspect of BIPQ measurement) which is associated with poorer outcomes such as quality of life (Timmers et al., 2008), while similar studies on DM patients found that illness identity varies significantly between individuals (Luyckx et al., 2008). Secondly, the impact of dialysis on ESRD patients includes a range of side effects, including pain in the area of the arteriovenous fistula graft that patients re-experience each time they undergo dialysis (Bhatia et al., 1996). While DM presents many complications and side effects to a patient as well, the negative experience may not be as frequent or severe compared to undergoing dialysis. This is also supported by the qualitative analyses results highlighting that more attention to bodily needs are required by the patient after dialysis of kidney failure compared to before (see *P4*).

In general, the BIPQ scores for both DM and ESRD indicate a degree of negative illness perception, and scores are comparable to studies on similar populations (e.g. in dialysis, Chilcot, 2012; in diabetes, Broadbent, Donkin & Strorh, 2011).

Overall, MULTIPleS results supplement the findings on BIPQ and suggest that patients may consider one of their conditions to have more of an impact on their lives, in addition to reporting that one of their conditions is more overwhelming (note that the questionnaire does not inquire on the specific conditions). The number of studies utilizing MULTIPleS is limited, considering that the conception of the instrument is relatively recent (Gibbons et al., 2013). A cohort study using MULTIPleS to examine the effect of multimorbidity on health outcomes in a primary care population did not provide descriptive statistics, but reported that the experience of burden associated with multimorbidity was related to poorer self-reported health status (e.g. self-help behaviors). Future research utilizing MULTIPles on general populations would be useful for population norms comparison.

Nutritional Quality of Life and Adherence

To present a more congruent discussion, nutritional QOL and adherence will be jointly discussed, as qualitative analyses suggest the existence of a relationship between nutritional QOL and adherence (mainly dietary adherence).

The NSQOL was developed specifically to assess appetite-related QOL in HD patients. Overall, NSQOL scores indicate comparable outcomes with other studies using the NSQOL on the HD population (Han et al., 2012), suggesting that the present patient population may face moderate malnutrition. In clinical populations, malnutrition is closely related to dietary nonadherence (Klahr, 1989). SDSCA-General Diet and DDFQ-Diet results concur that patients do not consistently follow their dietary recommendations. Qualitative interviews also highlight that patients report problems with dietary adherence. Sub-themes from the interviews also suggest that conflicting dietary requirements from different conditions and fluctuations in appetite after dialysis. Research examining dietary adherence is lacking, but one study identified knowledge of diet, language, socioeconomic status and attitudes toward the renal diet as important factors related to dietary adherence (Lopez, Burrowes, Gizis & Brommage, 2007). A Singaporean qualitative study examining barriers to treatment adherence in HD patients suggest that factors such as poor knowledge and/or understanding of treatment requirements potentially hinder adherence to diet, fluid and medication requirements (Griva et al., 2013). Overall, it makes sense that nutritional QOL deficiencies also reflect difficulties in dietary adherence.

However, results highlighting dietary nonadherence was incongruent with majority of patients (62%) reporting that they do not face difficulties following their diet on the ADAT scales. This suggests that while patients may not perceive that following their dietary guidelines are difficult, they make conscious decisions not to adhere to their recommended guidelines. This is supported by qualitative interviews revealing that patients consciously deviate from dietary guidelines during social and festive occasions. Further research is needed to explore the relationship between perceived difficulty of adherence and actual adherence behavior.

Medication adherence did not emerge as a theme in qualitative analysis, but a substantial portion of the quantitative sample reported medium and low levels of medication adherence on the MMAS (26% and 27% respectively, with a combined total of 53%). This finding is comparable to similar studies examining the Singaporean ESRD population. For example, a study examining adherence rates in PD patients found overall deviations from medication regimen to be around 47% (Griva et al., 2013). However, the medication nonadherence rates were slightly higher than those reported in studies on western populations (e.g. DeOreo, 1997; Holley & Devore, 2006; Russo et al., 2006). In addition, an examination of PD patients in Hong Kong found nonadherence rates for medication to be only 17%, although the operational definition in their study was less stringent (Lam et al., 2010). Research on understanding the causes of medication nonadherence is unclear, but associated factors with medication nonadherence usually include patient factors such as a lower education level (Fischer et al., 2010). Considering the documented negative impact of medication nonadherence (Kutner et al., 2002), interventions are needed to address these needs.

Interestingly SDSCA-diabetic medication suggests that patients rarely deviate from their diabetic medication regimen. This is supported by Balkrishnan and colleagues (2003) findings that adherence rates to diabetic medications were higher than other concurrent medications that a geriatric population may be prescribed. Medication adherence in the DM-ESRD population is not widely examined, but it may be possible that patients regard dialysis as more important than medication in terms of life sustenance (DeOreo, 1997), and thus may downplay the importance of ESRD medications.

Lastly, study results also indicate that some degree of deviation of fluid guidelines are present in the quantitative sample (DDFQ-Fluid deviation mean = 3.56 out of 14 days), which was also an emerging theme reported in qualitative analyses. In general, fluid nonadherence is consistently documented in studies examining the ESRD population. For example, a large cohort study examining fluid adherence in HD patients reported that as many as 74.6% of the HD population reported difficulty in following fluid guidelines (Kugler, Vlaminck, Haverish & Maes, 2005). However, correlates of fluid nonadherence in the HD population remain unexplored. No relationship between diabetes and thirst has been reported.

Section 3: Psychological Distress Subgroup Difference on Psychosocial Dimensions (Research Aims 1 and 2b)

The following section discusses all univariate results found in comparing psychological distress subgroups on the four psychosocial dimensions. While all statistically significant relationships in univariate results are eventually used as predictors in multivariate modelling (section 4), it would nonetheless be useful to discuss these results considering that no prior studies have examined the relationship between psychological distress and the four psychosocial dimensions in DM-ESRD patients.

Health Literacy Subgroup Differences

Across the board for all psychological distress subgroups, distressed subgroups scored worse on each respective health literacy dimension. Significant differences in each of the health literacy dimensions are briefly discussed below. All significant differences are uni-directional (i.e. distressed subgroups score lower on all health literacy dimensions):

1. <u>Health literacy dimension 1</u> – *"Feeling Understood and Supported by Healthcare Providers"*: Significant differences were found for depression, anxiety and loneliness subgroups. Briefly, this dimension requires patients to have an established relationship with at least one healthcare provider (Osborne et al., 2013). A suggested explanation for this may be that depression, anxiety and loneliness have all reported to impair the ability to form established relationships with others, which can in turn be extended to healthcare providers as well (Jones, 1982; Friedmann et al., 2006).
2. <u>Health literacy dimension 2</u> – *"Having Sufficient Information to Manage My Health"*: Significant differences were found for the loneliness subgroup. This was also an emerging theme in the qualitative component. A study reviewing loneliness consequences in a geriatric population suggests that feelings of loneliness can adversely affect cognitive ability and in turn, impair confidence with managing information (Hawkley & Cacioppo, 2010). This explanation may be applicable to the present study as the mean age was relatively high (mean age = 58.84, *SD* = 9.43).
3. <u>Health literacy dimension 3</u> – "*Actively Managing my Health"*: Significant differences were reported for the depression subgroup. Briefly, the description of this dimension involves a patient to be able to take responsibility for their own health, and

proactively engage in their own health care (Osborne et al., 2013). Depressive symptoms have been reported to be inversely related to proactive behavior (Ironson et al., 2005), which may help explain this particular finding.

4. Health literacy dimension 4 – "*Social Support for Health"*: All subgroups reported significant differences in this dimension. In addition, this dimension was also identified as a theme in the qualitative component. In terms of social support, current literature is rich in documented an existing relationship between poor social support and depression/anxiety/loneliness (e.g. Griva et al., 2014) and hopelessness (e.g. Kimmel et al., 1993) in the ESRD population. One of the mechanisms underlying poor social support and general psychological distress is suggested to be because poor social support leads to deficiencies in cognitive and behavioral strategies for coping with stress, which in turn increases the risk of psychological distress (Holahan & Moos, 1981).

5. Health literacy dimension 5 – "*Appraisal of Health Information"*: Depression, loneliness and hopelessness subgroups reported significant differences in this dimension. Qualitative analyses also supplement this finding. As defined by Osborne et al (2013), "*Appraisal of Health Information* requires an ability to identify good information and reliable sources of information, including a resolution of conflicting information by themselves or with help from others". A meta-analysis examining the relationship between depressed/anxious mood and cognitive bias modification suggest that depressed and anxious moods may negatively impact cognitive appraisal of information (Hallion & Ruscio, 2011). Similarly, another review examining the impact of loneliness on cognitive appraisal also suggested that loneliness led to an impaired ability to process information (Omdahl, 2014). However, the mechanisms behind the impact of these moods on appraisal of health information remain uncertain.

6. Health literacy dimension 6 – "*Ability to Actively Engage with Healthcare Providers*": All subgroups reported significant differences in this dimension. This also concurs with results from qualitative analyses. The description of this dimension by Osborne et al (2013) includes the ability of the patient to have a sense of agency in interactions with healthcare providers and be able to seek advice from healthcare providers when necessary. Studies examining the relationship between these two constructs are limited, but some findings examining the chronic disease population indicate that patient engagement (by healthcare providers) is dependent on patients' emotional state, such that a poor emotional state can function as a barrier to effective patient engagement (Barello, Graffigna & Vegni, 2012). The relationship between psychological distress and health literacy may be explained by some findings that poor mental health may lead to a stigmatizing attitude that hinders help-seeking behavior (Jorm, 2000). Stigmatizing attitudes can also be extended to approaching medical professionals as well, which may further worsen health literacy behaviors such as in this particular health literacy dimension (Raguram et al, 1996).

7. Health literacy dimension 7 – " *Navigating the healthcare system*": All subgroups reported significant differences in this dimension. Qualitative analyses also identify this dimension as a theme. Broadly, patients' ability to find out about health services and supports in order to get their needs met (Osborne et al., 2013) may require proactive behavior (as discussed in dimension 3). Extrapolating part of the description from this health literacy dimension suggests that some desire for independence is required from patients to be able to advocate on their own behalf to address their health needs. Relatedly, some studies report that psychological distress (specifically, depression, anxiety and loneliness) is likely to interfere with the desire to find proper healthcare

(e.g. Sharp et al., 2002). The psychological constructs of hopelessness remains to be further explored.

8. Health literacy dimension 8 – "*Ability to find good health information*": All subgroups reported significant differences in this dimension. The authors of the HLQ instrument suggest that an individual scoring high on this construct is an "information explorer" and actively uses a diverse range of sources to find information and is up to date with information (Osborne et al., 2013). Macfarlane et al (1999) found that the influence of psychological distress (in general) can negatively impact health-seeking behavior, which in the current study's context, affect how much of an "information explorer" the patient can be.

9. Health literacy dimension 9 – "*Understanding health information well enough to know what to do":* Depression, loneliness and hopelessness subgroups reported significant differences in this dimension. The description of this dimension requires patients to be "able to understand all written information…in relation to their health and be able to write appropriately on forms where required" (Osborne et al., 2013). This construct is in part dependent on the literacy. Thus, relatedly, the education level of the individual can also influence this dimension (take note that about 47% of the quantitative sample received only primary education or below). This finding supports the advocacy for literacy interventions, which has been found to have a degree of effect on improving psychological distress (e.g. Sorensen, 2012).

Taken together, it is clear that psychologically distressed subgroups report poorer health literacy outcomes compared to non-distressed subgroups. However, the mechanisms underlying the relationship between these two constructs require further theoretical testing and validation.

Illness Perception Subgroup Differences

The depression subgroup reported poorer illness perception of dialysis/ESRD compared to non-depressed subgroups on the BIPQ. This finding is consistent with many existing studies examining the relationship between dialysis and depression (e.g. Chilcot et al., 2008), with the finding that depression is the most common psychopathology reported by ESRD patients. Some of the explanations for depression in ESRD patients include poor locus of control and the invasive routine of dialysis being the greatest cause of associated stress, poor coping strategies, which in turn amplifies risk of depression (Chilcot et al., 2008). In addition, considering that 74% of the quantitative sample in the present study have been on dialysis for more than 2 years, temporal factors may increase the negativity of ESRD illness perception.

Findings indicate that the hopeless subgroup reported poorer illness perception of DM compared to non-hopeless subgroups on the BIPQ. No studies have yet examined the relationship between hopelessness and DM, but some evidence suggests that hopelessness has an impact on the prognosis of diabetes, although more research into the potential mechanisms is needed (Pedersen et al., 2009).

The anxiety subgroup reported prioritizing one condition over another. A review examining self-management of multiple chronic diseases and illness prioritization suggested that because prioritizing an illness was often linked with feelings of uncertainty, patients usually report feeling being out of control which in turn promotes feelings of anxiety (Lindsay, 2009).

Across all psychological distress subgroups, the quantitative sample reported significant differences in the treatment burden subscale of MULTIPleS, suggesting that depression, anxiety, loneliness and hopeless patients are more likely to form perceptions that consider multimorbidity to cause additional burden. Qualitative analyses also suggest that patients face treatment burden and a high “workload” of health care. Treatment burden has been referred to as “self-care practices that patients with chronic illness must perform…as well as the impact that these practices have on patient well-being” (Gallacher et al., 2013). The relationship between treatment burden and depression/anxiety has been found in a number of other chronic illnesses, including DM (Kaptein et al., 2006; Ponzo et al., 2006). However, there is a dearth of research examining the relationship between treatment burden and loneliness/hopelessness. In terms of the related mechanisms, it is suggested that treatment burden impacts the overall well-being and reduces patients’ capacity to follow treatment management plans, which in turn leads to poorer physical health and increases the risk of patients developing psychological distress (Gallacher et al., 2013). However, a complete understanding of the phenomena is yet to be achieved.

Nutritional Quality of Life Subgroup Differences

All psychologically distressed (i.e. depressed, anxious, lonely and hopeless) subgroups reported poorer scores on the NSQOL. As discussed earlier, the NSQOL is a measure of appetite-related QOL and is also based on tools examining nutritional status (Han et al., 2012), and although the use of NSQOL in empirical studies is gaining traction, available studies utilizing the NSQOL are not widely available. Thus, the discussion will use studies examining nutritional status instead.

Literature generally documents a relationship between depression and poor nutrition. A study reported that DM-ESRD patients reported poorer depression and nutrition scores compared to subsets of ESRD patients without DM, along with an overall high correlation between the severity of depression and degree of malnutrition in HD patients (Koo et al., 2005). However, the reasons for the relationship between depression and malnutrition remain unclear, but some suggested reasons include findings that depression is associated with a loss or alteration of appetite, particularly in the elderly population (Akbaraly et al., 2009).

Furthermore, these studies have usually examined under-nutrition instead of over-nutrition in examining depression.

The relationship between anxiety and poor nutritional QOL has not been thoroughly examined, but anxiety has been reported to be a symptom of malnutrition, along with other behavioral changes (Miranda et al., 2007). In addition, anxiety disorders are common in both anorexics and obese populations (Pollice et al., 1997; Strine et al., 2008).

Loneliness and poor nutrition is commonly studied in the context of the geriatric population, as the elderly demographic has been described to be at most risk of loneliness (Chen, Schilling & Lyder, 2001). The relationship between loneliness and poor nutrition is highlighted by findings that loneliness is associated with reduced number of daily meal intake (especially of protein, fruits and vegetables) (Ramin et al., 2011). The authors further propose that physiological decrease in appetite is related to loneliness, but further studies are required.

Lastly, existing studies examining hopelessness and nutritional status are very limited. Studies usually examine the relationship between nutritional status and psychological distress/poor mental health in general, and hopelessness is often part of instruments used to assess psychological distress and not a separate construct on its own (e.g. Galler et al., 2010; Kvamme et al., 2011).

Overall, further research is required to uncover the mechanisms linking psychological distress to poor nutrition/nutritional QOL.

Adherence Subgroup Differences

Depressed patients reported difficulty in following their diet regimen, compared to non-depressed patients on the 1-item ADAT (i.e. yes/no answer to "*Do you have difficulty following your diet?")*. In the context of multimorbidity, depressed patients with coexisting conditions is reported to have a multi-fold chance of being at risk for non-adherence (Ito, 2013). A suggested mechanism underlying this relationship is that depression is often associated with reductions in cognitive functioning that governs memory and following through with treatment recommendations (e.g. diet) (DiMatteo, 2000).

Anxious patients reported difficulty in following their diet compared to non-anxious patients on the ADAT. Anxious patients also reported a greater degree of deviation from their diet in DDFQ-Diet. Current literature is mixed on identifying the relationship between anxiety and adherence. A recent cohort study examining the association between anxiety symptoms and adherence in a clinical population reported that anxiety was associated with self-efficacy, which may in turn function as a mediator adherence as low self-efficacy reduces motivation and perseverance required in adherence behavior (Bautista, Vera-Cala, Colombo & Smith, 2012). In addition, because the concept of anxiety is not heterogeneous, it may be noteworthy to mention that paradoxically, some forms of anxiety (i.e. generalized anxiety about health) might actually improve adherence to treatment, as patients are over-concerned about their health (Mineka, Watson & Clark (1998)

Hopeless patients reported difficulty in following their diet, compared to non-hopeless patients on the ADAT. In terms of underlying mechanisms, current literature suggests that hopeless patients, with little optimism that any action they take will be worthwhile, would have little interest in complying to the strict dietary guidelines that DM and ESRD both demand (DiMatteo et al., 1993).

Interestingly, while loneliness has been documented to influence adherence (because social isolation is associated with lack of emotional support and assistance, in turn influencing the likelihood of adherence) (DiMatteo, 2000), differences between loneliness subgroups were not documented in the current study.

Overall, future research is suggested to rigorously test the proposed mechanisms, ideally in a multidimensional model to discern the exact explanations to the significantly disconcerting relationship between psychological distress and adherence.

Section 4: Biopsychosocial Determinants of Psychological Distress (Research Aim 1 and 3)

Overview

Results in the present study suggest that psychological distress is determined by a combination of biopsychosocial factors. The most consistent predictor of psychological distress (across all subgroups) was Nutritional QOL. Some of the predictors have been discussed briefly in the previous section, but the discussion in this section aims to explore significant predictors in-depth.

An interesting finding in the present study emerged: that is, the significant predictors identified using stepwise logistic regression models for both depression and hopelessness were identical (i.e. being Chinese, HLQ-Social Support, HLQ – Ability to Actively Engage with Healthcare Providers, and NSQOL). To present a more congruent discussion, depression and hopelessness will be discussed under the same subsection, but the differences these two constructs will be highlighted accordingly.

Depression and Hopelessness

Earlier in the introduction chapter, the paper has presented a review of the literature and argued for the cause for examining depression and hopelessness as separate constructs. While multivariate modeling revealed the identical variables in predicting depression and hopelessness, different underpinning mechanisms and theoretical implications may be applied in their respective discussions.

Ethnicity.

Ethnicity was found to be a significant predictor of both depression and hopelessness. More specifically, the Chinese were more likely to exhibit depression and hopelessness than the non-Chinese. This finding rallies the need for further research into ethnic differences on depression/hopelessness in the DM-ESRD population specifically, particularly so because previous studies examining mental health in both general and clinical populations did not find any differences between different ethnic groups (Ko & Kua, 1995; Lim et al., 2005; Stahl et al., 2008). Studies examining depression in the Singaporean ESRD population also did not report similar findings (e.g. Griva et al., 2014). In addition, results in the present study were contrary to findings from a cross-sectional epidemiology study of Singaporean DM patients in that Indians were more likely to exhibit depression (Chong et al., 2009).

Few studies have documented ethnic differences in hopelessness in Singapore. However, noting that hopelessness is predictive of suicide ideation, studies on ethnic differences in suicide behavior in Singapore have similarly not reported significant differences between ethnic groups (Mak, Ho, Chua & Ho, 2015). However, the study did mention that Indians were more likely to have more protective factors than the Chinese (which runs contrary to findings for depression). Therefore, while ethnicity is found to be a common predictor in two separate multivariate models for depression and hopelessness, further research is required to tease out the different impact ethnicity has for these two psychological constructs.

Nutritional QOL.

Poor nutritional QOL was found to be a significant predictor of both depression and hopelessness. As discussed earlier, a review of the literature on DM or ESRD populations suggests that the relationship between nutritional QOL and depression/hopelessness is limited.

In general, several studies have reported that individuals who have poor quality diet are more likely to report symptoms of depression (Jacka et al., 2010). Underlying mechanisms proposed by neurology studies on rats suggest that poor diet and nutritional status may alter biological processes underpinning depression, such as negatively affecting brain plasticity and function (Molteni et al., 2002) and a maladaptive stress response system stemming fron the hypothalamus (Tannenbaum et al., 1997). The loss of appetite as a result of depression was briefly mentioned in the last section. An in-depth review of literature examining depression and appetite in other clinical populations suggests that depression is accompanied by both a reduction and increment of appetite, and the amount of change in either direction is a function of the severity of depression (Paykel, 1977). Suggested mechanisms underlying appetite and depression include disruption of patterns of sleep typical of depressed individuals that lead to fluctuations in appetite (Silverstein, 1999), fluctuations in food cravings that are reportedly related to exhibiting symptoms of depression (Weingarten & Elston, 1991) and in addition, reductions in food intake that are reported to be related to associated symptoms of depression, such as self-doubt and pessimism (Capuron et al., 2002).

Studies examining feelings of hopelessness and nutritional QOL suggest that the underlying biological processes may be different from depression. Hopelessness, characterized as a pessimistic cognitive style, is associated with a feeling that it is most improbable that any plans made will achieve goals (Melges & Bowlby, 1969). Plans of goals and actions primarily involve the prefrontal cortex, which is found to exhibit neural pattern impairments in several neurology studies examining effects of poor nutrition (e.g. Soto-Moyanoet al., 1987; De Bellis et al., 2005). In addition, while explanations for the relationship between depression and poor nutrition primarily involve patients’ subjective experiences (e.g. food cravings, sleep disruptions), explanations for hopelessness involve patients’ cognitive experiences (e.g. optimism). For example, studies have reported that better diet quality and the likelihood of making healthy food choices were related to optimism (Hingle et al., 2014). An emerging theme in qualitative analyses was that patients report not following their dietary recommendations. Considering that dietary adherence is reported by the overall study sample to be one of the more challenging aspects of treatment, it then makes sense to suggest that because hopelessness is associated with loss of hope for improvement or recovery (Jones et al., 2003), poor nutritional QOL (representing dietary nonadherence) will be predictive of hopelessness as well.

Overall, more research is required to examine the connection between depression, hopelessness and nutritional QOL.

HLQ – Ability to actively engage with HCP

Higher scores in the HLQ Item *"Ability to actively engage with HCP"* were found to be predictive of a less likelihood of exhibiting depression and hopelessness. The ability to actively engage with healthcare providers is briefly described as the extent to which patients are "proactive about their health and feels in control in relationships with HCPs and is able to seek advice from additions HCPs when necessary" (Osborne et al., 2013). It is necessary to note that research examining HCP engagement and depression/hopelessness in the context of DM-ESRD is unavailable.

Chronic disease patients with documented rates of depression have been known to report a loss of interest in engagements with resident physicians and nurses in an inpatient setting (Miranda et al., 2003). In the context of ESRD, the fact that patients go for dialysis thrice weekly can lead to a sense of independence and at the same time, desensitize them to the HCPs in the DCs, thus promoting the lack of a sense of agency with HCPs (Hunkeler et al., 2006; Tamura, Goldstein & Perez-Stable, 2009). An experimental study targeting the improvement of primary care patients' involvement in decision-making with HCPs using an educational intervention reported that depression rates were significantly improved after the intervention (Clever et al., 2006). Some patients have expressed the desire for greater HCP engagement, as described in the qualitative analyses.

Hopelessness is associated with the lack of proactive behavior, which makes good sense explaining why hopelessness would be associated with the lack of proactive behavior in engagement with HCPs. This is supported by psychotherapy research highlighting a strong relationship between being hopeful about the future and good client engagement in patients suffering from debilitating conditions (Quinlivan et al., 2013). Overall, the evidence describing good HCP engagement in improving feelings of hopelessness are available (Collins & Cutcliffe, 2003)

In psychotherapy research, concepts such as having a therapeutic relationship have been found to improve both depression and hopelessness rates (Lambert & Barley, 2001). Therefore, this supports the need for cross-disciplinary education to increase HCP awareness of effective methods discussed in psychotherapy research, especially in the present study's context community DCs and hospitals.

HLQ - Social Support

Higher scores in the HLQ Item *"Social Support"* were found to be predictive of a less likelihood of exhibiting depression and hopelessness. Social support is found to consistently predict survival in ESRD patients (Thong et al., 2007).

The negative correlation between depression and social support in ESRD patients has been documented in several studies (Watnick et al., 2003; Asti et al., 2006; Thong et al., 2007). For ESRD patients, the strict requirements in the treatment regimen severely restricts patients' social activities and causes disruptions in family and social life. As described in the qualitative results, patients usually feel too fatigued after dialysis to do anything, and the frequency of attending dialysis sessions per week severely limits their capacity for social activities. With decreased social engagements and/or support, patients may be cut off from important relationships that help mitigate feelings of depression that accompanies ESRD treatment (Littlefield et al., 1990).

Fewer studies examine the relationship between hopelessness and social support in ESRD patients. In studies examining other chronic disease populations (e.g. cancer), social support is not only documented to act as a buffer to harmful events, but is also found to decrease thoughts of hopelessness (Tan & Karabulutlu, 2005). In addition, social support has been found to be key factor in increasing the subjective feeling of treatment efficacy (Brent et al., 1998).

It is clear that depression and hopelessness may be examined as two distinct constructs (in that depression may be related to feelings and/or mood, and hopelessness with cognition), but further research is needed to identify the exact relationship between depression, hopelessness and the four psychosocial dimensions.

Anxiety

Study results indicate that the significant predictors identified using stepwise logistic regression models for anxiety were gender, Kt/V, HLQ-Actively Managing my Health and Nutritional QOL.

Gender

Results suggest that females have more likelihood of reporting anxiety as compared to males. Examination of anxiety in the ESRD population in general state that either females report higher rates of anxiety (e.g. Cukor et al., 2008) or that they do not report any differences (e.g. Alavi et al., 2009). Females in general have been found to present a higher prevalence of trait anxiety (Kendler et al., 1995). Gender differences in psychological outcomes have been well studied, and neurological explanations suggest that these differences may be due to a “flight-or-fight” response activated more readily in women (and also stays activated for a longer period) compared to men due to high contents of estrogen and progesterone (Almeida et al., 2009). In addition, the neurotransmitter serotonin (regulating stress response and anxiety responsiveness) has also been reported to be processed less quickly in the female brain (Almeida et al., 2009). In addition, women are also found to be more sensitive to low levels of Corticotropin-Releasing Factor (CRF) (a hormone organizing stress response), potentially making them more vulnerable to stress-related disorders compared to men (Valentino et al., 2013).

Kt/V

As a number used to quantify hemodialysis treatment adequacy, Kt/V indicates how well the dialysis treatment is working for a patient. Kt/V has been found to correlate with survival rates (Horigan, 2012). The recommended rate of Kt/V is 1.2mL. A study found that a 3-month average Kt/V that is consistently below 1.2mL is associated with increased mortality (Held et al., 1996).

The present study reports that a decrease in 0.1mL of Kt/V was associated with greater likelihood of reporting anxiety. This finding is previously undocumented in studies examining anxiety in ESRD populations (e.g. Bossola et al., 2012; Ng et al., 2015). A possible explanation for this is that dialysis inadequacy may have somatic feedback to the patient, which in turn increases worries and concerns about their general health. However, further research is necessary in examining Kt/V and psychological outcomes.

HLQ – Actively Managing my Health

Results suggest that an increase in scores on HLQ – Actively Managing my Health was associated with less likelihood of reporting anxiety. Osborne et al (2013) suggest that individuals who score highly on this HLQ dimension recognize the importance and are able to take responsibility for their own health, in addition to proactively engaging in their own health care. Although this dimension has yet to be examined in the ESRD population, findings suggest that improving self-care management behaviors leads to greater confidence in managing a patient's illness (Fredericks et al., 2012). Feelings of confidence have consistently been reported to be negatively correlated with anxiety (e.g. Lent & Brown, 2013). Thus, it makes sense that patients who take control and responsibility for their own health experience a better health locus of control, which acts as a buffer against feelings of anxiety (Cheng et al., 2013).

Nutritional QOL

Lower nutritional QOL is reported to be a predictor of anxiety. As discussed in the previous section, the relationship between anxiety and poor nutritional QOL has not been examined in the literature. However, it is interesting to note that anxiety disorders are common in both anorexics and obese populations (Pollice et al.,1997; Strine et al., 2008). The suggested mechanism primarily involves a obsessive-compulsive trait typical of persons suffering from anxiety disorders that leads to compulsive rituals connected to food (e.g. weighing every bit of food or binge eating). However, these findings relate to the official DSM-V diagnosis of eating disorders and may not be applicable to the present study. Nonetheless, future research on DM-ESRD should focus on examining the anxiety-nutritional QOL link.

Loneliness

Study findings indicate that the significant predictors identified using stepwise logistic regression models for loneliness were HLQ – Social Support, HLQ – Navigating Healthcare System, MULTIPles – Treatment Burden and Nutritional QOL.

HLQ – Social Support

Social support was associated with the less likelihood of reporting loneliness in the present study. As discussed in the previous section, current literature is rich in documenting an existing relationship between social support and feelings of loneliness (e.g. Griva et al., 2014). Poor social support is documented to lead to feelings of isolation and loneliness, and in particular to the context of chronic diseases, it has been found to contribute to poor coping strategies (Lazarus & Folkman, 1991). The documentation of the link between social support and loneliness rallies for future interventional efforts to target this area.

HLQ – Navigating the Healthcare System

A higher score on the HLQ – Navigating the Healthcare System was associated with the less likelihood of reporting loneliness. Osborne et al (2013) describes this HLQ dimension to involve patients' ability to advocate on their own behalf, or at least, find someone who can help them use the healthcare system to address their health needs if they are unable to do so. Hence, if patients are unable to make decisions on their own or find someone else to assist them in doing so, we may reasonably infer that these patients have a poor support network in the first place. However, it remains unclear how exactly a person's ability to navigate the healthcare system affects their levels of loneliness. Hence, further research is necessary in examining this HLQ dimension in the DM ESRD population.

MULTIPles – Treatment Burden

Treatment burden was associated with a greater likelihood of reporting loneliness. As chronic conditions, DM and ESRD are expected to cause feelings of burden on the population. Qualitative results suggest that patients experience treatment burden as a result of the high demands of dialysis, and that they often have to face the management of their conditions alone. Research examining the relationship between treatment burden and loneliness suggests that treatment burden is related to feelings of a loss of freedom with engaging in social activities, as well as feeling isolated and inadequately supported (and experiencing relationship strain) (Demain et al., 2015). Relationship strain is also documented in the qualitative results, where some elderly patients state that their children do not spend enough time with them and instead work too much.

Nutritional QOL

Poor nutritional QOL is found to be predictive of loneliness in the present study. In current literature, research is lacking in explaining the link between these two constructs. In the context of debilitating illnesses, the lack of social support is found to be related to poor nutrition, although the study did not examine the concept of loneliness per se (Gibbons et al., 2013). Proposed reasons include that patients with debilitating chronic conditions often rely on their caregivers and/or family members to look after aspects of their treatment (e.g. diet), and thus a poor network of such support may lead to the patient not receiving adequate nutrition. It is suggested that further research examine the biopsychosocial contexts surrounding ESRD patients and how it might affect nutrition.

Section 5: Study Strengths/Limitations and Future Directions.

Strengths and Limitations

The strengths of this study include a sample that is highly representative of the Singapore HD population. Selection bias was minimized as participants were not limited to patients who could read and complete the questionnaires by themselves.

Additionally this is the first systematic study to examine the prevalence and predictors of psychological distress in DM ESRD patients. A number of predictors were identified which offers future research some options for targeting psychological distress.

Although the qualitative component of the study is able to provide a rich description of patients' experience with multimorbidity, it is important to note that typical of qualitative studies, results may be more easily influenced by research bias.

The quantitative component of the study was cross-sectional, which disallows the conclusion of causality in the significant relationships documented. In addition, the present study extrapolated cut-off/classification categories from the original ULS-20, as there are no recommended guidelines for the proper cut-off/classification of ULS-8 score. While the reliability of the ULS-8 in the present study is accounted for, further validation of the ULS-8 would nonetheless be beneficial to determine the exact cut-off scores required for classification of lonely vs non-lonely.

Future Directions

The present study was able to successfully document the effect of psychological distress on the four measured psychosocial dimensions. However, current literature is lacking in exploring this particular subject area. Theoretical underpinnings behind psychological distress and the four psychosocial dimensions should be explored as a way to guide further research into the phenomena and inform intervention efforts.

The present population also reports poor health literacy, particularly so with psychologically distressed patients. Potential strategies to address health literacy in patients with chronic conditions include the increased use of patient navigators in supporting patients through the system (Manderson et al., 2012) such as the use of online methods of information delivery, which could be a viable option considering the increasing uptake of technology in the general population.

Illness perception is associated with a myriad of patient-reported outcomes. This study documents the presence of treatment burden perceptions and that the DM-ESRD population may face coping problems in prioritizing one illness over another. In addition, the study also found less-than ideal rates for nutritional QOL and problems with adherence. These psychosocial dimensions are important in improving the overall patient well-being and thus further studies/interventions need to address these areas.

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Appendix A
Interview Questions

A. INTRO BY FACILITATOR
Interviewer to introduce him/herself and outline purpose of interview - (emphasis on confidentiality)

B. INTERVIEW QUESTIONS

Diabetes & Dialysis	
1.	Could you give me a brief history of your diabetes and kidney problem(s) from when it started to you beginning dialysis?
2.	Are there any aspects of the HD or diabetes that you find particularly difficult to manage? Why?
3.	How do you feel about having to be on dialysis as well as managing diabetes? Have you ever felt that being on dialysis affects your diabetes or the opposite that diabetes affects how well you do on dialysis? In what ways and why? Prompt: Has there ever been a time when you have felt frustrated with having to manage both diabetes and dialysis? Please describe/give an example
4.	What is the physician's role/responsibility for the management of diabetes and kidney condition?
5.	What is the role/responsibility of your family for the management of diabetes and kidney condition?
6.	What are your treatment goals for your conditions? Prompt: Who set your treatment goals; Are you involved and if so is this effective?
7.	What are the main reasons for failing to achieve treatment goals (diabetes/kidney conditions)? Any other reasons? Prompt: What are the most important reasons for achieving treatment goals?
8.	On a day-to-day basis, how do you deal with diabetes and kidney

	conditions? Prompt: Do you have particular strategies for helping you with…?
Diet	
9.	What are the main challenges for people who have to follow diet for both diabetes and dialysis and why?
10.	How do you manage your diet for diabetes and dialysis on day-to-day basis? Prompt: Has there been a time when you had to prioritise one condition over other and when or why? Please describe or give an example.
11.	Can you think of any problems you have with following your diet or situations that make it more difficult? Prompt: Mood, special/social events, family outings
12.	Are there some aspects of your diet for either diabetes and/or kidney condition) that harder to follow than others/ that you find particularly (more) troublesome than others? Why?
13.	Are there any aspects of your diet for either diabetes and/or kidney condition) that you find hard to understand or remember? Why?
14.	Do you have any concerns regarding your dietary recommendations? Prompt: Is this more in relation to diabetes, kidney condition or both?
Fluid Intake	
15.	How do you manage with fluid intake?
16.	Can you think any problems you have with following your fluid intake recommendations?
17.	To what extent diabetes may affect or interfere with your fluid control? Why? (Give an example)
18.	Are there any things that you do that make it easier for you to regulate fluid intake?
Medication	
19.	What medication are you currently on as part of your treatment for diabetes and kidney condition?
20.	Do you have any concerns or worries relevant to the prescribed

	medication? Prompt: Side effects; addictive; costs
Support/Information Needs	
21.	Thinking of your health condition and all aspects of your treatment for both diabetes and kidney condition which do you think you could use the most help with? In what way you could use help?
22.	What do patients and their families need to know to manage better diabetes and dialysis?
23.	What more can be done to support patients and their families? What do you really think may be missing that could useful/helpful for patients with diabetes and on dialysis?
24.	What are some of the difficulties you foresee for running a program for people with diabetes and on dialysis? How to best work round or overcome these?
25.	When would be the best time to deliver any intervention, why and who would you like to deliver it?
26.	To what degree would you like your caregiver / family members to be involved in the intervention/program?
27.	Would you be interested in to engage with technology as part of intervention if at no extra costs for you but provided free (e.g. interactive applications, or mobile technology etc.) Why and why not?
28.	What program would be interested to participate? Why?
29.	Is there anything else on these topics or anything else that you would like to share?

Appendix B
Information Sheet and Consent Form

Project Title: IMPROVING OUTCOMES IN PATIENTS WITH DIABETES AND ON DIALYSIS – GAINING INSIGHT TO DESIGN A PROGRAM OF SUPPORT

Principal Investigator: National University of Singapore
A/Professor Griva Konstadina
[tel: 65163156; 81861423]

Co – Investigators: National Kidney Foundation
Dr Nandakumar Mooppil [tel: 95735564]

National University Hospital
Dr Eric Khoo [tel: 97220379]

You are invited to participate in a research project. This information sheet provides you with information about the research. The Principal Investigator or her representative will also describe this research to you and answer all of your questions. Read the information below and ask questions bout anything you don't understand before deciding whether or not to take part.

After you are satisfied that you understand this study and that you wish to take part in the study you must sign the consent form. You will be given a copy of this consent form to take home with you.

(1) What is the purpose of this research?

Managing diabetes and dialysis at the same time can be a particularly diffcult. Accomodating treatment in everyday life and following recommendations regarding self-care, diet and medication for both conditions can be quite overwhelming.

The purpose of this study is to develop a support intervention for patients with diabetes and on dialysis. To do so first we wish to understand better patients' and family members' experience with diabetes and dialysis, how they manage their treatments, the difficulties they are facing and the aspects with which they can use most help with.

By focusing on their perspectives we hope to be able to develop a service that would be better suited to meet patients' needs for support and improve on the health care they receive.

(2) Who can participate in the research? What is the expected duration of my participation? What is the duration of this research?

You were selected as a possible subject in this study because we are approaching all patients with diabetes who receive hemodialysis in the participating NKF centres as long as they have been on hemodialysis for more than 3 months, are over the age of 21 years, and are willing to participate in the study.

Individuals who only speak dialects (for example Teochew, Hokkien), or those with health concerns such as severely impaired hearing or vision or speech, or a comorbid diagnosis of dementia or severe cognitive impairment will not be eligible to take part in this research. Also, those who do not agree to the audio-recording of the interview will not be eligible to participate.

The research study will be running for 12 months but your actual participation will be no more than 40-60 minutes as it only involves one interview.

(3) What is the approximate number of participants involved?

Overall, we hope to invite approximately 20 patients, 20 family members and 10 health care professionals to take part in this study.

(4) What will be done if I take part in this research?

You will be asked to take part in one interview on your experience with managing diabetes and dialysis and your resources and preference for support. The interview will take place at a time and place convenient for you. This can be at one of your routine dialysis clinic visits or at different place and time if you so wish. The interview will take about 40-60 minutes depending on your sharing and wish to discuss your experience.

Should you feel too tired to complete the interview in a single session, you can ask the researcher to return for another session, if necessary. Please note that your interview session will be audio-recorded to facilitate transcriptions and analysis. The transcription will bear no personal information, i.e., it will be anonymized. Once transcribed the recordings will be destroyed.

Medical data will also be retrieved from your medical records only if you consent to this. These will include recent laboratory test results and interdialytic weight gains, information on treatment such as prescribed medications, how long you have been diagnosed with diabetes, how long you have been on dialysis and any other additional medical conditions and hospitalisation rates.

(5) How will my privacy and the confidentiality of my research records be protected?

All information collected during the course of the research will be kept strictly confidential. The National University of Singapore will overview the collection, storage, handling and processing of the data and Associate Professor Griva Konstadina, in her capacity as the principal investigator, will be responsible for security and access to the data. The information collected, except your name and NRIC number, will be stored and analysed confidentially in a computer. No personal information on the data held in the computer will enable a third party to link the data to you.

All your research data will be coded (i.e. only identified with a code number) at the earliest possible stage of the research. Only the principal investigator will know that the information is related to you and will have access to your identifiable information (i.e., your name, NRIC and contact information). This will not be released to any other person, including members of the research team. Your research data (including anonymized interview transcripts and medical information bearing only your study ID number) will be archived for 10 years after the completion of the research – after which time they will be deleted.

Personal identifiers such as name and NRIC number are required to facilitate retrieval of medical information from your medical records. This personal information will only be kept for 3 years after completion of study, after which it will be safely destroyed. We will be adhering to local and national data protection laws. We therefore need your permission to allow access to the parts of your medical records that are related to this study.

The results of the study may be published in the medical literature, but any identifiable information (e.g. name) will not be revealed. Quotes from your interview may be used in publications/presentations of this research without identifying you.

(6) What are the possible discomforts and risks for participants?

We do not expect there to be any discomfort or distress arising from this study. You are welcome to share and discuss as much or little as they like. You are in control of how much you want to share or which questions you like to answer or not. You do not have to answer a question that makes you uncomfortable or a question you do not wish to answer.

(7) What is the compensation for any injury?

The study procedures have been carefully designed to be completely non-invasive – none of the procedures is likely to pose any risk of harm or injury to you. As such there are no compensation arrangements in place.

(8) Reimbursement

You will receive $20 as a token of appreciation for study participation. This will be handed over after the completion of the interview.

(9) What are the possible benefits to me and to others?

There is no direct benefit to you from participating in this research. Most patients however enjoy the opportunity to express their views and report on their illness and treatment experience.

The knowledge gained will benefit the public and other patients in the future. We hope that the information produced by this study will help us to better understand patients' experiences with diabetes and dialysis and hence develop an intervention program that will be better meeting their needs and supporting them in making lifestyle changes related to medication, diet and fluid intake.

(10) Can I refuse to participate in this research?

You are entitled to refuse to participate or discontinue participation at any time in this research without giving any reason, by informing the Principal Investigator, and all research data relating to you will be destroyed. Refusal to participate or withdrawal from participation will not affect your medical management at or cause loss of benefits to which you are otherwise entitled either now or in the future.

(11) Whom should I call if I have any questions or problems?

Please contact the Principal Investigator, A/Professor Griva Konstadina at **telephone 65163561 and email psygk@nus.edu.sg** for all research-related matters and in the event of research-related injuries.

For an independent opinion regarding the research and the rights of research participants, you may contact a staff member of the National University of Singapore Institutional Review Board (Attn: Mr Chan Tuck Wai, at telephone 6516 1234 or email at irb@nus.edu.sg).

Consent Form

Project Title: IMPROVING OUTCOMES IN PATIENTS WITH DIABETES AND ON DIALYSIS – GAINING INSIGHT TO DESIGN A PROGRAM OF SUPPORT

Principal Investigator: Associate Professor Griva Konstadina (Tel: 65163156) National University of Singapore

I hereby acknowledge that:

1. My signature is my acknowledgement that I have agreed to take part in the above research.
2. I have received an information sheet that explains study aims and procedures and the use of my *data* in this research. I understand its contents and agree to take part in this research.
3. I can withdraw from the research at any point of time by informing the Principal Investigator and all *my data* will be discarded.
4. I will not have any financial benefits that result from the commercial development of this research.
5. I agree/ do not agree* to the use of my medical records for this research.
6. I agree to the audio-recording of the interview.

* This research has been explained to me in _________________ (state language), which I understand, by ____________ (name of translator) on _______ (date)

________________________________ ___________

Name and Signature (Participant) Date

________________________________ ___________

Name and Signature (Consent Taker) *
Date

________________________________ ___________

Name and Signature (translator) * Date

Appendix C
Quantitative Study Questionnaires (Without HLQ)

IMPROVING OUTCOMES IN PATIENTS WITH DIABETES AND ON DIALYSIS – GAINING INSIGHT TO DESIGN A PROGRAM OF SUPPORT

Your response to the following questions about yourself (e.g. age, employment status) would be very helpful. Please circle one number for each question or write in the answer on the lines provided.

[A1] **What is your gender**? (*please tick*): MALE ______ FEMALE _____

[A2] **What is your age and date of birth?** __________ _____________

[A3] **What is your first language?** *(please write in)* _________________

[A4] **What is your ethnic group?** (**according to NRIC**)

Chinese	**1**
Malay	**2**
Indian	**3**
Others: please specify ________________	**4**

[A5] **How many years of full-time education have you received?** _____ years

[A6] **What is your highest educational qualification?** _____________________

[A7] **What approximately is the current estimated monthly income of your *__overall__* family?** (Please remember your answers are confidential)

1	\$ 0 - \$ 2,000	4	\$ 6,001 – above
2	\$ 2,001 - \$ 4,000	5	don't know
3	\$ 4,001 - \$ 6,000	6	don't wish to answer

[A8] **How would you describe your relationship status?**
(please circle one number)

1	Married	4	Single
2	Divorced	5	Living with partner
3	Widowed	6	Others ________________

[A9] **Are you now able to work for pay full-time, part-time or not at all?**
(please circle one number)

1 I am able to work for pay full-time
2 I am able to work for pay part-time
3 I am unable to work for pay

[A10] **Which of the following responses best characterises your __current__ work activity or employment status?** *(please circle one number)*

1 employed full-time
2 employed part-time
3 self-employed
4 unemployed, laid off looking for work
5 retired
6 looking after home and family
7 student
8 other/none of the above

[A11] **Which of the following best describes your living arrangements:**
(please circle one number)

1 rent from private landlord
2 own home
3 live with parents/children
4 other

[A12] **Which of the following best describes your housing:**
(please circle one number)

1 1-2 HDB flat
2 3-4 HDB flat
3 HDB 5 room/executive/maisonette
4 Condominium, including executive condominium or private apartment
5 Terrace / Semi – Detached / Bungalow
6 Other (please specify____________________)

[A13] **What is your current living arrangement?** *(please choose that apply)*

1 staying alone
2 with spouse
3 with children
4 with parents
5 with siblings
6 extended family members
7 landlord and/or flatmate
8 friend
9 nursing home

[A14] **Do you have any long-standing illness, disability or infirmity other than diabetes and kidney failure?** *(If yes please give details)*

[A15] **How old were you when you have been diagnosed with diabetes?**
________ years old

[A16] **When did the doctor first tell you that you had kidney problems caused by diabetes?**

Age when told ___________
(or) Year when told |___|___|___|___
(or) _________ years ago
Not sure **999**

[A17] **How long have you been on hemodialysis?**

1 6 to 12 months
2 13 to 24 months
3 More than 24 months (2 years) __________

[B1] **Have you been told by a physician (Western-trained) that you have diabetic eye disease?** *(please circle one number)*

Yes	**1**
No	**2** (Go to **B2**)
Refuse to answer	**888** (Go to **B2**)
Do not know	**999** (Go to **B2**)

[B1.1] **When did the doctor first tell you you had diabetic eye disease?**

Age when told ___________
(or) Year when told |___|___|___|___
(or) _________ years ago
Not sure **999**

[B1.2] **Did you have eye surgery or laser procedure for your diabetic eye disease?** *(please circle one number)*

Yes	**1**
No	**2**
Refuse to answer	**888**
Do not know	**999**

[B2] **Have you ever been told by a physician (Western-trained) that you have nerve problems in your arms or legs caused by your diabetes?**
(please circle one number)

Yes	**1**
No	**2** (Go to **question B3**)
Refuse to answer	**888** (Go to **question B3**)
Do not know	**999** (Go to **question B3**)

[B2.1] **When did the doctor first tell you that you had nerve problems in your arms and legs caused by your diabetes?**

Age when told ___________

(or) Year when told |___|___|___|___

(or) _________ years ago

Not sure	**999**

[B3] **Has a doctor, a nurse, or healthcare professional told you that you have high blood pressure?** *(please circle one number)*

Yes	**1**	
No	**5**	(Go to **next questionnaire; turn page**)
Do not know	**999**	(Go to **next questionnaire; turn page**)

[B3.1] **How many years have you had high blood pressure?** ______ no. of years

[B3.2] **Are you currently on regular medications from your physician for high blood pressure?** *(please circle one number)*

Yes	**1**
No	**5**

THE BRIEF ILLNESS PERCEPTION QUESTIONNAIRE

For the following questions, please circle the number that best corresponds to your views:

DIABETES

1. How much does your diabetes affect your life?

0 1 2 3 4 5 6 7 8 9 10

no affect
severely at all
affects my life

2. How much control do you feel you have over your diabetes?

0 1 2 3 4 5 6 7 8 9 10

absolutely extreme
no control amount of control

3. How much do you think your treatment can help your diabetes?

0 1 2 3 4 5 6 7 8 9 10

not at all extremely
helpful

4. How much do you experience symptoms from your diabetes?

0 1 2 3 4 5 6 7 8 9 10

no symptoms many severe
at all
symptoms

5. How concerned are you about your diabetes?

0 1 2 3 4 5 6 7 8 9 10

not at all extremely
concerned concerned

6. How well do you feel you understand your diabetes?

0 1 2 3 4 5 6 7 8 9 10

don’t understand understand
at all very clearly

KIDNEY DISEASE

7. How much does your kidney disease affect your life?

0 1 2 3 4 5 6 7 8 9 10

no affect	severely
at all	affects my life

8. 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
no control	amount of control

9. 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

10. 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	

11. 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

12. 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

MULTIMORBIDITY ILLNESS PERCEPTIONS SCALE

Thinking about your diabetes and kidney disease, for the following questions, please circle the number that best corresponds to your views:

Treatment Burden Scale

1. Taking different medications for each of my conditions has caused me problems

0 1 2 3
4 5
Strongly Disagree Strongly Agree

2. Having more than one condition makes my treatments less effective

0 1 2 3
4 5
Strongly Disagree Strongly Agree

3. It is difficult to take all my medications the way I am supposed to

0 1 2 3
4 5
Strongly Disagree Strongly Agree

4. Having more than one condition makes it difficult to get the best available treatment

0 1 2 3
4 5
Strongly Disagree Strongly Agree

5. I don't like mixing medications for different conditions

0 1 2 3
4 5
Strongly Disagree Strongly Agree

6. I feel so overwhelmed by the treatment for one condition that it is hard to manage any others

0 1 2 3
4 5
Strongly Disagree
Strongly Agree Prioritisation Scale

1. One of my conditions is more serious than the others

0 1 2 3 4 5

Strongly Disagree Strongly Agree

2. One of my conditions has more of an impact on my life

0 1 2 3 4 5
Strongly Disagree Strongly Agree

3. One of my conditions dominates the others

0 1 2 3 4 5
Strongly Disagree Strongly Agree

4. One of my conditions is more worrying than the others

0 1 2 3 4 5

Strongly Disagree Strongly Agree

HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Please circle your answer to indicate whether you have been feeling this way the last 14 days.

		0	1	2	3
1	I feel tense or ‘wound up’	Most of the time	A lot of the time	Time to time, occasionally	Not at all
2	I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Not at all
3	I get a sort of frightened feeling like something awful is about to happen	Not at all	A little, but it doesn’t worry me	Yes but not too badly	Very definitely and quite badly
4	I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
5	Worrying thoughts go through my mind	Only occasionally	From time to time but not too often	A lot of the time	A great deal of the time
6	I feel cheerful	Most of the time	Sometimes	Not often	Not at all
7	I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
8	I feel as if I am slowed down	Not at all	Sometimes	Very often	Nearly all the time
9	I get a sort of frightened feeling like ‘butterflies in the stomach’	Not at all	Occasionally	Quite often	Very often

10	I have lost interest in my appearance	I take just as much care as ever	I may not take quite as much care	I don’t take as much care as I should	Definitely
11	I feel restless as if I have to be on the move	Not at all	Not very much	Quite a lot	Very much indeed
12	I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
13	I get sudden feelings of panic	Not at all	Not very often	Quite often	Very often indeed
14	I can enjoy a good book or radio or TV programme	Often	Sometimes	Not often	Very seldom

SHORT-FORM UCLA LONELINESS SCALE (ULS-8)

Please circle your answer.

(a) I lack companionship

Never Rarely Sometimes Always

(b) There is no one I can turn to

Never Rarely Sometimes Always

(c) I am an outgoing person

Never Rarely Sometimes Always

(d) I feel left out

Never Rarely Sometimes Always

(e) I feel isolation from others

Never Rarely Sometimes Always

(f) I can find companionship when I want it

Never Rarely Sometimes Always

(g) I am unhappy being so withdrawn

Never Rarely Sometimes Always

(h) People are around me but not with me

Never Rarely Sometimes Always

BECK HOPELESSNESS INVENTORY – Short Version

Please circle your answer for the statements below. Based on the past week:

1. I feel that the future is hopeless and that things cannot improve.

0 – Not typical	1 – Rarely typical	2 – Typical	3 –Very typical

2. My future seems dark to me.

0 – Not typical	1 – Rarely typical	2 – Typical	3 –Very typical

3. Things just won't work out the way I want them to.

0 – Not typical	1 – Rarely typical	2 – Typical	3 –Very typical

4. There's no use in really trying to get something I want because I probably won't get it.

0 – Not typical	1 – Rarely typical	2 – Typical	3 –Very typical

DIET AND FLUID INTAKE QUESTIONNAIRE

A. Nutrition-Specific Quality of Life (NSQOL)

Please circle your answer.

1. Since I started dialysis treatment food smells worse than before

(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

2. Since I started dialysis treatment I like different foods than I used to

(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

3. Since I started dialysis treatment I enjoy mealtimes
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

4. Since I started dialysis treatment I do not feel like eating
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

5. During the past 4 weeks how often have you had difficulty following your diet?
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

6. During the past 4 weeks how often have you not felt like eating?
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

7. Overall how do you rate your appetite over the past 4 weeks?
(1) Very good
(2) Good
(3) Fair
(4) Poor

(5) Very poor

8. During the past week (7 days), how would you rate your usual appetite?
(1) Very good
(2) Good
(3) Fair
(4) Poor
(5) Very poor

9. Please select the appropriate statement
(1) Over the past 7 days my appetite has remained good
(2) Over the past 7 days my appetite has changed from good to poor
(3) Over the past 7 days my appetite has changed from poor to good
(4) Over the past 7 days my appetite has remained poor

10. How would you rate your appetite on days that you have dialysis?
(1) Very good
(2) Good
(3) Fair
(4) Poor
(5) Very poor

11. Describe how you usually eat on days that you have dialysis?
(1) I usually don't eat enough food
(2) I usually eat the right amount of food
(3) I usually eat too much food

12. How often do you enjoying eating on days that you have dialysis?
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

13. How would you rate your appetite on days that you do not have dialysis?
(1) Very good
(2) Good
(3) Fair
(4) Poor
(5) Very poor

14. Describe how you usually eat on days that you do not have dialysis?
(1) I usually don't eat enough food.
(2) I usually eat the right amount of food.
(3) I usually eat too much food

15. How often do you enjoying eating on days that you do not have dialysis?
(1) Never
(2) Rarely
(3) Sometimes
(4) Usually
(5) Always

B. Appetite and Diet Assessment Tool (ADAT) + Additional diet and fluid intake questions

Please answer the following.

1. Do you have difficulty following your diet? Please tick your answer.

☐ 0 = No (Proceed to question number 2)
☐ 1 = Yes

If you answered “yes,” which of the following (1.1 – 1.6) describes why you are having difficulty. Please circle YES or NO.

1.1 I do not feel like eating.

YES	NO

C. Thirst/Dry Mouth

Please answer the following questions by circling the number that is appropriate to you.

1. On a scale of 0 – 10, how much of a problem is thirst for you on an everyday basis?

0	1	2	3	4	5	6	7	8	9	10
Not a problem										Very much a problem

2. On a scale of 0 – 10, how much of a problem is dry mouth for you on an everyday basis?

0	1	2	3	4	5	6	7	8	9	10
Not a problem										Very much a problem

DIALYSIS DIET AND FLUID NON-ADHERENCE QUESTIONNAIRE (DDFQ)

Please answer the following.

1. How many times in the last 14 days did you not follow your diet guidelines? Your response can range from 0 to 14 days.

_____

2. To what degree did you deviate from your diet guidelines? Please circle your answer.

No deviation Mild Moderate Severe Very severe

0________1_______2________3________4

3. How many times in the last 14 days did you not follow your fluid guidelines? Your response can range from 0 to 14 days.

_____

4. To what degree did you deviate from your fluid guidelines? Please circle your answer.

No deviation Mild Moderate Severe Very severe

0________1_______2________3________4

THE SUMMARY OF DIABETES SELF-CARE ACTIVITIES (SDSCA)

The questions below ask you about your diabetes self-care activities for the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

DIET

1.1	How many of the last SEVEN days have you followed a healthful eating plan?						
☐ **0**	☐ **1**	☐ **2**	☐ **3**	☐ **4**	☐ **5**	☐ **6**	☐ **7**

1.2	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?						
☐ **0**	☐ **1**	☐ **2**	☐ **3**	☐ **4**	☐ **5**	☐ **6**	☐ **7**

MEDICATIONS

5.1	Which of the following medications for your diabetes has your doctor prescribed? Please tick all that apply. _ a. An insulin shot 1 or 2 times a day. _ b. An insulin shot 3 or more times a day. _ c. Diabetes pills to control my blood sugar level. _ d. Other (specify): ____________________ _ e. I have not been prescribed either insulin or pills for my diabetes.

5.2	On how many of the last SEVEN DAYS, did you take your recommended diabetes medication?

☐ **0**	☐ **1**	☐ **2**	☐ **3**	☐ **4**	☐ **5**	☐ **6**	☐ **7**

ADHERENCE TO MEDICATIONS (MORISKY)

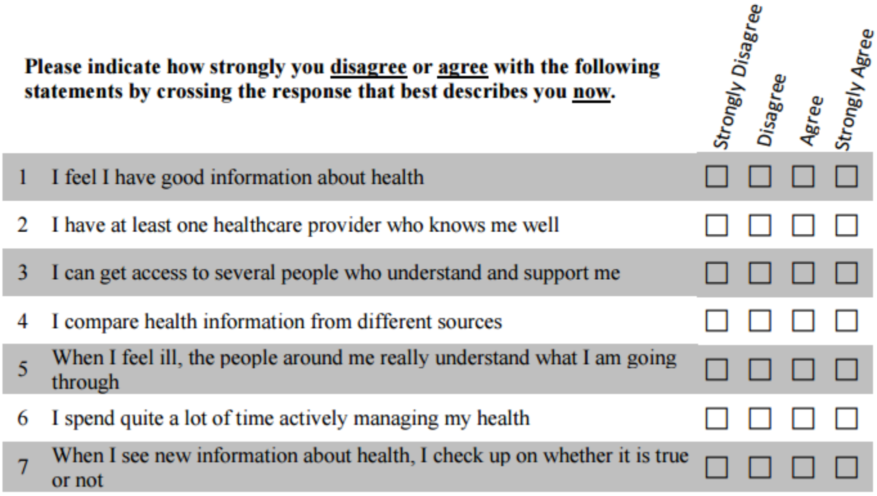
You indicated that you are taking medications for your diabetes and kidney disease. Individuals have identified several issues regarding their medication-taking behaviour and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your diabetes and kidney disease medications.

Please put an “X” in the box that best indicates your response to each item.

		NO	**YES**
M1	Do you sometimes forget to take your diabetes and kidney disease medication(s)?	☐ 0	☐ 1
M2	People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two (2) weeks, were there any days when you did not take your diabetes and kidney disease medication(s)?	☐ 0	☐ 1

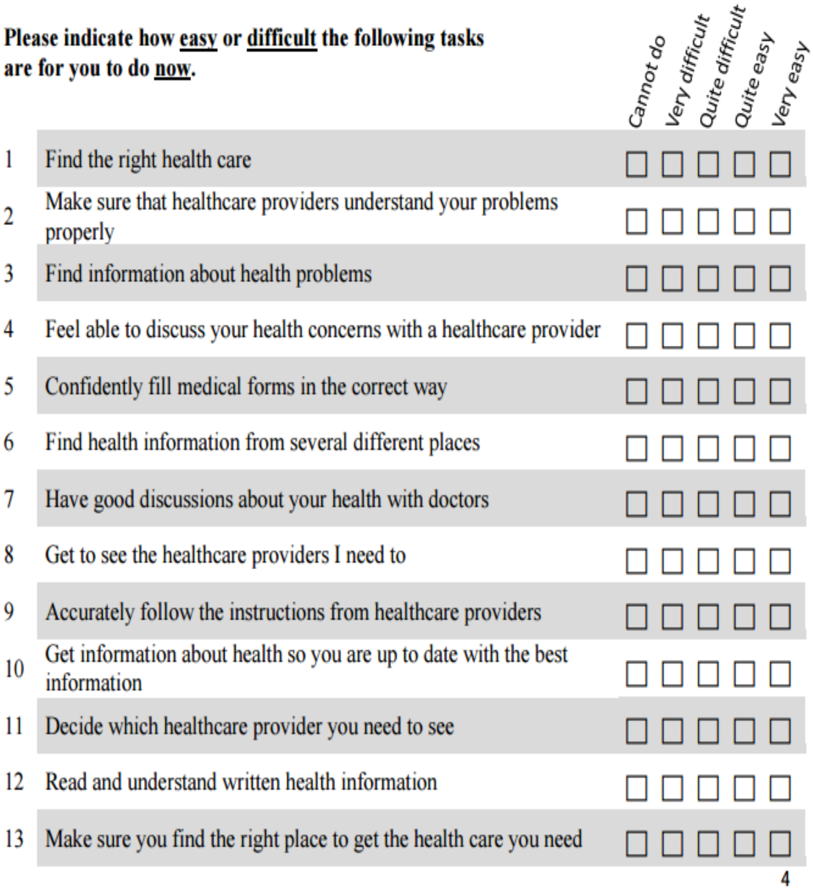
M3	Have you ever cut back or stopped taking your medication(s) without telling your doctor, because you felt worse when you took it?	☐ 0	☐ 1
M4	When you travel or leave home, do you sometimes forget to bring along your diabetes and kidney disease medication(s)?	☐ 0	☐ 1
M5	Did you take your diabetes and kidney disease medication(s) yesterday?	☐ 0	☐ 1
M6	When you feel like your diabetes and kidney disease is under control, do you sometimes stop taking your medication(s)?	☐ 0	☐ 1
M7	Taking medication everyday is a real inconvenience for some people. Do you ever feel hassled about sticking to your diabetes and kidney disease treatment plan?	☐ 0	☐ 1
M8	How often do you have difficulty remembering to take all your medication(s)? ☐ 0 **Never / Rarely** ☐ 1 **Once in a while** ☐ 2 **Sometimes** ☐ 3 **Usually** ☐ 4 **All the time**		

Appendix D
Health Literacy Questionnaire



Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

		Strongly Disagree	Disagree	Agree	Strongly Agree
1	I feel I have good information about health	☐	☐	☐	☐
2	I have at least one healthcare provider who knows me well	☐	☐	☐	☐
3	I can get access to several people who understand and support me	☐	☐	☐	☐
4	I compare health information from different sources	☐	☐	☐	☐
5	When I feel ill, the people around me really understand what I am going through	☐	☐	☐	☐
6	I spend quite a lot of time actively managing my health	☐	☐	☐	☐
7	When I see new information about health, I check up on whether it is true or not	☐	☐	☐	☐



Please indicate how easy or difficult the following tasks are for you to do now.

		Cannot do	Very difficult	Quite difficult	Quite easy	Very easy
1	Find the right health care	☐	☐	☐	☐	☐
2	Make sure that healthcare providers understand your problems properly	☐	☐	☐	☐	☐
3	Find information about health problems	☐	☐	☐	☐	☐
4	Feel able to discuss your health concerns with a healthcare provider	☐	☐	☐	☐	☐
5	Confidently fill medical forms in the correct way	☐	☐	☐	☐	☐
6	Find health information from several different places	☐	☐	☐	☐	☐
7	Have good discussions about your health with doctors	☐	☐	☐	☐	☐
8	Get to see the healthcare providers I need to	☐	☐	☐	☐	☐
9	Accurately follow the instructions from healthcare providers	☐	☐	☐	☐	☐
10	Get information about health so you are up to date with the best information	☐	☐	☐	☐	☐
11	Decide which healthcare provider you need to see	☐	☐	☐	☐	☐
12	Read and understand written health information	☐	☐	☐	☐	☐
13	Make sure you find the right place to get the health care you need	☐	☐	☐	☐	☐

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Please indicate how easy or difficult the following tasks are for you to do now.

		Cannot do	Very difficult	Quite difficult	Quite easy	Very easy
14	Get health information in words you understand	☐	☐	☐	☐	☐
15	Discuss things with healthcare providers until you understand all you need to	☐	☐	☐	☐	☐
16	Find out what healthcare services you are entitled to	☐	☐	☐	☐	☐
17	Read and understand all the information on medication labels	☐	☐	☐	☐	☐
18	Get health information by yourself	☐	☐	☐	☐	☐
19	Work out what is the best care for you	☐	☐	☐	☐	☐
20	Ask healthcare providers questions to get the health information you need	☐	☐	☐	☐	☐
21	Understand what healthcare providers are asking you to do	☐	☐	☐	☐	☐

Please indicate how strongly you disagree or agree with the following statements by crossing the response that best describes you now.

		Strongly Disagree	Disagree	Agree	Strongly Agree
8	I have at least one healthcare provider I can discuss my health problems with	☐	☐	☐	☐
9	I make plans for what I need to do to be healthy	☐	☐	☐	☐
10	I have enough information to help me deal with my health problems	☐	☐	☐	☐
11	If I need help, I have plenty of people I can rely on	☐	☐	☐	☐
12	I always compare health information from different sources and decide what is best for me	☐	☐	☐	☐
13	Despite other things in my life, I make time to be healthy	☐	☐	☐	☐
14	I am sure I have all the information I need to manage my health effectively	☐	☐	☐	☐
15	I have at least one person who can come to medical appointments with me	☐	☐	☐	☐
16	I know how to find out if the health information I receive is right or not	☐	☐	☐	☐
17	I have the healthcare providers I need to help me work out what I need to do	☐	☐	☐	☐
18	I set my own goals about health and fitness	☐	☐	☐	☐
19	I have strong support from family or friends	☐	☐	☐	☐
20	I ask healthcare providers about the quality of the health information I find	☐	☐	☐	☐
21	There are things that I do regularly to make myself more healthy	☐	☐	☐	☐
22	I can rely on at least one healthcare provider	☐	☐	☐	☐
23	I have all the information I need to look after my health	☐	☐	☐	☐