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# Health Beliefs And Medication Taking Behaviour Of Individuals Living With Mild To Moderate Chronic Kidney Disease

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HEALTH BELIEFS AND MEDICATION TAKING BEHAVIOUR OF INDIVIDUALS  
LIVING WITH MILD TO MODERATE CHRONIC KIDNEY DISEASE

by

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A thesis  
presented to Ryerson University

in partial fulfillment of the  
requirements for the degree of  
Master of Nursing  
in the Program of  
Nursing

Toronto, Ontario, Canada, 2010

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## **Abstract**

Health Beliefs and Medication Taking Behaviour of Individuals Living with Mild to Moderate Chronic Kidney Disease (CKD)

Adelaide Kit-Ling Hui, Master of Nursing, Daphne Cockwell School of Nursing, Ryerson University, 2010

The aims of this secondary analysis were to describe medication taking behaviour and health beliefs among people with mild to moderate CKD, examine differences in health beliefs according to age and gender, and examine relationships between health beliefs and medication taking behaviour. The sample consisted of 30 men and 30 women between 19 and 72 years old. Forty-two participants reported they did not miss medication doses, but remembering to take all the pills was the most challenging. Women were more likely to believe their kidney function would improve in the future and to believe treatment would keep them from becoming ill. No statistically significant differences were found in health beliefs by age. Perceived barriers were the strongest indicator of medication taking behaviour. Findings from this study shed light on the complexity of the medication regimen in CKD, and could guide health care providers to better support medication taking behaviour.

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## **Chapter 1 Introduction to Medication Taking Behaviour and Mild to Moderate Chronic Kidney Disease**

Chronic kidney disease (CKD) is a growing health problem with increasing incidence and prevalence (Levey et al., 2003). On a daily basis, 14 Canadians are told they have CKD (The Kidney Foundation of Canada, 2010); and in 2006, 33,823 Canadians, diagnosed with CKD, required replacement therapy such as dialysis or kidney transplant (The Kidney Foundation of Canada, 2010; Schaubel, Morrison, Desmeules, Parsons, & Fenton, 1999). Despite advances in treatment, managing CKD may be challenging for the individual due to treatments related to kidney function decline, comorbid conditions associated with CKD, and frequent hospitalizations (The Kidney Foundation of Canada, 2010; Schaubel et al., 1999). Because of the increasing incidence of CKD and the potential impact of CKD on the individual, it is a serious health concern for Canadians.

According to the Canadian Society of Nephrology, CKD is a broad diagnosis defined as the “presence of kidney damage for a period greater than 3 months” (Levin, Hemmelgarn, & Culeton, 2008, p. 1154). Causes of CKD vary, and can either be primary or secondary in nature. Primary kidney disease originates within the kidneys (Leaf, Appel, & Radhakrishnan, 2010), whereas secondary kidney disease can be a result of other underlying medical conditions such as cardiovascular illnesses, diabetes, infection, or lupus (National Kidney Foundation (NKF), 2002). The course of CKD depends on the severity of kidney damage, and has been characterized by five progressive stages ranging from mild CKD to kidney failure (NKF, 2002). Mild to moderate CKD, or stages 1-3, represents the early phase of the illness trajectory where an individual has normal or mildly reduced kidney function (NKF, 2002). On the other end of the

spectrum, stage 4 represents severe reduction in kidney function; and stage 5, also known as kidney failure, requires replacement therapy such as dialysis or transplantation (NKF, 2002).

To prevent and minimize progression of CKD to kidney failure, attention has shifted towards early interventions and promotion of illness management early in the course of the illness (Bello, Nwankwo, & Nahas, 2005; Levey et al., 2003). In mild to moderate CKD, taking medications is one of the strategies used to prevent illness progression and promote renal health (Nicholas et al., 2005). However, medication taking may pose a challenge when the diagnosis necessitates the consumption of multiple medications in a day, such as the case in mild to moderate CKD (Nicolas et al.). Failure to take medication consistently has been identified as one of the main causes of illness progression in CKD, and can place individuals at increased risk of developing co-morbidities, such as uncontrolled blood pressure, cardiovascular illnesses, bone disorders, malnutrition, and infections (Bello et al., 2005; Levin et al., 2008); these additional health problems may contribute to a decreased level of well-being and increased hospitalization (Bello et al.; Levin et al.). Although taking medications early in the course of the illness is important, little is known about how individuals living with mild to moderate CKD manage their medications.

Managing the complexity of the medication regimen can be difficult. Although no research has described or examined medication taking behaviour in mild to moderate CKD, dialysis and transplant studies have revealed that approximately 50% of kidney transplant recipients, and 50% of the patients on dialysis were successful in managing their medication regimens (Bernadini, Nagy, & Piraino, 2000; De Geest et al., 1995). Similarly, only 50% of the patients living with chronic illnesses similar in nature to CKD were reported to be successful in

managing their medications (Claxton, Cramer, & Pierce, 2001; Cramer, Benedict, Muszbek, Keskinaslan, & Khan, 2008; Roter, Merisca, Nordstrom, Cretin, & Svarstad, 1998). Because patients diagnosed with mild to moderate CKD may take similar medications as those who are being treated with kidney failure, these statistics suggest individuals living with mild to moderate CKD may experience similar challenges in managing their medication regimens. However to date, this has not been examined in CKD, and therefore further research is required to determine if results from other illness populations are comparable to mild to moderate CKD.

Mild to moderate CKD is often asymptomatic (Brantsma et al., 2008), which sets individuals in this population apart from those who are experiencing the severe symptoms related to rapid decline in kidney function and kidney failure. In the absence of symptoms, integrating an ongoing medication regimen into their life circumstances may require a tremendous effort from the individual. Costantini et al. (2008) reported that those living with mild to moderate CKD encountered daily challenges in managing their prescribed medications. For example, some respondents from this study reported the regimens to be restrictive whereas others felt the number of medications to be excessive when they were physically “feeling well” (Costantini et al., 2008, p. 152). Although there is no other published research substantiating these results, these preliminary findings indicate that patients diagnosed with mild to moderate CKD may require more guidance to understand the need for medications and to manage their medications. To better assist these individuals to integrate their medication regimens into their daily lives, it is necessary to first understand the manner in which individuals living with mild to moderate CKD manage their medications.

Adverse health outcomes related to kidney function decline can be ameliorated and prevented if medication taking behaviour is supported and promoted in earlier stages of the illness (Locatelli, Vecchio, & Pozzoni, 2002). Research focus should therefore be directed towards understanding medication taking behaviour, and identifying factors that can influence such behaviour for people with mild to moderate CKD. Minimal research has addressed factors influencing medication taking in this population. However, one factor identified in the literature among other populations with chronic illnesses is health beliefs (Gregmigni et al., 2007; Russell, Kilburn, Conn, Libbus, & Ashbaugh, 2003; Russell et al., 2006; Svensson, Kjellgren, Ahlner, & Saljo, 2000). In general terms, health beliefs can be understood as an individual's perceptions about his/her own health, and vulnerability to an illness, as well as his/her perceptions on treatment efficacy (Rosenstock, 1974). Health beliefs, such as perceptions about medications, have been shown to shape medication taking behaviour among kidney transplant recipients (Gregmigni et al., 2007; Russell et al., 2003). One theoretical perspective commonly used to examine the role of health beliefs in shaping health behaviour is the Health Belief Model.

### **The Health Belief Model and Medication Taking Behaviour**

According to the Health Belief Model (HBM), which describes and predicts health behaviours, such as medication taking behaviour, health beliefs are comprised of perceived susceptibility to an illness, perceived severity of the illness, as well as perceived benefits and barriers to interventions directed towards the illness (Rosenstock, 1974). Currently, it is unclear how health beliefs affect medication taking behaviour in mild to moderate CKD. However, empirical evidence suggests that health beliefs (such as perceived benefits and perceived barriers) towards the uses and properties of immunosuppressive medications post kidney

transplant (Gregmigni et al., 2007; Russell et al., 2003), or antihypertensive medications (Johnson, Williams, & Marshall, 1999) may influence an individual's decision to take medications consistently. For example, if the individual believes a medication is effective in treating the condition (perceived benefits), he or she will be more likely to take the medications consistently. On the other hand, if the individual believes there are barriers which prevent them from taking medications consistently (perceived barriers), he or she will be more likely to miss doses of medications. Given the similarity in the types of medications used in kidney transplant or hypertension with those being prescribed in mild to moderate CKD, these findings may apply to mild to moderate CKD as well. However to date, limited research has explored the relationships between health beliefs and medication taking behaviour in this population. Ultimately, understanding health beliefs held towards CKD and the medications used to treat it might be useful in the development of interventions directed at supporting effective medication taking behaviour in this population.

The HBM further suggests that sociodemographic variables, such as gender and age, may shape health behaviours through health beliefs (Rosenstock, 1974). In particular, the model suggests that men and women may hold different health beliefs about their illnesses and treatments, which may result in different health behaviours. Furthermore, the model also suggests that health beliefs may differ between younger and older individuals. Researchers have examined the relationships between these sociodemographic variables and medication taking behaviour to identify those who are at greater risk of developing poor medication taking behaviour. However, inconsistent results have been reported across these studies.

The literature examining gender differences in medication taking behaviour in CKD is scant. However, available data suggest that men and women may hold different health beliefs, which may in turn, lead to different medication taking behaviour. In general, women with chronic illnesses are more likely to report greater levels of perceived barriers than men. For example, women living with CKD (Sacks, Peterson, & Kimmel, 1990) and hypertension (Johnson et al., 1999) reported experiencing more barriers related to the use of medications, including medication side effects, such as headaches, dizziness, vomiting, and physical body changes, which resulted in inconsistent medication taking behaviour in comparison to men. These findings suggest that medication taking behaviour may differ between genders due to different health beliefs. Because differences in health beliefs between men and women have not previously been explored in mild to moderate CKD, additional research is needed in this area.

Similarly, the literature exploring medication taking behaviour between younger and older patients with CKD also yielded varying results. For example, older patients living with various chronic conditions, including CKD, perceived being forgetful as a barrier to managing and maintaining medication taking behaviour (Banning, 2008; Gray, Mahoney & Blough., 2001; Gregmigni et al., 2007; Whetstone & Reid, 1991); whereas younger kidney transplant recipients reported they were less likely to take medications due to competing roles and responsibilities (Orr, Orr, Willis, Holmes, & Britton, 2007). These results suggest that medication taking behaviour between younger and older patients may differ because they hold different health beliefs towards the use of medications at different developmental stages. Given that the association between age and health beliefs reported in the literature is inconsistent, and because

this has never been explored in mild to moderate CKD, future studies need to examine this relationship further.

### **Research Problem**

Much attention has been devoted to examining medication taking behaviour among individuals in kidney failure with little emphasis in the early course of the illness. Given the variation in experiences between mild to moderate CKD and kidney failure, it is difficult to apply research findings from kidney failure to mild to moderate CKD. Thus, little is known about medication taking behaviour among people with mild to moderate CKD, or the factors affecting it. Understanding medication taking behaviour in mild to moderate CKD is important because proper use of medication can dramatically improve clinical symptoms, delay illness progression, and minimize adverse health consequences associated with illness deterioration (Bello et al., 2005; Levin et al., 2008; Nicholas et al., 2005). Studies are therefore needed to understand medication taking behaviour and factors which can influence it in mild to moderate CKD.

### **Purpose**

The purpose of this study was to: 1) describe medication taking behaviour among people with mild to moderate CKD, 2) describe health beliefs associated with CKD and medication taking, 3) explore the differences in health beliefs between genders, 4) explore the relationship between age and health beliefs, and 5) examine the relationships between health beliefs and medication taking behaviour among individuals living with mild to moderate CKD.

## **Significance**

With the number of individuals being diagnosed with CKD continuing to rise every year in Canada (The Kidney Foundation of Canada, 2010), it is important to identify those who are at risk for poor medication taking behaviour, and to seek an understanding of the factors associated with medication taking behaviour in order to support early interventions for people living with mild to moderate CKD. The current study has the potential to improve our limited knowledge of medication taking behaviour among a group of individuals who may benefit from early intervention to prevent illness deterioration.

## **Chapter 2 Background and Literature Review**

This chapter will begin with a brief summary of chronic kidney disease and the different types of medications used to treat it. Next, the literature review will include both theoretical and empirical works examining concepts related to medication taking behaviour, as well as the components of the HBM. Because medication taking behaviour is closely related to medication adherence and compliance, studies related to medication adherence and compliance will be considered to provide a thorough understanding of the concept.

### **Literature Search Strategy**

The search strategy employed the following data bases: CINAHL, Medline, and Psychology and Behavioural Sciences Collection. The following search terms were used in combination: medication taking behaviour, medication taking, adherence, compliance, CKD, mild CKD, early CKD, moderate CKD, dialysis, hemodialysis, transplantation, kidney transplant, renal transplant, hypertension, chronic illnesses, health beliefs, medication taking, age, and gender. Hypertension and cardiovascular illness studies were included in the literature search because these illness populations are similar in nature, and components of the medication regimens are comparable to those living with mild to moderate CKD. Literature that investigated medication taking, adherence, or compliance specifically in mild to moderate CKD was not found. One study explored the self-management experiences of people living with mild to moderate CKD and was included.

## Background of Chronic Kidney Disease

Chronic kidney disease is defined as the presence of kidney damage for a period greater than 3 months (Levin et al., 2008). The severity of CKD is categorized according to the level of glomerular filtration rate (GFR), which is an indicator of how well the kidney filtration system works (NKF, 2002). Stages of CKD have been established by the Kidney Disease Outcomes Quality Initiative (K/DOQI) in order to improve the diagnosis and treatment of CKD (NKF, 2002). Table 1 outlines the staging of the CKD spectrum.

Table 1

*Stages of CKD*

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Stage 1/Mild CKD	Kidney damage with normal GFR
Stage 2/Mild CKD	Kidney damage with mildly reduced GFR
Stage 3/Moderate CKD	Moderate reduction in GFR
Stage 4/ Severe CKD	Severe reduction in GFR
Stage 5/ Severe CKD	Kidney failure

---

NKF (2002)

Mild CKD, classified as stages 1 and 2 under the K/DOQI guidelines, is generally characterized by normal or mildly reduced kidney function (NKF, 2002); and moderate CKD, stage 3, is associated with a moderate decrease in kidney function (NKF). Presentation of mild to moderate CKD can range from an absence of signs and symptoms to the presence of signs, such as high blood pressure (Brantsma et al., 2008). As the illness progresses to kidney failure, or

stage 5 of the CKD spectrum, renal function is markedly reduced to the point where renal replacement therapy such as dialysis or transplantation is required (NKF, 2002).

CKD has many different causes and this study is focusing on primary kidney disease. Primary kidney disease is comprised of a group of illnesses that are limited to the kidneys (Alexopoulos, 2004; Leaf et al., 2010). Glomerular kidney disease, which is a type of primary kidney disease, is associated with damage to the glomeruli, which leads to the inflammation or scarring of the kidneys (Alexopoulos, 2004; Leaf et al., 2010). Primary kidney disease in the early stage can be asymptomatic, but common signs and symptoms of primary kidney disease may include hematuria, proteinuria, reduced GFR, or swelling of body parts (Alexopoulos, 2004; Leaf et al., 2010). A diagnosis is often made after the completion of a kidney biopsy, and treatment modalities vary considerably depending on the cause as well as the stage of the illness (NKF, 2002; The Kidney Foundation of Canada, 2006). However, regardless of the cause of CKD, individuals diagnosed with mild to moderate CKD are at risk of progressing to severe kidney impairment resulting in kidney failure (Bello et al., 2005).

Any medical intervention, which serves to protect renal function and prevent illness progression, is extremely important as empirical evidence supports that interventions are more effective if initiated as early as possible (Bello et al., 2005; Locatelli et al., 2002; Nicholas et al., 2005; Wuhl & Schaefer, 2010). Therefore, once a CKD diagnosis is confirmed, measures to preserve kidney function should start immediately. Taking medication is one crucial component of illness management as pharmacological intervention can dramatically slow progression of CKD (Bello et al., 2005; Wuhl & Schaefer, 2010).

For primary glomerular disease, several families of medications can be used in synergy to achieve renoprotective results. Firstly, because there is a strong link between autoimmunity and kidney damage in primary kidney disease, individuals in the early phase of the illness are often prescribed immunosuppressants or steroids (Alexopoulos, 2004). Secondly, because the kidneys are responsible for managing blood pressure, hypertension can be a complication of CKD (Collins et al., 2003; Sarnak et al., 2003). In fact, the NKF has identified that people living with CKD have a heightened risk of developing cardiovascular illnesses such as stroke and peripheral vascular disease, and more people with CKD die of cardiovascular related problems rather than kidney failure (NKF, 2002). As a result, antihypertensive medications make up a large component of the daily medication regimen. Choices of medications to achieve good blood pressure control may vary, but in general they consist of agents such as Angiotensin-Converting Enzyme (ACE) inhibitors and diuretics (Alexopoulos, 2004; Snively & Gutierrez, 2004). In addition to the uses of immunosuppressants and antihypertensives, patients may also need anti-hyperlipidemic agents, bone protective and anti-anemic agents to treat other medical conditions associated with CKD (Alexopoulos, 2004; Snively & Gutierrez, 2004).

While some medications require the individual to take them once a day, others such as antihypertensives and immunosuppressants, may necessitate the patient to take several doses in a day, and may need frequent dose adjustments based on individual responses to the medications (Alexopoulos, 2004; Munar & Singh, 2007; Nicholas et al., 2005; Snively & Gutierrez, 2004; ). Another major challenge in managing the medication regimen can be related to side effects of medications. Side effects of medications such as antihypertensives, immunosuppressants, and diuretics include light headedness, frequent urination, hair loss, dry mouth, or sleep disturbances

(Gregmigni et al., 2007; Butler et al., 2004; DeGeest et al., 1995; Karamanidou, Clatworthy, Weinman, & Horne, 2008; Stamatakis, Pecora, & Gunel, 1997). In some instances, these side effects have prevented individuals, such as transplant recipients (Butler et al.; Gregmigni et al.) and individuals on dialysis (Curtin, Svarstad, & Keller, 1999; Karamanidou et al.; Stamatakis et al.), from continuing with their prescribed medication regimens. Because antihypertensives, immunosuppressants, and diuretics are common medications for individuals diagnosed with mild to moderate CKD, it is likely that some of these individuals may also experience the side effects reported in the literature, thus placing them at greater risk of developing poor medication taking behaviour. The medication regimen for CKD is complex, multifaceted, and may be associated with unpleasant side effects; all of which may present challenges for patients with mild to moderate CKD in establishing medication taking behaviour. As such, future research studies need to focus on better understanding the manner in which medications are being managed by individuals living with mild to moderate CKD in order to assist those who may be at risk of developing poor medication taking behaviour.

### **Theoretical Review of the Literature**

The following section will present the theoretical review of the literature. This section will begin with a discussion of health behaviours and specifically, medication taking behaviour. Related concepts such as compliance and adherence will then be explored. Finally, health beliefs as they pertain to the understanding of medication taking behaviour within the context of the HBM will be discussed.

## **Health behaviours.**

The concept of health behaviour is multidimensional, and can be considered as the actions taken by an individual to prevent illnesses and to maintain health. A common form of health behaviour is that of health promoting behaviour. Laffrey, Loveland-Cherry, and Winkler (1986) defined health promoting behaviours to be activities directed towards achieving a greater level of health. Health promoting behaviours may include activities geared towards improved health states, such as engaging in exercises, taking medications, following diets, or any other types of preventative measures which minimize the chance of contracting an illness or illness progression (Laffrey et al., 1986; Pender, 1996). One type of health promoting behaviour is medication taking behaviour.

### ***Medication taking behaviour.***

Medication taking behaviour is a concept that is complex, multifaceted, and challenging to describe. Broadly defined, medication taking behaviour is the manner in which individuals manage their medication regimen (Banning, 2008). A medication regimen is a plan of therapy, which includes the choice of drugs, prescribed dosages, medication forms, and dosage frequency (Russell et al., 2006). Medication taking behaviour has been described among kidney transplant recipients, and includes a set of actions requiring patients to repetitively perform complex activities, including identifying pills, counting pills, timing pill taking, and periodically refilling medication prescriptions (Russell et al.). In mild to moderate CKD, medications can be in pill form or in liquid suspension, whereas medication dosing frequency may vary from taking medications once a day to several times a day (Bello et al., 2005; Munar & Singh, 2007).

Given the complex nature of medication taking behaviour, a number of actions related to medication taking have been studied and reported, such as how individuals perform the routines of taking medication, timing medication, refilling medications, and taking medications. Because there are numerous ways to understand and report medication taking behaviour, the language used to describe it can be confusing and has undergone several transitions in the literature (Vermiere et al., 2001). Two core concepts, compliance and adherence, are commonly used to describe medication taking behaviour despite subtle differences in the meanings associated with them (Pound et al., 2005).

#### *Compliance.*

The majority of the studies have theoretically defined compliance as the “extent to which the patient’s actual history of drug administration corresponds to the prescribed regimen” (Urquhart, 1996, p. 8). Compliance has also been defined as the extent to which a person’s health behaviour, such as medication taking, following diets, or executing life-style changes, corresponds with medical or health care advice (Sackett et al., 1975). Compliance within the context of medication taking has also been understood in terms of the process of successfully taking medications; and on the contrary, non-compliance refers to an inability to carry out the process of medication taking as prescribed (Vermiere et al., 2001).

Although many conceptualizations of compliance have been established, it is undeniable that the term implies a negative connotation of obedience. According to Vermiere et al. (2001), a compliant patient follows the doctor’s prescriptions, whereas a non-compliant patient fails or refuses to comply. Such patriarchal dominance not only enforces the power disparity between the health care provider and the patient, it also undermines the ability for someone to make

independent decisions (Vermiere et al.). Hence, the term adherence was put forward in the literature to expand the perspectives associated with the term compliance.

*Adherence.*

Several conceptual definitions of adherence can be found in the literature, and some of these definitions are very similar to compliance. For example, adherence has been conceptualized as the extent to which patients follow instructions (Haynes et al., 2005), or the extent to which an individual's actions or behaviours coincide with medical instructions (Christensen, 2004). McElnay (2005) further described adherence to specifically include "patient's behaviour in terms of taking medicines, following diets, or executing lifestyle changes, which coincides with the advice given by health care professionals" (McElnay, 2005, p.20). The notion of partnership was incorporated in Rose et al.'s (2000) and Vlasnik et al.'s (2005) definitions of adherence by acknowledging that medication adherence is attained after "making an informed choice in a supportive environment" (Vlasnik et al., 2005, p. 47) based on mutually derived goals (Rose et al., 2000). Because the term adherence suggests patients are partners with health care providers in managing their illness, the term adherence is generally preferred in the literature.

Although both compliance and adherence are perceived as narrower descriptions of medication taking behaviour, the language used in the literature is still vexing. In fact, it is not uncommon to find authors considering the terms, and phenomena of compliance and adherence synonymously and interchangeably even among recent research (Banning, 2008; Haynes et al., 2005). To maintain a level of consistency in this research study, the terms adherence and nonadherence will be used in discussing the literature on medication taking behaviour.

*Non-adherent behaviours.*

The body of literature examining adherence among chronic illnesses in general, tends to focus on non-adherence rather than adherence, which may reflect concerns associated with non-adherence and poor outcomes (Banning, 2008; Breiterman-White; 2004; Christensen, 2004; Claxton et al., 2001; Cramer et al., 2008; De Geest et al., 1995; DiMatteo, 2004; Wainwright & Gould, 1997). Non-adherent behaviours have been conceptualized in various ways. The literature review by Vermiere et al. (2001) identified non-adherent behaviours among chronic illnesses in general, to include the following: delay in seeking care, not attending follow-up appointments, or not following a physician's instructions for treatments. Although many definitions of non-adherent behaviours related to medication taking have been discussed in the literature, no references were found that described and defined medication taking behaviour or non-adherent behaviours in mild to moderate CKD. Among kidney transplant and dialysis studies, non-adherent behaviours are generally considered to be the result of ineffective establishment of medication taking patterns, which may include not refilling prescriptions on time (Butler et al., 2004; Chisolm, Lance, & Mulloy, 2005; Nevins, Kruse, Skeans, & Thomas, 2001), taking an incorrect dose or missing doses (Ghods, Nasrollahzadeh, & Argani, 2003; Cleary, Matzke, Alexander, & Joy, 1995; Curtin et al., 1999; Greenstein & Siegal, 1997; Raiz, Kilty, Henry, & Ferguson, 1999), and taking the medication at the wrong time (Sketris, Waite, Grober, West, & Germs, 1994). Among patients taking antihypertensive medications, non-adherence can also include skipping doses intentionally (Ali, 2002; Benson & Britten, 2002; Dowell & Hudson, 1997; Johnson et al., 1999; Svensson et al., 2000).

## **Health Beliefs and Medication Taking Behaviour**

There is evidence to suggest that health beliefs influence medication taking behaviour. Health beliefs, such as an individual's understanding of the diagnosis (Wang et al., 2009) and the understanding of treatment efficacy (Orr et al., 2007), have been shown to shape an individual's preference and decision to take medications (Donovan, 1995). In addition, health beliefs such as perceived benefits of medications have been considered to be a major factor in determining medication non-adherence post kidney transplant (Butler et al., 2004). Because health beliefs are potentially modifiable through education, they are a promising target for interventions to improve non-adherence and outcomes (Becker & Maiman, 1980; Butler et al., 2004; DiMatteo Haskard, & Williams 2007; Donovan, 1995). Therefore, gaining knowledge about health beliefs, such as how individuals perceive the diagnosis or how they perceive treatments, may shed light on the ways in which medication taking behaviour is developed in mild to moderate CKD.

### ***Conceptualization of Health Beliefs and the Health Belief Model.***

The concept of beliefs has been described in different ways in the literature, but central to all these definitions, is the notion that beliefs encompass a person's attitudes, perceptions, expectations and values (Richer & Ezer, 2000). Although there is no formal definition of health beliefs found in the literature, health beliefs can be understood as a set of beliefs, perceptions, or attitudes held by an individual about his/her health, susceptibility or vulnerability to contracting an illness, as well as the cost or benefit of undertaking a health behaviour.

Rosenstock (1974) first described four dimensions of health beliefs and proposed how they related to health behaviours through the Health Belief Model (HBM). The four dimensions

of health beliefs are perceived susceptibility, perceived severity, perceived benefits, and perceived barriers (Rosenstock, 1974). *Perceived susceptibility* to an illness is one's "subjective perception of the risk of contracting an illness", whereas an individual's perception about the "seriousness and consequences of the illness if left untreated" is referred to as *perceived severity* (Janz & Becker, 1984, p. 2). *Perceived benefits* are identified as perceptions related to the effectiveness of the health behaviour in reducing the susceptibility to an illness and severity of the illness; and *perceived barriers* are perceptions related to the negative attributes of initiating and engaging in a health behaviour (Janz & Becker, 1984).

These four dimensions of health beliefs have been suggested to play a role in shaping the decision to undertake a health behaviour. Rosenstock (1974) proposed that prior to the initiation of a health behaviour, the individual assesses the level of perceived susceptibility to the illness and the perceived severity of the illness to determine the level of perceived threat. For example, if an individual views themselves to be highly susceptible to the illness or the illness as very serious, there is an increased likelihood that the individual will take on the health behaviour.

Although a strong perception of threat can be a sufficient propelling force for an individual to engage in a health behaviour, the HBM also predicts that the likelihood of taking on the recommended health behaviour is further dependent on the individual's cost-benefit analysis of the perceived benefits weighed against the perceived barriers of the health behaviour (Rosenstock, 1974). For example, if an individual believes the level of benefits is greater than the barriers, the individual is more likely to engage in the health behaviour. The HBM also proposes that modifying factors may shape health behaviours by influencing health beliefs (Rosenstock, 1974). According to the HBM, modifying factors may include sociodemographic variables, such

as gender and age. Because these modifying factors may influence health beliefs, they may also be important in the understanding of health behaviours.

Health beliefs derived from the HBM have been used to study and to predict health behaviours across a wide variety of settings. For example, the HBM has been used as a guiding framework to study medication taking for antihypertensive medications (Kirscht & Rosenstock, 1977), and diabetic regimens (Becker & Janz, 1985), as well as other health promoting behaviours such as weight management (Daddario et al., 2007), and testicular self-examinations (McClenahan et al., 2007). In general, results from these studies continue to lend support that health beliefs contribute to the initiation of and engagement in a particular health behaviour. Due to the wide application of the HBM in understanding health behaviours among individuals living with a chronic illness, the HBM can be useful in understanding medication taking behaviour in mild to moderate CKD and was chosen as a guiding framework for this study.

### **Empirical Review of the Literature**

This section of the literature review will first discuss medication taking within the context of self-management in mild to moderate CKD. Next, the prevalence of medication non-adherence in CKD will be reported. A general description of attributes of medication non-adherence in the literature will be introduced. The empirical literature review will then examine the relationships between health beliefs and medication taking behaviour. Finally, the role of gender and age as modifying factors will be explored.

### **Medication taking behaviour in CKD.**

Very little is known about medication taking behaviour in mild to moderate CKD, with only one study examining aspects of self-management (including medication management) among adults with mild to moderate CKD (Costantini et al., 2008). Because there is only one study which provides insight on medication taking in mild to moderate CKD, this study will be presented first, followed by a consideration of the literature on medication non-adherence in latter stages of CKD.

The Costantini et al. (2008) study is part of a larger descriptive, quantitative investigation looking at psychosocial variables and health behaviours among individuals living with mild to moderate CKD. A subset of 14 individuals from the 60 participants of the primary study were invited to participate in face-to-face interviews where investigators used semi-structured questionnaires to elicit participants' perceptions of health, kidney disease, illness management, and the level of support needed for self-management (Costantini et al.). With respect to the use of medications, one of the main challenges reported was that some patients expressed they did not feel all the recommended treatments were necessary or beneficial, and the amount of medications prescribed seemed excessive when they felt physically well (Costantini et al.). In addition to managing a multi-drug regimen, participants also felt they were left to make decisions on their own, such as how to correctly self-administer numerous medications, or to incorporate treatment recommendations into their daily routines. Although no other studies were found that explored experiences related to medication management in mild to moderate CKD, the Costantini et al. (2008) study highlighted some of the inherent challenges associated with managing multiple medications, supporting the need for further research in this area.

### **Medication non-adherence in CKD.**

The examination of medication non-adherence in CKD has focused primarily on post-kidney transplant recipients as well as individuals on dialysis. The rate of medication non-adherence reported in these populations generally clustered at 50% of the sample being studied (Claxton et al., 2001; Denhaerynck et al., 2005; Denhaerynck et al., 2007; Karamanidou et al., 2008). Because there is no gold standard of measurement for medication non-adherence, reported non-adherence rates are also inconsistent. However, results from CKD studies collectively suggest medication non-adherence is problematic in this population. While medication non-adherence has not been described in mild to moderate CKD, several studies have reported non-adherence in transplant and dialysis populations and these will be discussed below.

#### ***Kidney transplant.***

A recent review of the literature indicates that medication non-adherence for immunosuppressants falls between 2 to 67% among kidney transplant recipients, with an average prevalence at 28% of the sample (Danhaerynck et al., 2005). This variation in rates is due, in part, to the different operational definitions, as well as the variations in the cut-off values used to determine medication non-adherence. In one study, Kalil, Heim-Duthoy, and Kasiske (1992) reported 2% of the sample was non-adherent to immunosuppressants solely based on data obtained from chart reviews. Other researchers have used self-reported measures of non-adherence. For instance, Ghods et al. (2003) determined that 7.9% of respondents were non-adherent based on self-reported missed doses of more than 3 pills per month, but failed to specify the types of pills used to calculate non-adherence. Others established criteria on the basis that medications were not taken as per instructions more than once a week (Raiz et al., 1999), or the

person missed more than or equal to 1 dose of immunosuppressants in the past 4 weeks (Greenstein & Siegal, 1997).

Although in the kidney transplant literature self-reported medication non-adherence is commonly based on quantifying missed doses, prescription refill as a measurement of non-adherence has also been documented. Chisolm et al. (2000) found 67% of the sample to be non-adherent to immunosuppressants because these participants refilled less than 80% of their medications, whereas both Butler et al. (2004) and Nevins et al. (2001) reported non-adherence rates of 26% and 20% respectively when respondents reported they had refilled or taken less than 90% of any prescribed medications. One quantitative study by Sketris et al. (1994) incorporated 3 specific criteria in defining the behavioural attributes of non-adherence among 529 kidney transplant recipients: taking a smaller or larger dose of immunosuppressants than prescribed more than once per week, not taking a dose more than once per month, and having a 2 hour delay in taking a medication more than once per month. Based on these defined criteria, this study revealed that 65% of the participants were non-adherent (Sketris et al.)

### *Dialysis.*

Rates of medication non-adherence in dialysis are usually reported as a composite which combines medication non-adherence with several aspects of treatment adherence, such as attending dialysis sessions and adherence to fluid restrictions (Hilbert, 1985; O'Brien, 1990; Tracy, Green, & McClearly, 1987; Vives et al., 1999). Gathered from these studies, typically 50% of the sample is considered to be non-adherent to at least one aspect of their treatment including the use of medications (Danhaerynck et al., 2005; Loghman-Adham, 2003). Few studies were found that specifically examined medication nonadherence among patients on

dialysis (Cleary et al., 1995; Curtin et al., 1999). In Curtin's (1999) quantitative study including 135 participants, non-adherence with oral medication (antihypertensives and phosphate binders) was defined as taking medications more or less often than prescribed, or missing an entire day's dose. Results demonstrated that 42% of the sample was non-adherent based on pill counts. In another quantitative study, Cleary et al. (1999) examined medication non-adherence patterns in the use of oral medications among 72 hemodialysis and peritoneal dialysis patients. Information about medication non-adherence in this study was gathered from self-reported missed doses. Results demonstrated that patients on average missed  $13.0 \pm 4.7$  phosphate binder doses and  $2.6 \pm 5.6$  antihypertensive doses over the past month (Cleary et al.). Despite the variability in the conceptualization and measurement of medication non-adherence, these CKD studies suggest that some people living with kidney failure do experience difficulties in managing their medication regimens as prescribed. Although the rate of medication non-adherence in mild to moderate CKD is not known, the comparability of the medications used suggest that this population may experience similar challenges to those identified in kidney failure and hypertension, suggesting the need for further research in this area.

### **The Health Belief Model and Medication Taking Behaviour**

Patient's health beliefs about medication taking in mild to moderate CKD may include their health beliefs about their susceptibility to or severity of the illness, in addition to the perceived risks and benefits associated with taking medications as suggested by the HBM. Because health beliefs are potential predictors of medication non-adherence (Horne & Weinman, 1999), exploring health beliefs may inform researchers about medication taking behaviour in a population that has not been examined. The following section of the literature review will

explore studies investigating health beliefs in relation to medication taking behaviours according to the dimensions of health beliefs outlined in the HBM. Because the body of literature on medication taking behaviour in CKD is limited, the review of the literature will also draw on other chronic illnesses.

*Perceived susceptibility and severity.*

Engaging in health behaviours can be influenced by an individual's understanding of their susceptibility to the illness and the severity of the illness. Ali. (2002) examined preventive health behaviours and health beliefs among 178 women with coronary artery disease using the HBM as a guiding framework. *Perceived susceptibility* was measured by asking participants "how likely do you think you might get heart disease" (p. 88), and *perceived severity* was assessed by asking participants to agree or disagree the following statements: 1) "heart disease in women has more dangerous consequences than breast cancer" and 2) "more women die from breast cancer than from heart disease" (p.88). Preventive behaviours included adhering to medication regimens for controlling hypertension, high cholesterol levels and diabetes, participating in physical activities, and weight control. Using correlational and regression analyses, results indicated that 76% of the variance in preventive behaviours in this study was explained by several variables: perceived susceptibility to coronary heart disease (50.7%), perceived severity of coronary heart disease (3.5%), knowledge of risk factors of coronary heart disease (19.5%), and general health motivation (2.3%). These results suggested perceived susceptibility was an important determinant of preventive health behaviour. Perception of severity in this case was not a strong predictor of health behaviours and this might be explained

by the fact that participants failed to recognize the significance of risk factors related to their illness.

Other research has supported the notion that understanding and accepting one's susceptibility to an illness and the severity of an illness can be a motivator to drive medication taking behaviour (Hudson and Dowell, 1977). In a grounded theory study examining the decision making process about medication taking among 50 patients diagnosed with various chronic conditions, Dowell and Hudson, (1997) found that motivation to initiate the medication regimen was driven by an understanding of susceptibility to and severity of the chronic illness. For example, few participants understood asthma to be more unpleasant due to shortness of breath and feeling "a lot wheezier" when they missed medications, and recognized that this on-going condition could potentially be life-threatening. This understanding of their susceptibility to asthma and the seriousness of asthma gave these participants the motivation to "fight" the illness by taking anti-asthmatic medications and steroids consistently (Dowell and Hudson). Furthermore, motivation to commit to long term treatment was enhanced if the individual accepted that medications could reduce the severity of the illness. In this study, this was established through an explicit testing process whereby patients tested whether symptoms would re-emerge once they stopped taking the medications (Dowell and Hudson). If the symptoms re-emerged or worsened after the medications had been stopped, then the participants would hold stronger beliefs that the medications were important and beneficial to their illness. Responses from this study suggest that participants' perception of susceptibility to or severity of an illness may shape medication taking behaviour, and that perceived benefits of the medications in reducing the symptoms is an important consideration in the commitment to a life-long regimen.

*Perceived benefits of medications.*

Perceived benefit of medications is another health belief described in the HBM, which may influence an individual's decision to engage in a health behaviour (Rosenstock, 1974). The perceived benefits of taking medications that have been reported among people with kidney failure include better quality of life without being on dialysis, keeping kidneys healthier, living longer, and protecting against future adverse consequences as a result of kidney function decline (Breiterman-White, 2004; Kammerer et al., 2007; Russell et al., 2003, 2006; Ruppap & Russell, 2009). Similarly, among other chronic illnesses such as coronary heart disease, the protective function of antihypertensives has been described by participants in several studies in the sense that these medications could decrease the chances of being hospitalized, reduce anxiety about illness deterioration and symptoms such as swelling, and minimize difficulty breathing (Ali, 2002; Bennett et al., 1997; Bennett et al., 2005; Lehane et al., 2008).

Despite holding positive beliefs about the medications, a desire to test the need for medications in order to assess the efficacy of medications is evident among some people with chronic illnesses, such as hypertension. This "lay-testing" of medications by skipping or altering dosages as a way to evaluate the value and benefits of medications was reflected in a small number of qualitative studies examining non-adherence with antihypertensives (Dowell and Hudson, 1997; Johnson et al., 1999; Lehane & McCarthy, 2007). In a qualitative descriptive study examining adherent and non-adherent medication taking behaviour among 21 people with hypertension, the belief that medications were effective in reducing blood pressure was an important motivator for participants to continue with their medications (Johnson et al., 1999). Although all of the participants perceived hypertension to be a serious condition, almost 50% of

the informants (10 out of 21 participants) indicated they tested the effectiveness of medications by stopping the medications prematurely because they believed they had achieved adequate blood pressure control (Johnson et al.). This phenomenon of “lay-testing” was also previously described in Dowell and Hudson’s study (1997), where participants evaluated the level of perceived benefits of medications by stopping the medications prematurely to determine their effectiveness in reducing the symptoms they were experiencing. These findings suggest that perceived benefits may influence medication taking behaviour by shaping one’s understanding about the necessity of taking the medications. These findings also suggest that failure to perceive the medication is beneficial can lead to uncertainty about the need to continue taking the medication consistently.

*Perceived barriers to taking medications.*

Research has generally supported that self-reported barriers towards medication taking are associated with poor medication taking behaviour and non-adherence (Allen, 1998; Zyczynski & Coyne, 2000, Vermiere et al., 2001), and perceived barriers have been proposed to be one of the strongest predictors of health promoting behaviour (Janz & Becker, 1984). In the CKD literature, perceived barriers to taking medications have been most frequently examined in kidney failure. A total of 4 kidney transplant and 2 dialysis studies examined aspects of barriers associated with medication taking. The most commonly described perceived barrier reported post kidney transplant is medication side effects, which include weight gain, diarrhea, and nausea (Gregmigni et al., 2007; Butler et al., 2004; Ruppap & Russell, 2009; Russell et al., 2003). The qualitative study by Russell et al. (2003) contrasted some of the barriers to using immunosuppressants post kidney transplant between 8 younger and 8 older participants.

Participants in this study reported a wide range of side effects which prevented them from taking medications consistently. Younger participants reported medication adverse effects to include sleep disturbances due to dosing frequency, food cravings, acne, swelling/bloating, mood swings, dehydration, and teeth pain. The older participants in this study listed side effects such as sweating, hair loss, dry mouth, tremors, and infection. Studies in other CKD populations have also reported concerning side effects. For people on dialysis, side effects associated with certain medications such as phosphate binders have been described and linked to medication non-adherence; these side effects include diarrhea, constipation, and bloating (Bernardini et al., 2000; Stamatakis et al., 1997).

Side effects ascribed to using antihypertensives have been commonly reported among studies examining non-adherence among people diagnosed with hypertension. For example, Svensson et al. (2000) found that light headedness and frequent urination were the common reasons why individuals chose not to take antihypertensives regularly. In another qualitative study, Benson and Britten (2006) specifically explored 38 patients' decisions to take antihypertensive medications. Twenty six patients (68%) reported missing antihypertensive medications and 14 participants informed the researchers they altered the timing of the medications without informing their health care providers. These participants stated side effects were a major factor in deciding whether to skip doses, or to alter the timing of the medications. For example "unsteadiness", weight gain, headache, fatigue, urinary urgency, and swelling were the most frequently reported side effects which led participants to intentionally discontinue their medications without informing their primary health care providers (Benson & Britten).

Apart from adverse effects of using various medications, the complexity of the medication regimen is also perceived to be a barrier. In a qualitative study examining 26 patients' attitudes towards medication and non-adherence following kidney transplant, all patients perceived it was important to take medications properly following their surgery, but participants believed it was challenging to "get into the routine" of taking medications due to forgetfulness (Orr et al., 2007). On the other hand, in another qualitative study among transplant recipients, a change in medication routine was one of the main reasons why younger kidney transplant recipients had difficulties remembering to take all the pills (Russell et al., 2003).

Similarly, among individuals using antihypertensives, remembering to take multiple medications was facilitated through establishing a pattern and having reminders or cues available (Johnson et al., 1999). This was especially important when participants were required to take multiple medications (Johnson et al.). Respondents from this study, who reported fewer missed doses, stated they linked taking medications to a certain place such as the dining table, and at a specific time, such as before a meal. Establishing set routines and physical reminders such as the ones described by the participants in this study facilitated the incorporation of a complex medication regimen into one's lifestyle, thus enhancing successful medication taking behaviour (Johnson et al.).

One study quantitatively examined the relationships between patient's beliefs about the benefits and barriers of their medication and self-reported non-adherence among 324 patients living with 4 chronic conditions, including 47 individuals on dialysis (Horne & Weinman, 1999). Health beliefs about medications were obtained using the Beliefs about Medicines Questionnaire, which assessed patient's health beliefs about the necessity of medications in controlling their

illness, as well as their concerns about the potential side effects of using the medications (Horne & Weinman). Medication adherence in this study was assessed by a four-item self-report scale; necessity of medications was measured by patients' beliefs about the need for medication to control their illness; and concerns scale included items that measured patients' beliefs about medications had long term side effects. Two of the items asked questions relating to missed doses, and adjusting medication doses to suit participants' own needs (Horne & Weinman). Findings from this study revealed that the majority of the sample (89%) held strong beliefs that their medications were necessary in maintaining their health. However, over one third of the sample expressed concerns about the adverse effects of taking medications. A total of 55 patients (17.3%) obtained higher "concern" scores than "necessity" scores in this study, suggesting these participants perceived the barriers of taking medications to be greater than the benefits of medications; thus, these individuals were found to be more likely to miss doses or to alter dosing frequency.

In terms of the relationships between medication beliefs and reported nonadherence, results demonstrated consistent and significant relationships between health beliefs and non-adherent behaviours across all illness groups (Horne & Weinman, 1999). In general, higher necessity scores were correlated with higher reported adherence rates, and higher concern scores were correlated with higher non-adherence rates. To test whether health beliefs were a more powerful predictor of reported medication adherence than demographic variables (such as age, gender, and education levels), stepwise linear regression analysis was employed (Horne & Weinman). Statistical analysis revealed that patients' health beliefs about their medications were the strongest predictor, accounting for 19% of the variance in the reported adherence, suggesting

it is important to assess health beliefs in order to improve our understanding of medication taking behaviour.

### ***Modifying Factors- Sociodemographic Variables***

According to the HBM, sociodemographic variables (gender and age) may act as modifying factors on health behaviour by influencing health beliefs. There is a paucity of research examining the relationships between sociodemographic variables and health beliefs in CKD. However, a limited number of studies have examined the influence of sociodemographic variables directly on medication non-adherence in this population (Chisolm et al., 2008; Orr et al., 2007; Lindqvist et al., 2000). The following section of the review of the literature will therefore discuss studies that have examined the sociodemographic variables of gender and age in relation to health beliefs and medication taking behaviour.

#### *Gender.*

Although no studies were found that examined the role of gender in mild to moderate CKD, there is evidence to support that men and women with kidney failure respond differently to the illness experience which may shape their medication taking behaviour differently. A qualitative study conducted by Lindqvist, Carlsson, and Sjoden (2000) explored the perceived consequences of living with kidney failure among 30 participants requiring hemodialysis, and 30 post kidney transplant recipients. Participants were invited for interviews and results were analyzed by content analysis. Findings identified that more women than men expressed negative beliefs about their body images as a result of treatments, with women often expressing a general feeling of disgust towards themselves due to visible body changes associated with being on dialysis (Lindqvist et al.). Some of these negative health beliefs were related to treatments

associated with dialysis, such as a “bump on the forearm” while other changes were related to side effects of medications, such as “bloated face or hairy arms” (Lindqvist et al., 2000, p. 295-296). Comparable findings were reported in another qualitative study by Lanuza et al. (1999) which set out to explore gender differences in psychosocial responses after lung transplant among 48 participants. Results from this study demonstrated that more women than men reported barriers to the use of triple immunosuppressants therapy due to adverse effects, and therefore women were found to be less likely to adhere to medications than men (Lanuza et al.). Some of the distresses related to medications that these women reported included a change in facial appearance, excessive hair growth, and tremors which led to the forming of negative health beliefs about these medications (Lanuza et al.).

There is also evidence to suggest men may experience barriers to taking medications. In a quantitative study examining the relationship between demographic and cultural factors among older Chinese immigrants, medication adherence was defined as achieving a score greater than 80% on the Morisky scale, which was developed to assess the extent a participant was adherent to prescribed antihypertensive medications (Li, Wallhagen, & Froelicher, 2008). A total of 75 older men and 69 older women were recruited. Data related to health beliefs were assessed using four scales that quantify participants’ perceived susceptibility to the illness and perceived benefits of Chinese herbal medications and Western medications for hypertension (Li et al.). Perceived severity and perceived barriers were not addressed in this study. In terms of adherence, the reported rates of adherence to antihypertensives in men and women were 69% and 75% respectively. Perceived susceptibility and perceived benefits were not found to be statistically significantly associated with medication adherence. Although the health beliefs examined in this

study were not found to be related to medication adherence, the differences in adherence rates between genders may be explained by other factors not measured in this study, such as perceived barriers to taking antihypertensives. Future studies should further strive to examine the differences in health beliefs between men and women to expand the current understanding of the ways in which men and women develop medication taking behavior.

#### *Age.*

There is an indication from the literature that age may act as a modifying factor on the relationship between health beliefs and medication taking behaviour. Chisolm, Kwong, Mulloy, and Spivey (2008) examined non-modifiable characteristics, such as gender and age, in relationship with non-adherence to immunosuppressant among 70 renal transplant recipients. In this quantitative study, immunosuppressant monthly refill records were compared to the prescribed medication regimen to provide an objective measure of medication access, and ‘presumably’ medication adherence. Data about sociodemographic variables such as gender and age were collected. Results demonstrated that older recipients of ages 60 years and above were at higher risk of being non-adherent compared to younger participants, mainly due to forgetfulness and a change in routine. These results were similar to those reported in a qualitative study by Orr et al. (2007) who explored medication taking beliefs and non-adherence among 26 elderly patients (of age 65 and above) living with kidney transplants. All participants in this study had a clear understanding of their illness, realized and accepted the necessity to take medications to maintain their overall health. However, failure to take medications consistently was found to be mostly unintentional and was reported to be largely attributed to forgetfulness and a change in routines of the medications resulting in missed doses. These findings suggest medication taking

behavior may differ between age groups due to the differences in barriers perceived at different developmental stages (Orr et al., 2007).

Another renal transplant study conducted by Russell et al. (2006) contrasted medication taking beliefs between 16 adult kidney transplant recipients of two age groups. Eight patients, aged 18 to 49 years, and 8 aged 50 years and above were recruited. Using semi-structured interviews, beliefs and attitudes held towards immunosuppressive medications were explored. Respondents all expressed they understood the link between taking immunosuppressive medications and sustaining renal health, and associated medications with feeling better and having a better quality of life. Interestingly, younger participants listed 5 types of barriers associated with the medications and these included side effects, adjusting medication times, type of medication being dispensed (i.e. liquid medication versus tablets), the number of medications, and size of pill. Older participants only reported 3 barriers: side effects, keeping medications with them, and travelling inconvenience. Four younger adults reported that it was more difficult to adhere to the medication regimen successfully due to the complexity of dosing routines (e.g. taking immunosuppressants every other day), and the frequency of taking immunosuppressants. On the other hand, five older adults reported physically taking medications to be the most challenging, suggesting younger and older individuals may experience different perceptions of barriers to medication taking, and managing a medication regimen.

In a quantitative study, Gregmigni et al. (2007) performed a cross-sectional analysis of some of the psychological factors associated with medication non-adherence following renal transplant among recipients above 18 years of age. A total of 34 kidney transplant recipients participated, and the mean age of the sample was 49 years old. Non-adherence to

immunosuppressive medications was measured by two items, 1) self-reported frequency of not taking medications, and 2) frequency of experiencing difficulty in taking medications exactly as prescribed. A total of 76% of the patients indicated they never forgot to take their medications. Overall, 24% of the respondents acknowledged they were experiencing some degree of difficulty in taking immunosuppressive medications, and age appeared to be a predictor of non-adherence in this study. Younger adults were found to be less likely to adhere to medications than older participants, and this finding was attributed to different coping styles between younger and older participants, as well as a perceived barriers related to medications and interference of the regimen with daily life activities. These findings collectively suggest that health beliefs may differ between younger and older participants, and these differences in health beliefs may account for the ways in which medication taking behaviour is established differently between the age groups.

There is no research investigating the relationship between age and health beliefs in mild and moderate CKD. However, available studies have found some differences in health beliefs between younger and older patients living with CKD. These findings are inconclusive, thus limiting the understanding of how health beliefs may differ by age. Future studies are needed to further explore this relationship in order to better understand how medication taking behaviour is shaped in mild to moderate CKD.

### **Critique of the Literature**

The current understanding of how someone manages a complex medication regimen in mild to moderate CKD is limited. The majority of the studies examining medication taking behaviour and non-adherence considered in this review were qualitative in nature, which did not

allow direct examination of the relationships between health beliefs and medication taking behaviour, or the relationships between health beliefs and sociodemographic variables. Among the studies reviewed, behaviours used to describe medication taking were inconsistent, and different information about medication non-adherence was collected. For example, medication non-adherence has been reported as not taking medications as prescribed, taking medications (such as immunosuppressants or phosphate binders) less than a threshold (e.g. <80%) set by the researchers over a period of time (e.g. in a week or in the past month), not refilling medications in a period of time, and self-reported skipped doses (Chisholm et al., 2005; Cleary et al., 1995; Curtin et al., 1999; Denhaerynck et al., 2007; Ghods et al., 2003; Gregmigni et al., 2007; Russell et al., 2003). All of these different operational definitions only illustrated one aspect of medication taking behaviour, and make comparative analyses across studies difficult. In addition to the various operational definitions of medication taking behaviour, the relatively small number of participants with CKD in some of the quantitative studies (Gregmigni et al., 2007; Horne & Weinman, 1999) may limit generalizability to other CKD populations.

Although reported non-adherence rates in CKD suggest individuals with CKD are experiencing challenges engaging in and maintaining medication taking behaviour, these statistics are only a way of quantifying the magnitude of the problem of medication non-adherence by examining one type of medication in the whole regimen, or by measuring one specific type of behaviour associated with medication non-adherence. Given the fact that individuals with CKD must take on a complex medication regimen with multiple medications, studying medication non-adherence based on one or two types of medications may not be sufficient in the pursuit of understanding how patients manage their entire medication regimen,

or why some patients are more successful in managing medication taking routines than others. An understanding of the behaviours associated with managing all the medications in the regimen will provide a better understanding of how individuals engage in medication taking behaviour, thus ultimately allowing clinicians to develop interventions that can potentially facilitate the development and maintenance of medication taking behaviour.

There is empirical evidence to support health beliefs as predictors of medication non-adherence (Horne & Weinman, 1999). In CKD studies, results collectively highlighted that the side effects of medications were perceived to be the most common barriers preventing individuals from engaging in medication taking behaviour successfully (Gregmigni et al., 2007; Butler et al., 2004; Ruppap & Russell, 2009). Other health beliefs (perceived susceptibility, perceived severity, and perceived benefits) have been explored in the literature among other chronic illness populations (Ali et al., 2002; Dowell and Hudson, 1997; Lehane et al., 2008; Johnson et al., 1999). However, most of the studies examined one to two dimensions of health beliefs, and not all studies reported rates of non-adherence, which prevented the examination of the relationships between health beliefs and medication taking behaviour. Among these studies, only one study by Horne and Weinman (1999) was quantitative in nature, and explored the relationships among perceived benefits and perceived barriers and self-reported medication non-adherence in several chronic conditions including CKD. Since the HBM suggests that health behaviours can be shaped by four dimensions of health beliefs (Rosenstock, 1974), an examination of the relationships between all dimensions of health beliefs and medication taking behaviour can be useful towards better understanding how medication taking behaviour is being established.

The literature suggests that health beliefs may differ between men and women. Studies exploring gender differences in medication taking behaviour generally pointed to the fact that women perceived greater levels of barriers in the form of side effects of medications than men did, thus placing women at greater risk of becoming non-adherent. While these findings suggest that gender may influence some health beliefs (i.e. perceived barriers) (Lanuza et al., 1999; Lindqvist et al., 2000), none of these studies examined gender differences in other health beliefs which may shape medication taking behaviour. On the other hand, there is evidence to support that medication taking behaviour may differ by age groups because individuals at different ages perceived different types of barriers to medication taking (Gregmigni et al., 2007; Orr et al., 2007; Russell et al., 2006). However, the differences in health beliefs between younger and older patients in mild to moderate CKD have not been explored. Future studies are needed to further examine the differences in health beliefs between men and women, and the relationship between health beliefs and age in mild to moderate CKD.

### **Summary of Literature Review**

The manner in which someone diagnosed with mild to moderate CKD manages the medication regimen remains relatively unexplored. However, the complexity of the regimen itself, such as the types of medications being prescribed, dosing frequency, or medication side effects may place an individual at an increased risk of developing poor medication taking behaviour in CKD. Many researchers have aimed to identify predictors of medication taking behaviour in CKD, and one example of a modifiable predictor is health beliefs. According to the HBM, health beliefs may shape health promoting behaviour, such as medication taking behaviour by way of influencing one's perceptions about the diagnosis and treatments associated

with it. Specifically, perceived barriers have been most frequently studied in relation to medication non-adherence in CKD. Moreover, the relationship between sociodemographic variables and health beliefs has also been explored with varying results in CKD. For example, more women than men expressed barriers towards medication taking due to unpleasant side effects associated with medications. With respect to age, evidence suggests that medication taking behaviour may differ by age due to different health beliefs perceived at different ages. Although there is evidence to suggest that perceived barriers are the strongest predictor of health behaviour, the relationship between health beliefs and medication taking behaviour in mild to moderate CKD remains unclear.

## Chapter 3 Framework

Derived from a well established body of literature describing psychological and sociological theories, the HBM was first developed to help understand the reasons behind why individuals do not take precautionary measures to prevent illness or illness deterioration (Hochbaum, 1958; Lancaster & Stead, 2005). A number of studies have examined the propositions outlined in the HBM to understand, explain, and predict health behaviours in smoking cessation (Lancaster & Stead, 2005), preventive behaviours for coronary artery disease (Ali, 2002), diabetes (Charron-Prochownik et al., 2008), asthma (De Smet et al., 2006), breast cancer (Spector, 2007), and osteoporosis prevention (Turner et al., 2004). Although the HBM has never been applied to examining medication taking behaviour in mild to moderate CKD, the propositions outlined in the HBM were supported by studies examining medication adherence/compliance among diabetic (Cerkoney & Hart, 1980) and hypertensive (Kirscht & Rosenstock, 1977) populations, as well as individuals on dialysis (Cummings et al., 1982). Due to the wide application and adaptability of the HBM in understanding medication adherence and health promoting behaviours among individuals living with chronic conditions including CKD as well as those, the HBM has been chosen as the guiding framework for this study.

### **An Overview of the Health Belief Model**

A major tenet of the HBM is that an individual must feel threatened by a health condition before he/she is likely to undertake the recommended preventive health action (Rosenstock, 1974). *Perceived threat of the disease* can be conceptualized as the primary motivator to take a precautionary or preventive health behaviour and is represented at the core of the model (Rosenstock, 1974). Perceived threat is comprised of perceived susceptibility to contracting the

illness and perceived severity to the disease. *Perceived susceptibility* to an illness refers to one's "subjective perception of the risk of contracting a condition" (Janz & Becker, 1984, p.2).

*Perceived severity* of the illness refers to an individual's opinion about the "seriousness and consequences of the illness if left untreated" (Janz & Becker, 1984, p. 2). Perceived severity may also include a personal evaluation of medical consequences (such as pain, disability, or death), or social consequences (such as impact on work, daily life or social role changes) of the illness (Janz & Becker, 1984). According to Rosenstock (1974), the combined beliefs of susceptibility and severity provide the energy or force to undertake, or not undertake health behaviours.

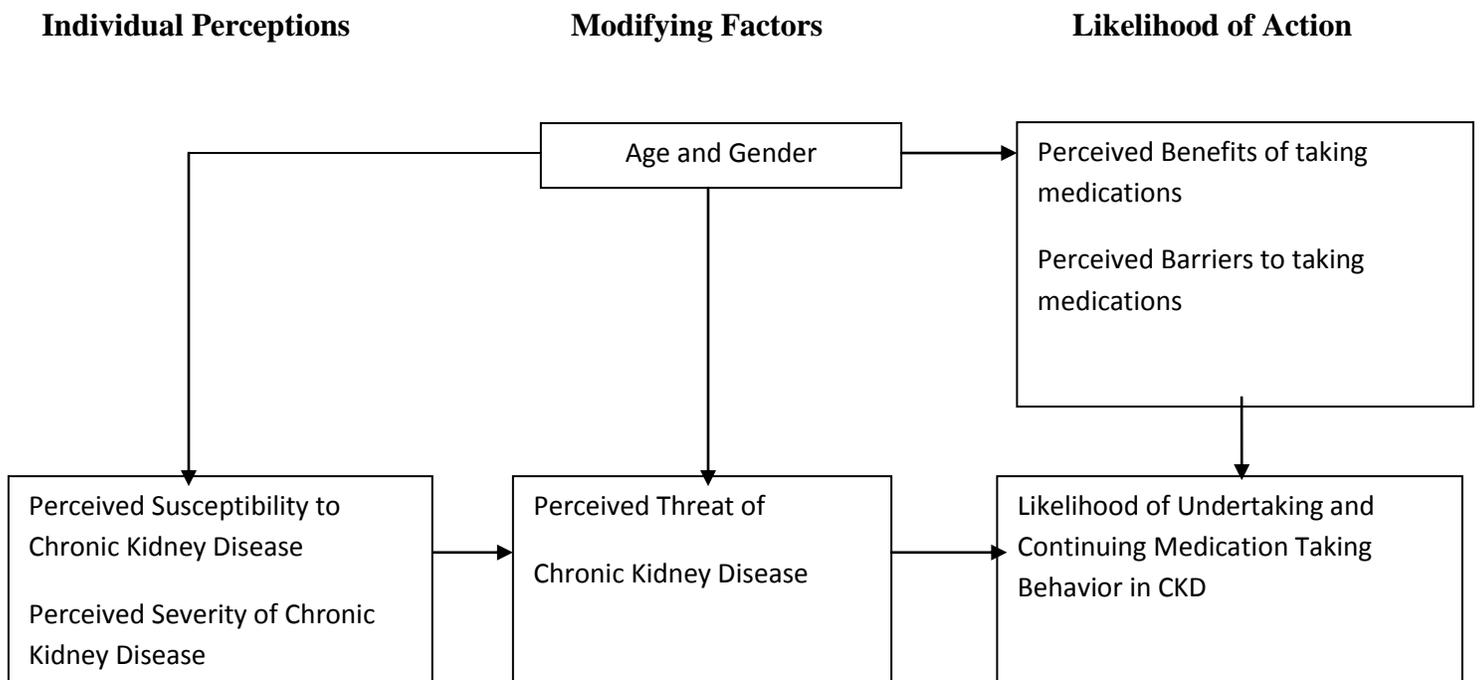
Although a strong perception of threat from a condition can be a sufficient propelling force to engage in a preventative health behaviour, Rosenstock (1974) also predicted that the likelihood of taking on the recommended health behaviour was further dependent on an individual's beliefs regarding the relative effectiveness of a health behaviour undertaken. This evaluation is done by what is commonly referred to as a cost-benefit analysis, conceptualized as the balance between *perceived benefits* and *perceived barriers* in the HBM (Janz & Becker, 1983). *Perceived benefits* are identified as beliefs regarding the effectiveness of a health behaviour. An individual who engages in the recommended health action is more likely to perceive the health action to be effective and feasible (Janz & Becker). The negative aspects of a health action, which are considered to act as impediments to the successful initiation and engagement of the recommended health behaviour, are known as *perceived barriers* (Janz & Becker). These negative perceptions can relate to costs, side effects, adverse outcomes, unpleasant sensations (such as pain), inconvenience, and so forth (Janz & Becker).

Apart from examining beliefs that may promote or interfere with a health action, the HBM also takes into consideration sociodemographic characteristics such as age and gender, which may modify and shape health beliefs. Specifically, men and women may hold varying health beliefs towards medication taking behaviour due to the differences in their experiences in taking the medications. Similarly, younger and older individuals may also engage in medication taking behaviour differently due to a difference in health beliefs. For example, older individuals may perceive being forgetful to be a form of barriers to medication taking, whereas younger individuals may perceive the medication regimen itself to be a barrier or intrusion to their daily life routines.

### Framework

The framework for this study is adapted from the HBM (Janz & Becker, 1984). The HBM adapted for CKD is illustrated in Figure 1.

*Figure 1* Framework adapted from Janz & Becker, 1984.



### **Perceived susceptibility and perceived severity.**

An individual's perception of susceptibility to and severity of mild to moderate CKD may shape medication taking behaviour. For example, those who perceive CKD to be more severe, or those who believe themselves to be more susceptible to consequences of CKD are more likely to engage in medication taking. *Perceived susceptibility* was defined in this study as the individual's perception of whether their illness would become worse in the future. Perceived susceptibility was measured by asking whether participants believed their kidney function would improve, remain the same, or decline in the future. In this study, *perceived severity* was defined in terms of participant's beliefs about the seriousness of CKD. Perceived severity was measured by individual's perception of the seriousness of their diagnosis in general and in comparison with other illnesses, such as flu, diabetes, and cancer.

### **Perceived benefits and perceived barriers.**

The HBM suggests that a health behaviour can be influenced by an individual's assessment of the perceived benefits and the perceived barriers to the specific behaviours (Rosenstock, 1974). For example, those who perceive treatments to be beneficial are more inclined to continue with the health behaviour, whereas those individuals who perceive barriers to the treatments are more likely not to engage in the health behaviour. *Perceived benefits* in this study were identified as beliefs related to the effectiveness of taking medications. *Perceived benefits* were assessed by asking participants whether they believed the medications worked well for them. *Perceived benefits* were assessed by the person's belief in the effectiveness of using medications as measured by asking patients whether they believed the medications helped

improve their condition, and by asking whether patients believed the medications could prevent the symptoms associated with worsening of kidney function.

*Perceived barriers* were defined as beliefs about the impediments to performing behaviours associated with medication taking. *Perceived barriers* were measured based on behaviours that prevented patients from taking medications, such as opening and closing medication bottles, reading the label on the bottle, remembering to take all the pills, getting the refills on time, and taking so many pills at the same time. Specific barriers such as bothersome characteristics of medications were also explored.

#### **Modifying factors- gender and age.**

According to the HBM, modifying factors may influence health beliefs, and may therefore, indirectly influence medication taking behaviour (Rosenstock, 1974). In particular, men and women may hold different beliefs towards their illnesses and different beliefs towards the uses of medications due to the experiences with using the medications, which may shape their medication taking behaviour differently. Likewise, individuals at different ages may hold different health beliefs due to life priorities and goals set at different developmental stages, which may shape their medication taking behaviours differently.

#### **Medication taking behaviour.**

Medication taking behaviour is the manner in which individuals manage their medication regimen (Banning, 2008). In this study, information about the regimen, such as medication name, frequency of dosing, number of medications taken in a week, missed doses, and reasons for

taking medications was reported. For the purpose of hypotheses testing, medication taking behaviour was assessed by patient's self-reported missed doses.

## **Research Questions**

The following questions were used to guide this secondary analysis:

1. What are the medication taking behaviours of individuals living with mild to moderate CKD?
2. What are the health beliefs (perceived susceptibility, perceived severity) associated with CKD and the health beliefs (perceived benefits, and perceived barriers) related to taking medications for the diagnosis?
3. How do health beliefs (perceived susceptibility, perceived severity, perceived benefits, and perceived barriers) differ between men and women with mild to moderate CKD.
4. What is the relationship between age and health beliefs (perceived susceptibility, perceived severity, perceived benefits, and perceived barriers)?
5. What is the relationship between health beliefs (perceived susceptibility, perceived severity, perceived benefits, and perceived barriers) and medication taking behaviour among people living with mild to moderate CKD?

## **Hypotheses**

1. There will be a difference in health beliefs between men and women.
2. There will be a relationship between age and health beliefs.
3. There will be a relationship between health beliefs and medication taking behaviour.

## **Chapter 4 Methodology**

This study was a secondary analysis of the data collected as part of a study which examined gender differences in psychosocial variables and health promoting behaviours among individuals with glomerular kidney disease (Beanlands, McCay, Cattran, & Hladunewich, 2006). The following chapter will first begin by describing the methodology used in the primary study, followed by the specific approach that was used in this secondary analysis.

### **Primary Study**

The primary study had three main objectives: 1) to determine the degree to which individuals with glomerular disease were engaging in health promoting behaviours, 2) to examine gender differences in psychosocial variables in the earliest phases of glomerular kidney disease and 3) to examine the relationship between psychosocial variables and health behaviours by gender. The primary study used a descriptive, cross-sectional, correlational design to evaluate gender differences in psychosocial variables and relationships between these variables and health behaviours. Both quantitative and qualitative methodologies were employed.

Research ethics approval was obtained from all participating centers. The primary study recruited a convenience sample of 60 participants from nephrology units across Toronto, and purposive sampling strategy was used to ensure there were equal numbers of men and women. Participants who met the following criteria were recruited: 1) 19 years of age or older, 2) had undergone kidney biopsy, 3) diagnosed with mild to moderate primary kidney disease, 4) not diagnosed with another chronic condition, such as lupus or diabetes, 5) literate in English, and 6) provided informed consent.

Nephrologists, or their delegates, looking after patients with glomerular kidney disease notified potential participants of the study. Study information was provided through mail or explained during scheduled clinic visits. Patients had the opportunity to review the study information sheet before deciding to participate in the study. Potential participants were also welcome to contact the study research assistant directly for further information.

Respondents participated in a face-to-face session of approximately 90 minutes in length. Informed consent was obtained and participants were asked to complete a series of self-report questionnaires measuring variables such as demographic characteristics, medication taking history, health beliefs, subjective symptoms, quality of life, depression, engulfment, and self-management perspectives. The research assistant then reviewed participants' medical records and extracted information such as medical history, treatments received, and results of laboratory tests of kidney function.

### **Secondary Analysis**

The purpose of the secondary analysis was to 1) describe medication taking behaviour among people with mild to moderate CKD, 2) describe health beliefs associated with CKD and medication taking, 3) explore the differences in health beliefs between genders, 4) explore the relationship between age and health beliefs, and 5) examine the relationships between health beliefs and medication taking behaviour among individuals living with mild to moderate CKD.

### **Sample Size**

Because the relationships between health beliefs and medication taking behaviour have not been well explored in mild to moderate CKD, there is limited information available with

regards to the effect size. Therefore, a moderate effect size of 0.4 was chosen for this secondary analysis to be conservative (Burns & Grove, 2005; Cohen, 1988). For the secondary analysis, power analysis was performed to ensure an adequate level of power to test the following 3 hypotheses: #1) the difference in health beliefs between men and women, # 2) the relationship between age and health beliefs, and #3) the relationship between health beliefs and medication taking behaviours. All power analyses are based on an effect size of 0.4 and an alpha level set at 0.05 for two tailed tests. For all hypotheses, using Cohen (1988)'s approach for power of  $\chi^2$  test, alpha of 0.05, degrees of freedom of 1, a sample size of 60 participants will yield a power of 87%.

### **Data Collection Instruments**

The following questionnaires were used to collect data related to variables such as demographic data, medication taking behaviour, and health beliefs.

#### **Sociodemographic and Clinical Data Questionnaire.**

Data related to age, gender, level of education, marital status, and language spoken at home were reported by participants on a self-report questionnaire. This questionnaire also addressed questions related to the number of years that participants had been living with kidney disease, cause of kidney problems, and symptom manifestations.

#### **Brief Medication Questionnaire (BMQ).**

The Brief Medication Questionnaire is a patient self-report instrument designed to collect data on medication taking behaviour among patients who needed to self-administer multiple

drugs such as captopril and enalapril (Svarstad, Chewning, Sleathe, & Claesson, 1999). The BMQ is divided into three sections: Regimen screen, Belief screen, and Recall screen. According to Svarstad et al. (1999), the Regimen and Belief screens had 80-100% sensitivity for non-adherence, whereas the recall screen was 90% sensitive for non-adherence, suggesting the BMQ demonstrates good evidence of reliability.

In this study, general information related to medication taking behaviour was obtained from the Regimen Screen. Respondents were asked to first list all the medications they were taking and answer questions related to their regimen. This screen began by asking participants six questions about each medication they took in the past week: a) medication name and strength, b) how many days did you take it, c) how many times per day did you take it, d) how many pills did you take each time, e) how many times did you miss a pill, and f) for what reasons were you taking each medication? Each participant had the opportunity to report up to 10 medications they took over the week preceding the interview.

The Belief Screen was used to identify perceived benefits and perceived barriers of the reported medications (Svarstad et al., 1999). The two questions were 1) how well does the medication work for you (1= worked well; 2=worked okay; 3= not well at all), and 2) do any of the medications bother you in any way? (1= yes; 0 = no). If participants chose “yes” for the second question, they were asked to identify the names of the medications and were asked to identify how much the medications bothered them. Participants could choose “1” for “the medications never bothered them”, “2” for “the medications bothered them a little”, “3” for “the medications bothered them somewhat or a lot”. Next, participants were given the option to

describe the ways in which medications were bothersome. These responses were categorized by the researcher.

Perceived barriers were considered to be the negative aspects associated with medication taking behaviour. Participants were asked to choose from a list of 5 reasons which might kept them from taking their medications: “it may be addicting”, “cost inconvenience”, “I don’t like the way I feel taking it and the side effects”, “nothing keeps me from taking my medications, and “others”. To understand some of the ways medications were bothersome, participants were asked to list the way medications were bothersome. Responses were categorized by the investigator.

The Recall Screen consisted of 2 questions that measured perceived barriers associated with the activities of taking medications (Svarstad et al., 1999). Perceived barriers were measured by asking participants to rate how hard it was to perform 5 behaviours associated with medication taking for all the reported medications. Respondents were given the following options to choose from: 1) opening or closing the medication bottle, 2) reading the print on the bottle, 3) remembering to take all the pills, 4) getting the refills on time, and 5) taking so many pills at the same time. For each behaviour, “not hard at all” was given a score of “1”, “somewhat hard” a score of “2”, and “very hard” a score of “3”. A composite barrier score was then calculated to determine the overall level of barriers experienced with all the medications reported.

To determine the composite barrier score, a total score was obtained by summing the mean scores for the 5 behaviours for each medication. For example, if a participant listed he/she took 9 medications, and for all the medications, he/she stated it was not very hard to open or close the medication bottle, this participant would receive a score of “9” (1x9) for this activity. This score

of “9” was then divided by the total number of medications ( $n = 9$ ) to achieve a final score of “1”, indicating on average, it was not very hard for this participant to open or close the bottles for the 9 medications. The same calculation was applied for the other 4 barriers associated with medication taking. A composite barrier score was then calculated by adding all the mean scores for the 5 barriers. A score of 5 ( $1 \times 5$ ) indicated the participants experienced no barriers in performing behaviours and a score of 15 ( $5 \times 3$ ) indicated the highest level of barriers. Because more than half of the sample ( $n = 31$ , 52.5%) did not experience barriers, this variable was categorized into two groups for the purpose of hypotheses testing. Individuals who scored “5”, or no barriers, were given a score of “1”, and any individuals who obtained a score greater than 5 were assigned a score of “2” reflecting some forms of barriers.

### **The Modified Health Beliefs Questionnaire.**

To quantify perceived susceptibility, severity, and benefits, the Modified Health Beliefs Questionnaire was used. Adapted by McCay (1982) from the work of Becker and Maiman (1975), the MHB was modified for the primary study to include questions specifically addressing chronic kidney disease. The MHBQ began by asking general questions related to the illness diagnosis: 1) has the doctor/nurse/therapist told you what your illness or problem is. Participants could reply “yes” or “no”, and those who replied “yes” were asked to state what the doctor/nurse/therapist said was wrong with them. Those who replied “no” were asked to state what they thought might be the illness or problem. Participants could further elaborate their responses and list other problems that they believed they had.

Perceived susceptibility refers to whether participants believed their illness would become worse and what they believed would happen to their kidney function in the future.

Perceived susceptibility was measured by asking the following question, “what do you think will happen with your kidney function in the future”. Participants were given a score of “1” if they choose ‘improve profoundly’, a score of “2” for “improve somewhat”, “3” for “no change”, “4” for “decline somewhat”, and “5” for “decline severely”. Data collected from this question were treated as ordinal level of data. Participants were also asked to choose from a list of signs and symptoms they believed to be associated with the deterioration of kidney function that would indicate to them that their condition was getting worse. These signs and symptoms included swelling in hands or feet, headaches, fatigue, changes in blood pressure, creatinine level, the amount of protein in urine, urination pattern, and in appetite.

Perceived severity was examined in terms of participants’ beliefs about the seriousness of CKD. Perceived severity in this study was measured by the following question: 1) In general, do you consider your present illness or problem to be “not at all serious”, “not very serious”, “somewhat serious”, “moderately serious”, and “very serious”. Scores ranged from “1” to “5”, with “1” being “not at all serious” to “5” being “very serious”. Perceived severity was also assessed by eliciting participants’ perceptions of how CKD compared with other health illnesses such as the flu, diabetes, and cancer in terms of severity. For each of these illnesses, participants were asked 1) how serious an illness do you feel flu/diabetes/cancer is, and 2) how serious do you feel your illness or problem is in comparison to flu/diabetes/cancer. For both questions, possible scores ranged from “1” to “5”, with “1” being “not at all serious” to “5” being “very serious”. Results were then treated as ordinal level data for subsequent data analyses.

Perceived benefits were defined as beliefs about the effectiveness of using medications in treating and minimizing progression of CKD. Perceived benefits were measured by asking 2

questions: 1) “how likely do you think it is that the treatment you are being given will help your illness”, and 2) “do you think this treatment can keep you from becoming ill again?” For both questions, participants were asked to choose their responses on a 5-point Likert scale ranging from “1” to “5”, with “1” being “very likely” and “5” being “not at all likely”.

### **Ethical Considerations**

For this secondary analysis, Research Ethics Board approval at Ryerson University was obtained. Encoded data retrieved from the primary study were kept confidential at all times. Computer files were kept in a password-protected file only accessible by the research staff. Identities of each participant were not revealed and only summary statistics were reported in this secondary analysis.

### **Data Analysis**

Descriptive statistics were used to describe the sample. Measures of central tendency were calculated for demographic and clinical data respectively. Clinical data reported included the number of years participants had been living with kidney disease, causes of kidney problems, types of symptoms, and types of medications used. Nominal and ordinal level demographic variables and clinical data obtained from the questionnaires were reported using frequencies and percentages. Interval and ratio level demographic and clinical data such as age, years of education, and number of years living with CKD were reported using frequencies, range, means, and standard deviations.

The first of this study’s objectives was to describe medication taking behaviour among people living with mild to moderate CKD. Nominal level data such as the types of medications,

and frequency of taking medications were described and reported in tables and charts using frequencies and percentages. Ratio level data such as the number of pills that were taken in the last week, the number of days that the pills were taken in a week, the number of times a pill was taken in a day, and missed doses in a week were reported using means, ranges, and standard deviations. For hypotheses testing, self-reported missed doses as reported on the regimen screen of the BMQ, was used as a measure of medication taking behaviour.

The second objective of this study was to describe health beliefs associated with the illness and medication taking. Because data related to perceived severity, susceptibility, and benefits were treated as ordinal level data, frequencies and percentages were reported. Perceived barriers were presented in terms of composite scores from the BMQ. Perceived barriers to using medication were also categorized and presented in a table.

The third and fourth objectives were to explore the differences in health beliefs between genders and to explore the relationship between age and health beliefs. Gender was treated as nominal level data. Because questions related to health beliefs (severity, susceptibility, benefits, and barriers) were rank-ordered, chi square statistics were calculated to determine whether men and women differed in their health beliefs.

To examine the relationship between age and health beliefs, the age variable was first graphed to examine its distribution. Results revealed that age was positively skewed, suggesting normal distribution could not be assumed, and therefore non-parametric analyses were employed. To examine the relationship between age and health beliefs, age was categorized at the 50<sup>th</sup> percentile. The median age was 44 and younger participants, less than or equal to 44 years of age, were given a score of “1”, and older participants, 45 years old and older, were given

a score of “2”. Chi square statistics were then used to detect the differences in health beliefs between younger and older participants.

To examine the relationships between health beliefs and medication taking behaviour, the number of missed doses reported was used as an indicator of medication taking behaviour. Because a large number of respondents indicated they had never missed a dose ( $n = 42, 71.7\%$ ), the missed dose variable was categorized into those who had never missed a dose, and those who had missed dose. Chi square statistics were used to determine the differences in health beliefs between those who missed, and those who didn't miss doses. For all statistical tests, alpha was set at 0.05.

## **Chapter 5 Findings**

This chapter will present the findings of the study. Results are presented in order of the research questions outlined in Chapter 1. This chapter will first begin by discussing the characteristics of the sample, followed by a general discussion on the reported medications and medication taking behaviour. Health beliefs (perceived susceptibility and severity) about CKD and health beliefs (perceived benefits and barriers) related to the use of medications will then be presented. Next, differences in health beliefs between genders and age will be explored. Finally, the relationship between health beliefs and medication taking behaviour will be reported.

### **Characteristics of the sample**

This sample consisted of 30 males and 30 females between 19 to 72 years of age, with an average age of  $45 \pm 14.2$  years. Participants had been living with CKD on average for  $10.1 \pm 9.3$  years. Almost half of the participants ( $n = 27, 45\%$ ) had lived with mild to moderate CKD for 1-5 years, 13 (21.7%) had been living with it for 6-10 years, and the remainder had been living with it for more than 10 years. The majority of the sample ( $n = 40, 66.6\%$ ) were either married or in a common law relationship, with 17 participants (28.3%) reporting they were single, and 3 (5%) divorced or widowed. On average, study participants had  $14.6 \pm 3.5$  years of education, and worked  $31.7 \pm 21.5$  hours per week. Almost all participants ( $n = 54, 90\%$ ) spoke primarily English at home, with the remaining participants speaking Chinese, Tamil, Vietnamese or other languages at home. The following table summarizes the key demographic characteristics of the sample.

Table 2

*Sample demographic characteristics*

	Minimum	Maximum	Mean	Standard Deviation
Age in years	19	72	45.2	14.2
Years of education	5	24	14.6	3.5
Hours of work per week	0	105	31.7	21.5
Years aware of kidney disease	1	38	10.1	9.4

To explore the participant's understanding of their diagnoses, they were asked to report what the diagnoses were in their own words. Six participants did not respond to this question. Of those who responded, answers varied, ranging from the actual name of the disorder such as, IgA nephropathy, to a more general description of the diagnosis, such as loss of kidney function. For those who reported the actual name of the diagnosis, 12 individuals (22.2%) reported having IgA or IgA nephropathy, 10 participants (18.5%) stated they had focal segmental glomerulonephritis, 5 (9.3%) stated they had glomerulonephritis, and 2 (3.7%) stated they had membranous nephropathy. Of those who provided a general description of what their diagnoses were, 9 (16.7%) of the participants reported they had loss of kidney function, 8 (14.8%) stated they had unspecified kidney disease, 4 (7.4%) described they had proteinuria, and 4 (7.4%) stated they had "others".

The symptoms experienced when participants first became aware of CKD were also reported. Participants could report more than one symptom and respondents identified a wide range of symptoms. A total of 15 participants (20%) reported there were no symptoms associated with their diagnosis. However, for those who were symptomatic, a total of 75 symptoms were reported. The most commonly reported symptoms were noticeable swelling of body parts (n= 18, 24%), and a change in urine color such as “bloody urine” (n = 7, 9.3%). Although participants were asked to describe symptoms, several individuals reported signs, such as proteinuria, which were detected by laboratory tests. Table 3 presents the reported symptoms.

Table 3

*Reported Symptoms When Participants First Became Aware of CKD*

Reported Symptoms	Number of Responses	
	N = 75	% of total symptoms reported
Swelling	18	24%
No Symptoms	15	20%
Proteinuria	9	12%
“Bloody urine”	7	9.3%
Weakness/Malaise	6	8%
Pain	6	8%
High Blood Pressure	4	5%
Rashes	2	3%
Shortness of Breath	2	3%
Others	6	8%

## Types of Medications Reported

A total of 216 medications were reported and these were grouped into pharmacological categories by the researcher (presented in Table 4).

Table 4

### *Types of Medications Reported*

Types of Medications	Number of Medications	
	N= 203	% of Total Medications Reported
Anti-Hypertensives (n = 72)		
Ace Inhibitors	43	21.2%
Angiotensin II Receptor Blockers	15	7.4%
Calcium Channel Blockers	8	3.9%
Beta Blockers	6	3.0%
Statins	33	16.3%
Diuretics	24	11.8%
Immunosuppressants	18	8.9%
Vitamins	17	8.4%
Analgesics (Acetaminophen & Ibuprofen)	11	5.4%
Anti-coagulative agents	6	3.0%
Antibiotics	3	1.5%
Antihyper-urecemic agents	9	4.4%
Proton Pump Inhibitors	4	2.0%
Bone protective medications	3	1.5%
Anti-Histamine	3	1.5%

Of the 216 medications reported, a total of 13 medications were described in terms of pill colors. Because it was unclear what these pills were referring to, they were not included in the table but were listed under “Others” in Appendix A. Appendix A provides a complete list of medications reported. Antihypertensives made up of 35.5% (n = 72) of the medications reported. The second predominant group of medications were statins (n=33, 16.3%), followed by diuretics (n=24; 11.8%), and immunosuppressants (n=18, 8.9%). Apart from these 4 main categories of medications, 11 participants reported to use analgesics such as acetaminophen or ibuprofen. Vitamins such as, Vitamin A, C, multivitamins such as Centrum, fish oil, folic acid, calcium, iron, magnesium, or zinc were reported. Please refer to Appendix A for a complete list of all the medications reported.

Participants were also asked to indicate whether they were taking any non-prescribed medications. Approximately half of the participants (n = 32, 53.3%) indicated they used non-prescribed medications. Some of these non-prescribed medications were generally regarded as complementary therapies, such as “plant enzymes”, “natural pills”, “seeds”, “oil”, or “probiotics”. One of the other participants indicated that he/she was taking Calcium, but was not taking it because he/she was being told by the doctor to do so”.

### **Medication Taking Behaviour**

Fifty-nine participants reported they took medications every day of the week. One participant did not respond to the Brief Medication Questionnaire; however, this one participant stated he took naturopathic medications and answered all the questions from the MHBQ. Therefore, his responses about health beliefs will be incorporated into the discussion about health beliefs below. On average, participants took a total of  $4.0 \pm 2.9$  pills daily, with an average of 1.3

± 0.5 pills being taken each time. The majority of the participants (n = 39, 65%) reported taking between 1 to 4 different types of medications in the week preceding the interview, whereas the remainder (n = 20, 33.3%) reported they took 5 or more types of medications (Table 5). Of these 20 participants, 3 stated they took 10 types of medications in the past week. In terms of dosing frequency for each medication, 32 participants (54.2%) reported they needed to take their medications once a day and 27 participants (45.8%) took medications more than once a day.

Table 5

*Frequency table: number of medications taken over the last week*

Number of medications taken	Number of Participants (N = 59)	Percent
1	12	20.3
2	11	18.6
3	7	11.9
4	9	15.3
5	3	5.1
6	7	11.9
7	4	6.8
8	0	0
9	3	5.1
10	3	5.0

A total of 42 (71.2%) participants stated they did not miss a pill, 13 (22.1%) participants indicated they missed 1-4 pills, and 4 (6.8%) individuals stated they missed more than 5 pills

over the past week. Table 6 lists the numbers of missed pills reported in the week preceding the interview.

Table 6

*Reported number of missed pills in week preceding the interview*

Number of Missed pills	Numbers of Participants N = 59	Percent
0	42	71.2
1	6	10.2
2	2	3.4
3	2	3.4
4	3	5.1
5	1	1.7
6	1	1.7
10	1	1.7
14	1	1.7

With respect to the types of medications that were commonly missed, 7 participants (11.9%) missed antihypertensives such as Ramipiril, Cozaar, and Amlodipine; another 7 participants reported missing statins such as Lipitor and Simvastatin; 6 (10.2%) missed immunosuppressants such as Cyclosporine and MMF, and 4 (6.8%) missed diuretics such as Lasix and Aldactazide.

Participants reported their understanding of the reasons for taking each medication and their views varied greatly. A total of 216 reasons for taking medications were reported, reasons

were missing for 11 reported medications. Each reported reason was compared to the intent of the medication to determine whether the participants understood the uses of their medications. Table 7 illustrates the frequency of the correctly identified reasons for each category of drug. For example, out of 72 antihypertensives reported, 70 reasons were correctly identified. The percentage of correct responses in Table 7 is calculated based on the number of correct reasons for the drug category (e.g. 70) divided by the total number of medications reported in the drug category (e.g. 72).

Table 7

*Reasons for taking medications*

	Frequency	Percentage
<b>Correct Reasons by Drug Category</b>		
Anti-hypertensives	70	97.2
Statins	28	84.4
Diuretics	15	62.5
Immunosuppressants	11	61.1
Anti-coagulative agents	5	83.3
Antibiotics	3	100
Anti-hyperurecemic agents	7	77.8
Proton pump inhibitors	4	100
Bone protective medications	3	100
Over the counter medications	24	77.4
Total	170	
Missing Reasons	11	
Incorrect Reasons	17	
Unsure	2	
“colored” pills with reasons	13	
“doctors prescribed it”	3	
Total number of reasons	216	

Approximately, 78.7% (n = 170) of all responses correctly corresponded to the purposes of the reported medications. Incorrect reasons made up 17.9% (n = 17) of the total responses. For example, a participant might indicate immunosuppressants were used for lowering blood pressure. Interestingly, 3 responses stated that medications were used because “the doctor prescribed it”, and 2 identified they were unsure of the reasons for using the medications. A total of 13 (6.0%) of the responses described the reasons for taking medications that were identified by pill colors only. Although each participant who listed colored pills provided a reason for taking them, it was impossible to ascertain whether these reasons were reflective of the purposes of those pills.

### **Health Beliefs**

To understand some of the health beliefs about CKD, participants were asked to describe in their own words, what their illnesses might be. Responses were then categorized by the investigator and results illustrated that 25% (n = 15) of the participants understood they had loss of or reduced kidney function or “faulty filtering device”. Ten percent (n = 6) of the participants perceived their illness to be a result of inflammation or the immune system attacking their kidneys. Approximately 6.7% (n = 4) stated their illness meant their kidneys were spilling proteins and another 6.7% (n = 4) believed their diagnoses to be chronic in nature. A total of 3.3% (n = 2) of the participants believed their diagnoses to be the result of a kidney infection and 6.7% (n = 4) understood the diagnoses would require dialysis, medications, or transplantation in the future. Although the majority of the participants were able to express, in their own words, what the diagnosis meant, one participant felt unsure of what the problem was, and 16 other participants (26.7%) stated there were other meanings associated with their illnesses. For

example, one individual believed the kidney problems to be related to toxic exposure from food or environment whereas others believed problems to be related to stress, autoimmune disease, or a “ruptured kidney which never healed”.

### **Perceived susceptibility.**

More than half of the respondents (n= 34, 57.6%) believed their kidney function would decline in the future and 14 participants (23.3%) believed it would improve in the future. Approximately one fifth of the sample (n = 11, 18.3%) believed there would be no change and 1 individual did not respond. Participants were also asked to choose from a list some of the signs and symptoms they felt would be associated with worsening of kidney function. Frequent signs and symptoms reported by respondents included swelling (n = 55, 91.7%), proteinuria (n = 54, 90%), increase in creatinine (n = 44, 73.3%), increase in blood pressure (n= 42, 70%), and fatigue (n = 32, 53.3%). Headache, change in urine frequency and a lack of appetite were not believed to be indicators of worsening of kidney function.

### **Perceived severity.**

Approximately 60% (n = 35) of the participants believed their diagnosis to be moderately or very serious, 27.1% of the sample (n= 16) believed it to be somewhat serious, and 13.6% (n = 8) believed their illnesses to be not at all serious or not very serious. One respondent did not respond. Over three quarters of the sample (n = 49, 81.7%) believed CKD to be more serious than the flu, 3 (5%) believed CKD to be the same as the flu, and 8 individuals (13.3%) believed CKD to be much less or less serious than the flu. Sixteen participants (27.1%) believed CKD to be more serious than diabetes, 19 (32.2%) believed CKD to be the same as diabetes, and 24

(40.7%) believed CKD to be much less or less serious than diabetes. With respect to cancer, 52 (86.7%) believed CKD to be much less or less serious than cancer, 5 (8.3%) believed CKD to be the same as cancer, and 3 (5%) believed CKD to be more or much more serious than cancer.

### **Perceived benefits.**

When participants were asked about how well the medications worked for them on the BMQ, 71% (n = 152) of the responses indicated the medications worked well, 24% (n = 51) indicated they worked “okay”, and 5% (n = 11) not well at all. Based on the data derived from the MHBQ, the majority of respondents (n= 43, 71.7%) believed their treatment would moderately or very likely help their illness, 18.3% (n=11) of the participants believed the treatment would somewhat likely help their illness, and 8.3% (n = 5) did not believe the treatment would help their illness. When participants were asked if they believed these treatments would prevent them from becoming ill again, less than half of the participants (n =28, 46.7%) believed the treatment would moderately or very likely keep them from becoming ill, and 28.3% (n = 17) of the participants did not believe the treatment would likely keep them from becoming ill again.

### **Perceived barriers.**

From the Recall Screen of the BMQ, participants were asked to choose from a list of 5 potential barriers on the BMQ which could interfere with medication taking: 1) opening or closing the medication bottle, 2) reading the print on the bottle, 3) remembering to take all the pills, 4) getting refills in time, and 5) taking so many pills at the same time. One person did not

respond to this question. The two most difficult tasks were to remember to take all the pills (n = 16, 26.7%) and to take so many pills at the same time (n = 9, 15%). Please refer to Table 8.

Table 8

*Perceived barriers to taking medications (N = 59)*

Barriers	Not hard at all n (%)	Somewhat or very hard n (%)
Opening or closing medication bottle	55 (93.2)	4 (6.7)
Reading the print on the bottle	54 (91.5)	5 (8.3)
Remembering to take all the pills	43 (72.9)	16 (26.7)
Getting the refills in time	51 (86.4)	8 (13.3)
Taking so many pills at the same time	50 (84.5)	9 (15)

In order to quantify the level of barriers experienced with medication taking, a composite score was calculated by summing scores for all 5 behaviours for each participant. Total composite barrier scores could range from 5 to 15, with a score of “5” indicating there were no barriers and a score of “15” indicating the maximum number of barriers possible. Composite barrier scores have been captured in Table 9.

Table 9

*Composite barrier scores (N = 59)*

Scores	Frequency	Percentage
5	31	52.5
5.3-6.0	17	28.8
7-10	11	18.6

Composite barrier scores ranged from 5 to 10. More than half of the respondents (n = 31, 52.5%) did not experience any forms of barriers related to medication taking. Seventeen participants (28.8%) experienced some form of barriers and 11 individuals (18.6%) experienced moderate level of barriers to medication taking.

To further understand some of the reasons which participants felt might kept them from taking their medications, they were asked to choose from a list of 5 options from the MHBQ: “it may be addicting”, “cost inconvenience”, “I don’t like the way I feel taking it and the side effects”, “nothing keeps me from taking my medications, and “others”. Two participants did not respond to this question. Of those who responded, half of the participants (n = 29, 50%) indicated there were nothing to keep them from taking the medications, 10 (16.7%) stated they did not like the way they felt or the side effects associated with the medications, 8 (13.3%) stated cost inconvenience was a barrier, and 1 person indicated a belief that the medications might be addictive.

To understand the reasons why medications were bothersome, results from the BMQ were categorized. Participants were asked to list the way each medication bothered them. Not every participant responded to this question. A total of 70 ways in which medications were

bothersome were reported and results were categorized by the investigator. See Table 10.

Appendix B summarizes the reported bothersome characteristics on each type of medication.

Antihypertensives had the most number of bothersome characteristics followed by

immunosuppressants. Based on the responses, some of the common bothersome features seen

across the types of medications related to the difficulties in the actual taking of the medication

because the pills were “hard to swallow”, and they needed to be split. Other characteristics

related to the unpleasant flavours associated with the pills. Reported side effects of taking certain

medications were also common. For instance, antihypertensives were reported to be related to

the slowing of heart rate, nausea, sleepiness, and “makes me weak”; immunosuppressants were

perceived to cause decreased level of energy and being “hard on the liver”; diuretics resulted in

frequent urination. A disruption of daily routines, such as sleep pattern, was also connected to the

use of antihypertensives, immunosuppressants, and statins.

Table 10

*Ways in Which Medications Were Bothersome*

Reasons (N = 70)	Number of times reported	Percentage
Fatigue/Decreased level of energy	13	18.6%
Light headedness/drowsiness	8	11.4%
Hard to swallow	8	11.4%
Mentally and physically demanding	6	8.6%
Pain	5	7.1%
“The fact I need to”	4	5.7%
Nausea/Vomiting	3	4.3%
Bitter tastes/smell bad	3	4.3%
Low blood pressure	3	4.3%
Sleep disturbance	3	4.3%
Time consuming	2	2.9%
Upset stomach	2	2.9%
Forgetfulness	2	2.9%
Frequent urination	2	2.9%
Causes bruising	2	2.9%
“gives me shakes”	2	2.9%
Hard on liver	1	1.4%
Puffiness	1	1.4%

## Differences in Health Beliefs between Men and Women

To examine the difference in health beliefs (perceived susceptibility, perceived severity, perceived benefits, and perceived barriers) between men and women, crosstabs and chi-square statistics were computed. Table 11 summarizes the statistical results.

Table 11

### *Differences in health beliefs between men and women*

Health Beliefs	Men n = 30 n (%)	Women n = 29 n (%)	$\chi^2$	p-value
Perceived susceptibility				
Kidney function will decline somewhat or severely	22 (73.3)	12 (41.4)	7.771	0.021
Perceived Severity				
Illness is moderately or very serious	20 (66.6%)	15 (51.7)	1.448	0.485
Perceived benefits				
Very or moderately likely treatment can keep you from becoming ill again	9 (30)	19 (65.5)	7.315	0.026
Very or moderately likely treatment will help your illness	19 (63.3)	24 (82.6)	3.038	0.219
Perceived barriers				
No barriers to taking medications	18 (60)	14 (48.3)	1.071	0.301

### **Gender and perceived susceptibility.**

The majority of the participants (57.6%, n = 34) believed their kidney function would decline somewhat or decline severely in the future. Of those who believed their illness would worsen somewhat or severely, 12 were women (35.3%) and 22 (64.7%) were men. A statically significant difference in perceived susceptibility was detected between men and women,  $\chi^2 (2) = 7.771$ , p = 0.021. More men than women believed their kidney function would decline in the future. Women were more likely to believe that their kidney function would improve in the future.

### **Gender and perceived severity.**

Results demonstrated that 51.7% (n =15) of female participants versus 66.6% (n = 20) of male participants believed their diagnosis to be moderately serious or very serious. This difference was not statistically significant,  $\chi^2 (2) = 1.448$ , p = 0.485.

### **Gender and perceived benefits.**

A large proportion of participants (n = 43, 72.8%) held positive beliefs that their treatment would very likely or moderately likely help their illness. When respondents were asked whether the treatment could keep them from becoming ill again, a statistically significant difference was detected between men and women,  $\chi^2 (2) = 7.315$ , p = 0.026. More women (n =19) than men (n = 9) believed the treatment would very likely or moderately likely keep them from becoming ill again. When they were asked whether the treatments would likely help their illnesses, more women (n = 24) than men (n=19) believed the treatments would likely help. However, this difference was not statistically significant,  $\chi^2 (2) = 3.038$ , p = 0.219.

### **Gender and perceived barriers.**

Chi Square statistics showed that there was no statistically significant difference in the level of perceived barriers between men and women,  $\chi^2 (1) = 1.071, p = 0.301$ . However, more women (n = 16) than men (n = 12) experienced some forms of barriers to medication taking. With respect to the two most commonly identified barriers from the BMQ, more women (n = 10) than men (n = 6) believed it was hard to remember to take all the pills. An almost equal number of women (n = 5) and men (n = 4) believed it was hard to take so many pills at the same time. With respect to gender differences in reported side effects, an equal number of men (n = 7) and women (n = 7) stated side effects might keep them from taking their medications.

### **Difference in Health Beliefs between Older and Younger Individuals**

Younger adults were considered to be those who aged from 19 to 44 years of age, and older adults 45 years old or older. Chi square tests were calculated to examine if there were differences in health beliefs between younger and older participants. For statistical results, please refer to Table 12. Again, one participant did not respond to questions related to perceived susceptibility, severity, and benefits.

Table 12

*Difference in health beliefs between younger and older participants*

Health Beliefs	Younger Adults (≤ 44 years old)	Older Adults (> 45 years old)	$\chi^2$	p-value
	N = 30	N = 29		
	n (%)	n (%)		
<b>Perceived susceptibility</b>				
Kidney function will decline somewhat or severely	17 (56.7%)	17 (58.6%)	0.360	0.835
<b>Perceived severity</b>				
Illness is moderately or very serious	19 (63.3%)	16 (55.2%)	1.241	0.538
<b>Perceived benefits</b>				
The treatment will very likely or moderately likely help the illness	18 (60%)	25 (86.2%)	5.779	0.056
Treatment will very likely or moderately likely keep you from becoming ill again	13 (43.3%)	15 (51.7%)	1.426	0.490
<b>Perceived barriers</b>				
No barriers to taking medications	15 (50%)	17 (58.6%)	0.268	0.605

**Age and perceived susceptibility.**

Equal numbers of younger and older individuals believed that their kidney function would decline somewhat or decline severely in the future. This was not statistically significant,  $\chi^2 (2) = 0.360$ ,  $p = 0.835$ .

### **Age and perceived severity.**

No statistically significant difference was found in the level of perceived severity between younger and older adults,  $\chi^2 (2) = 1.241$ ,  $p = 0.538$ . A greater number of younger participants ( $n = 19$ ) than older participants ( $n = 16$ ) believed their diagnosis to be moderately serious or very serious in nature.

### **Age and perceived benefits.**

No statistically significant difference was found between younger and older individuals with respect to their beliefs that their treatment would help their illness  $\chi^2 (2) = 5.779$ ,  $p = 0.056$ . Similarly, there was no statistically significant difference in their beliefs that the treatment would keep them from becoming ill again,  $\chi^2 (2) = 1.426$ ,  $p = 0.490$ . However, older participants seemed to hold more positive beliefs that the treatment would likely help the illness and would likely to keep them from becoming ill again, as evidenced by a larger number of older participants ( $n = 25$ , 86.2%) versus 18 younger participants (60%) who believed treatment would very likely or moderately likely help the illness. Again, 15 older participants (51.7%) versus 13 younger participants (43.3%) believed the treatment would likely keep them from becoming ill again.

### **Age and perceived barriers.**

Composite barrier scores revealed that more than half of the participants ( $n = 32$ , 53.3%) indicated there were no barriers associated with medication taking. Seventeen younger participants and 15 older participants had no barriers to using medications. Results demonstrated

that there was no statistically significant difference in the level of perceived barriers between younger and older individuals,  $\chi^2 (1) = 0.268, p = 0.605$ .

### **Relationship between Health Beliefs and Medication Taking Behaviour**

The number of missed doses reported by participants was used as an indicator of successful medication taking behaviour. Because a large number of participants ( $n = 42, 71.2\%$ ) reported they had never missed a dose, the missed dose variable was categorized. Those who did not report any missed doses were given a score of “1”, and those who reported missed doses were assigned a score of “2”. Chi-square tests were calculated to examine the difference in health beliefs between those who missed and those who did not miss a dose. Results are reported in Table 13.

Table 13

*Difference in health beliefs between those who missed and those who did not miss a dose*

Health Beliefs	Participants who did not miss doses N = 42 n (%)	Participants who missed doses N = 17 n (%)	$\chi^2$	p-value
<b>Perceived susceptibility</b>				
Kidney function will decline somewhat or severely	23 (54.8%)	11 (64.7%)	1.954	0.376
<b>Perceived severity</b>				
Illness is moderately or very serious	27 (64.3%)	8 (47.1%)	0.896	0.639
<b>Perceived benefits</b>				
The treatment will very likely or moderately likely help the illness	31 (73.8%)	12 (70.6%)	0.512	0.774
Treatment will very likely or moderately likely keep you from becoming ill again	18 (42.9%)	10 (58.8%)	2.986	0.225
<b>Perceived barriers</b>				
No barriers to taking medications	30 (71.4%)	2 (11.8%)	16.469	0.000

### **Perceived susceptibility and missed doses.**

No statistically significant difference was found in perceived susceptibility between those who missed and those who didn't miss doses,  $\chi^2 (2) = 1.954$ ,  $p = 0.376$ . However, a greater number of individuals ( $n = 23$ , 54.8%) who did not miss doses believed their kidney function would decline somewhat or severely in the future. Among those who reported missed doses, a total of 11 individuals (64.7%) believed their kidney function would decline in the future as compared with 23 participants (54.8%) who did not miss doses.

### **Perceived severity and missed doses.**

No statistically significant difference was found in perceived severity between those who missed and those who didn't miss doses,  $\chi^2 (2) = 0.896$ ,  $p = 0.639$ . Among those who reported missed doses, 8 participants (47.1%) believed their diagnosis to be moderately or very serious compared with 64% ( $n=27$ ) of those who did not miss a dose.

### **Perceived benefits and missed doses.**

No statistically significant difference was found between individuals who didn't miss and who missed doses with respect to their beliefs that their treatment would help their illness  $\chi^2 (2) = 0.512$ ,  $p = 0.774$ . There was no statistically significant difference in their beliefs that the treatment would keep them from becoming ill again,  $\chi^2 (2) = 2.986$ ,  $p = 0.225$ . Interestingly, among the 17 respondents who reported missed doses, 12 (70.6%) held positive beliefs that treatment would likely help with their illness and 10 (58.8%) believed the treatment would keep them from becoming ill again.

### **Perceived barriers and missed doses.**

A statistically significant difference was found in the levels of barriers between those who missed and didn't miss doses,  $\chi^2 (1) = 16.469$ ,  $p = 0.000$ . The majority of the participants who never missed a dose reported no barriers to taking medications ( $n = 30$ , 71.4%). Among the 17 participants who reported missing doses, 15 of these participants reported barriers to taking medications.

### **Summary of Findings**

Individuals living with mild to moderate CKD in this sample took on average 4 pills a day. Categorization of medications revealed that participants were prescribed primarily antihypertensives, cholesterol lowering agents, diuretics, and immunosuppressants. Most participants believed their illness to be serious, and more than half of the participants believed their kidney function would decline in the future. In terms of the effectiveness of the medications, the majority of the sample believed the medications would help their illness; however, they were more pessimistic in the sense that they did not feel the medications would prevent them from becoming ill again. Some of the side effects associated with medications were fatigue, drowsiness, urge to urinate, sleep disturbances, and tremors.

Statistically significant differences were found in perceived susceptibility between men and women. Specifically, more men than women believed their kidney function would decline in the future. Women were more likely to believe that their kidney function would improve in the future. No statistically significant differences were found in perceived severity, or perceived barriers between men and women. However, statistically significant difference was found in one

aspect of perceived benefits between genders, where women were more likely than men to believe treatment would keep them from becoming ill again. No statistically significant differences were detected in health beliefs between younger and older participants.

A total of 42 participants reported they had never missed a medication dose in the week preceding the interview. No statistically significant differences were found in perceived susceptibility, perceived severity, and perceived benefits between those who missed and those who didn't miss doses. A statistically significant difference was found in perceived barriers between those who missed, and those who didn't miss doses. Of those who reported they had missed a dose, 15 participants stated they experienced some forms of barriers to medication taking.

## **Chapter 6 Discussion**

This purpose of the secondary analysis was to examine medication taking behaviour of individuals with mild to moderate CKD, and to examine factors associated with medication taking behaviour, specifically health beliefs. In particular, perceived susceptibility to and perceived severity of CKD, and perceived benefits of and barriers to taking medications were explored. Differences in health beliefs between men and women, as well as the relationship between age and health beliefs were examined. This chapter will discuss the study findings. The representativeness of the sample will be considered first, followed by a discussion of medication taking behaviour and health beliefs. Finally, relationships among health beliefs and medication taking behaviour will be discussed.

### **Representativeness of Sample**

This sample consisted of 30 men and 30 women, whose ages ranged from 19 to 72 years old, with a mean age of 45.2 years. Participants, on average had achieved some post-secondary education, and they had lived with CKD for approximately 10 years. The most commonly reported symptoms at time of diagnosis were swelling of body parts and changes in urine color. However, 20% of the sample was asymptomatic. The mean age reported in this study is slightly younger in comparison to a study examining cardiovascular and renal outcomes among individuals with mild to moderate CKD where mean ages for stage 1, stage 2, and stage 3 CKD were 48.2, 56.5, and 63.2 years old respectively (Brantsma et al., 2008). However, the difference between the mean age reported in this secondary analysis and the Brantsma's study was not large, particularly for the stage 1 group. The mean age of this sample is also similar to the ages

reported in later phases of CKD, such as kidney transplant recipients where mean ages ranged from 47.6 to 52.8 years (Gregmigni et al., 2007; Ruppap & Russell, 2009; Russell et al., 2003; Vasquez et al., 2003), and among patients on dialysis where mean ages ranged from 49.0 to 50.8 years of age (Horne and Weinman, 1999; Stamatakis et al., 1997), suggesting the mean age of the sample, while somewhat younger, is comparable to the mean ages reported among individuals living with CKD across various stages.

The equal number of men and women in this sample is a result of purposive sampling to facilitate the examination of differences in health beliefs between genders. The equal proportion of men and women in this study may not necessarily reflect the proportion of men versus women diagnosed with kidney failure based on the Canadian Institute for Health Information (CIHI). According to CIHI, for adults 18 years old and above who were being treated for kidney failure in Canada, 61.3% (n= 3317) and 38.7% (n = 2093) were men and women respectively (CIHI, 2010). Given the limited statistics available on earlier stages of CKD, it is difficult to determine the proportion of men versus women with mild to moderate CKD in this population, and it is difficult to determine the representativeness of the sample with regards to gender based on the statistics for kidney failure. However, it can be postulated that more men are being diagnosed with CKD suggesting the sample of men and women in this study may not represent the proportion of men and women being diagnosed with CKD.

With respect to other sample characteristics such as level of education, the findings reported by the participants from this secondary analysis are similar to the level of education reported among kidney transplant recipients where participants were well educated with the highest educational level obtained ranging from senior high school to some University education

(Ruppar & Russell, 2009; Russell et al., 2003). The level of education from this sample is also consistent with the participants enrolled in NKF's Kidney Early Evaluation Program (KEEP), which is a community-based health screening program that targets individuals who are at high risks for early kidney disease and kidney disease related comorbid conditions such as hypertension, diabetes, obesity, and history of cardiovascular illnesses (Jurkovitz et al., 2008). This suggests that the participants from the secondary analysis are fairly well educated, and the level of education reported in this study is comparable to the level of education reported among other studies examining CKD at different stages. However, given the fact that a large proportion of the participants in this study were literate in English, the education level reported in this study may not reflect the education level of the general CKD population since individuals were excluded from the study due to their limited English literacy.

In terms of illness presentation of mild to moderate CKD, experiences reported by participants in this study varied. The asymptomatic nature of CKD, represented by 20% in this sample, has been recognized in the literature to be a feature of mild to moderate CKD (Nissenson et al., 2001; Pereira, 2002). Among those who experienced signs and symptoms in this study, the participants' self-reported signs and symptoms were consistent with the hallmarks of early kidney damage (Wolf & Ziyadeh, 2007). For example, changes in urine color as well as proteinuria reported by this sample are commonly perceived to be markers of early kidney function decline represented by decreasing GFR (Levey et al., 2003). Other early markers of kidney damage, which were not expected to be reported by the participants in this study, could also include abnormalities in urine sediments, blood chemistry, and findings from imaging (Levey et al., 2003). In general, the representativeness of the sample with respect to self-reported

illness presentation of mild to moderate CKD is supported by the general signs and symptoms of early CKD in the literature (Levey et al., 2003; Wolf & Ziyadeh, 2007).

### **Medication Taking Behaviour**

The medication regimen described in this sample, which was on average comprised of 4 pills a day, and 1.3 pills taken at each dosing, highlights the complexity of the regimen and suggests management of the medication regimen can indeed be challenging for someone diagnosed with mild to moderate CKD. The medications reported by the participants in the sample are similar to those being reported by other CKD populations (Floege, 2003; Russell et al., 2003; Russell et al., 2006; Ruppap & Russell, 2009). For example, the use of antihypertensives as reported in this sample, was also the most prevalent medication in a study by the Renal Research Institute examining patterns of medication use among individuals with stages 2-5 CKD (Bailie et al., 2005), reflecting the importance of managing blood pressure not only in the early phase of the illness, but also in kidney failure. Furthermore, diuretics and statins have been found to be equally commonly used in conjunction with antihypertensives for someone living with CKD (Alexopoulos, 2004; Bailie et al., 2005; NKF, 2002), demonstrating the importance of achieving acceptable blood pressure using different classes of medications, and maintaining cholesterol levels to minimize further kidney damage in the early phases of CKD. Other medications, such as immunosuppressants (MMF, prednisolone, cyclosporine) reported in this study are also consistent with what has been described among other populations of CKD (Floege, 2003; Russell et al., 2003; Russell et al., 2006; Ruppap & Russell, 2009).

In addition to the use of conventional medications, the findings indicated that more than half of the participants in this study (n = 32, 53.3%) reported they used other types of

medications, such as vitamins or complementary medications that might not have been prescribed by the primary health care provider. For example, one respondent in this study indicated he/she only took “natural pills” and did not take any prescribed conventional medication for CKD. This finding is not unexpected as the literature acknowledges the rising number of patients with CKD choosing to use complementary therapies, such as herbal remedies (Wojcikowki, Johnson, & Gobe, 2006).

A total of 42 participants in this study stated that they took medications regularly and consistently in the preceding week, indicating that 71.2% of the sample with mild to moderate CKD reported being successful in carrying out medication taking behaviour. In comparison with other literature which has examined adherence rates, the self-reported rate of 71.2% in this study is higher than what has been previously reported in kidney transplant or dialysis (Claxton, 2001; Danaerynck et al., 2007; Vasquez et al., 2003). Several reasons might contribute to the higher than expected rate of medication taking behaviour in this study.

The first reason might be related to dosing frequency of the medications. Past research has identified a relationship between dosing frequency and medication adherence indicating higher adherence rates were associated with less frequent dosing regimens (Claxton, 2001; Saini et al., 2009). Once-daily dosing regimens generally yielded adherence rates ranging from 49% to 94% in antihypertensives studies, as compared with more frequent dosing which resulted in lower adherence rates (Andrejack et al., 2000; Leenen et al., 1997). Given the fact that more than 50% of this sample reported their dosing frequency for medications such as, antihypertensives, statins, diuretics, and immunosuppressants, to be once daily, less frequent dosing of the

medications in this sample could explain the success in maintaining medication taking behaviour reported by the participants.

Fewer missed doses reported in this study could also be linked to the length of time participants had been living with CKD. Empirical evidence from the kidney transplant literature supports that medication non-adherence rates are correlated with the length of time after kidney transplantation, suggesting medication non-adherence is more likely to develop in patients who have been living with transplant for a longer period of time (Vasquez et al., 2003). One possible reason for lower medication non-adherence rate immediately post kidney transplant might be a result of improved health states experienced by the recipients, which encouraged them to continue taking the medications consistently (Vasquez et al.). Another possible reason that recipients reported lower medication non-adherence rates immediately post transplant is perhaps these participants see the immediate benefits of taking medications and correlate the effectiveness of medications with improved kidney function or improved overall well-being. In this secondary analysis, because approximately 50% of the participants had been living with mild to moderate CKD for a short period of time (1-5 years), these participants may take medications regularly and consistently due to the perceived benefits of taking medications in improving their kidney function or their overall well being. Over time, individuals may report lower rates of adherence to medications because the initial perceived benefits of medications may have subsided due to the emergence of side effects, or as Vasquez et al. (2003) suggested, individuals no longer perceived they were susceptible to the consequences of poor outcomes due to non-adherence.

The low number of self-reported missed doses reported in this study could also be attributed to the measurement of medication taking behaviour. Measurement of medication adherence in the literature has generated much methodological debate. Although self-report is one of the most common methodological approaches to gathering adherence information due to its feasibility and adaptability virtually across all care settings (De Geest et al., 1996; Foley et al., 2005), results can be influenced by recall and self-presentation biases (Horne & Weinman, 1999). The literature indicates that self-report may be subject to biases, such as recall bias which could potentially underestimate the extent of non-adherence by 20% if participants were asked to recall information in the past month (Haynes, Taylor, Sackett, et al., 1980; Vermiere et al., 2001). However, the potential for recall bias was minimized in this study because participants were asked to recall medications taking over the preceding week only.

Self-presentation bias occurs when patients exaggerate their level of adherence to avoid being perceived negatively (Fincham, 2007). Underestimation of medication non-adherence may be linked to self-presentation bias where participants want to be a “good patient” and please the researcher; or they do not want to admit to poor medication taking behaviour for fear of being judged negatively on their efficacy to carry out a routine (Horne & Weinman, 1999). In light of the fact that the adherence rate reported in this study is higher than the reported rates from transplant or dialysis studies, it is important to acknowledge the potential for self-presentation bias to confound the self-reported missed dose in this study.

## **Health Beliefs**

### **Perceived susceptibility and perceived severity.**

More than half of the participants (57.6%) believed their kidney function would decline in the future, yet approximately one fifth (23.3%) believed their kidney function would improve, suggesting that participants held differing beliefs about their perceived susceptibility to CKD. Four participants associated the diagnosis of CKD with dialysis, medications, or transplantation in the future, suggesting these participants held stronger degree of perceived susceptibility associated with their diagnosis, as well as associating it with the need for medications or intrusive therapy such as dialysis or transplantation. Differences in perceived susceptibility to CKD between participants may reflect different coping strategies which allowed some of the participants to believe their kidney function would improve in the future. Although there has been little research conducted towards understanding coping processes in all stages of CKD, a study by Lindqvist et al. (2000) found that individuals on dialysis used various coping styles, and individuals who employed an optimistic coping style were more effective and successful in dealing with the stressful treatments associated with dialysis. Although the illness experience for someone living with mild to moderate CKD may not necessarily be equivalent to that of someone on dialysis or post kidney transplant, participants dealing with mild to moderate CKD may also adopt different coping styles, which may explain the differences in perceived susceptibility detected in this study.

Another possible reason why some participants in this study believed their kidney function would improve in the future might be a result of their beliefs about the effectiveness of medications, as evidenced by the finding that 90% of the participants believed their treatment

would help their illness. It is also possible that participants were more positive about their future kidney function because the medications were effective in delaying progression or improving kidney function. Thus the positive outlook reported by the participants may reflect a reduction in the level of perceived susceptibility to CKD and perceived severity of CKD as a result of the benefits of medications in reducing the signs and symptoms associated with declining kidney function.

Perceived severity of an illness has been demonstrated to vary across common diseases such as heart diseases, cancer, and diabetes where individual beliefs about one disease may not predict how they perceive the severity of other illnesses (Wang et al., 2009). In this study, a comparison of the participants' perceived severity of CKD with their perceptions of severity of an acute short term illness demonstrated that only a few individuals (n=8, 13.3%) believed CKD to be less serious than the flu. On the other hand, when perceived severity of CKD was compared to other chronic illnesses such as diabetes and cancer, 24 individuals (40.7%) believed CKD to be less serious than diabetes, and 52 participants (86.7%) believed CKD to be less serious than cancer. These findings are consistent with previous studies demonstrating different beliefs held towards different chronic illnesses where patients in general have heightened perceptions of severity to cancer, followed by heart diseases, then diabetes (Mosca et al., 2000; Wang et al., 2009). One explanation as to why participants from this secondary analysis believed CKD to be less serious than some chronic conditions such as diabetes, or cancer, may reflect a general lack of public awareness of CKD and its consequences. A search through the Public Health Agency of Canada revealed that educational information for cancer, diabetes, asthma, cardiovascular illnesses, or musculoskeletal diseases are readily available, with limited information raising

awareness of CKD. Therefore, Canadians who are living with mild to moderate CKD or those who are considered to be “high-risk” may not have as much exposure to CKD as other chronic illnesses, thus minimizing their perception of severity of CKD in comparison to other chronic illnesses. A second possible reason to explain why participants did not perceive their diagnosis to be as serious as cancer is perhaps they perceive CKD to be manageable by engaging in health promoting actions, such as medication taking, thereby reducing the severity of the illness and delaying progression.

### **Perceived benefits and perceived barriers.**

The majority of the participants (71.7%) believed their treatment would moderately or very likely help with their illnesses, and 46.7% of the participants believed their treatment would keep them from becoming ill again. A stronger belief in the benefits of the prescribed medications may be explained by the fact that a large proportion of the participants in this study were able to correctly articulate the reasons why the medications were used, suggesting the participants understood the reasons for taking the medications. However, not all participants held positive beliefs towards their medications. Of all the medications being reported, informants identified that approximately one third of all the medications did not work well with them and were perceived to be bothersome. Some of the identified barriers to using medications from this study ranged from the physical attributes of the pills/tablets (such as pill size, flavour, or smell) to unpleasant side effects associated with certain medications such as antihypertensives and immunosuppressants including headaches and fatigue. This finding is consistent with some of the commonly identified side effects to using medications reported among kidney transplant recipients on immunosuppressants (Gregmigni et al., 2007; Russell et al., 2003; Ruppert &

Russell, 2009), patients on dialysis (Stamatakis et al., 1997), as well as patients using antihypertensive medications (Benson & Britten, 2006; Svensson et al., 2000).

Apart from side effects, barriers could be related to the complexity of the regimen itself. Remembering to take all the pills was identified to be the top barrier which might prevent effective medication management in this study. This finding supports the results from two studies where kidney transplant recipients found that taking 1 to 16 types of medications (Ruppar and Russell, 2009), or 5 to 8 types of medications on top of immunosuppressants (Vasquez et al., 2003) was a major barrier and contributed to medication non-adherence due to interference with routines.

#### **Differences in health beliefs between genders.**

Findings from this secondary analysis add to the scant literature on gender differences in perceived susceptibility to and perceived severity of CKD. Men were found to hold stronger perceived susceptibility to mild to moderate CKD than women. Although there was no statistically significant difference in perceived severity between genders, a slightly larger number of men than women believed CKD to be serious. The finding that men perceived greater levels of susceptibility to their illness than women may be explained by the differences with which men and women establish coping strategies in the face of chronic illnesses. A study examining gender differences in the meanings ascribed to heart failure and health perceptions related to heart failure found that men were more bothered by the physical and role limitations linked to heart failure, resulting in the use of evasive coping strategies such as avoiding treatment plans (Evangelista et al., 2001). Women, on the other hand, were more likely to express acceptance of their conditions and learn to construct positive meanings ascribed to their illness due to the

greater likelihood for female participants to engage in and be emotionally supported by spiritual practices (Evangelista et al.). Another study which supported the particular approach to coping that women may take in face of chronic heart conditions is by Rhodes and Bowles (2002). In this study, women reported they believed their diagnosis gave them opportunities to change their lives and deepen their relationships with significant others. Deriving meaning from an illness has also enabled women with breast cancer to cope with their illnesses, which allowed them to be more hopeful in face of an acute crisis and gave them strength to participate in treatment decision making (Degner et al., 1997).

In this current study, it is possible that women may have constructed positive meanings related to mild to moderate CKD which enabled them to be more hopeful about their future kidney function. Men on the other hand, may not cope with their illnesses in the same manner as women do. In fact, there is empirical evidence to suggest that men in kidney failure, were found to be less optimistic about their future kidney function than women, and these health perceptions may have resulted in different ways of coping with the treatment related to kidney failure (Lindqvist, Carlsson, & Sjoden, 2000). These findings suggest that differences in coping strategies may reflect the differences in health beliefs held between men and women, which lead to different ways of managing the illness.

Men and women may experience barriers towards medication taking differently. Although results were not found to be statistically significant, a greater number of women in this study reported more barriers towards using medications than men. For example more women (n = 10, 34.5%) versus men (n = 6, 20%) found that it was difficult to remember to take all the pills. The literature also indicates that the experiences of side effects may differ between genders. For

example, side effects have been reported as a concern for women with kidney failure because of the adverse physical changes with the use of certain medications such as immunosuppressants (GREGMIGNI et al., 2007; DeGeest et al., 1995; Karamanidou et al., 2008; Stamatakis et al., 1997). Contrary to what has been reported in the literature, results from this study revealed that an equal number of men versus women experienced side effects to using medications. A possible explanation is that when participants were asked what might kept them from taking their medications, only a total of 10 participants (5 men and 5 women) responded they did not like the way they felt or the side effects associated with the medications. Given the limited number of participants who responded to this question, results may not be representative of the findings reported from other studies with larger samples. Moreover, because a large proportion of the sample understood the reasons behind taking each medication, they may have also understood the side effects associated with the medications, and therefore less likely to believe side effects should prevent them from taking the medications.

#### **Differences in health beliefs between younger and older individuals.**

A very limited number of studies have compared health beliefs between older and younger individuals with CKD. Findings from this study revealed that no differences in health beliefs were detected between younger and older participants. This finding is different than what has been reported in the literature where younger individuals with kidney failure were more likely to become non-adherent due to barriers related to the medication regimen (Russell et al., 2006), and older individuals were more likely to become non-adherent due to being forgetful (Chisolm et al., 2008; Orr et al., 2007). The inability to detect any statistically significant difference in health beliefs between older and younger participants this secondary analysis may

partly be due to the lack of variability in the age range in this study. Because the distribution of the age variable in this study was positively skewed with a median age of 44 years old, age was categorized and non-parametric statistical analysis was used. The use of a non-parametric approach may limit the power to detect significant findings especially if the sample size is small (Siegel & Castellan, 1988). Although this secondary analysis was determined to be sufficiently powered, inviting more participants into this study may change the distribution of the age variable. If a normal distribution could be assumed for age, then age could be treated as a ratio level of data, and parametric tests, which are generally considered to be more powerful (Siegel and Castellan, 1988; Whitley and Ball, 2002), could be used to determine the strength of the relationship between age and health beliefs.

In addition, the cut-off age used to differentiate between younger and older participants in this study is lower than other studies investigating differences in medication adherence between younger and older participants in kidney transplant studies, which typically used a cut off age of 60 or 65 years of age for the elderly (Chisolm et al. 2008; Orr et al., 2007). The cut off value of 44 was used in this secondary analysis is generally regarded as middle-age. Because the two age groups in this study may not have a sufficient difference in their ages, this may limit the ability to detect any differences in health beliefs between younger and older participants.

### **Health Beliefs and Medication Taking Behaviour**

From the results of this secondary analysis, perceived barriers was the strongest predictor of medication taking behaviour in this sample. This finding is supported by some other studies investigating the relationships between health beliefs and adherent health behaviours among chronic illnesses in general including CKD (Horne & Weinman, 1999), and particularly in

hemodialysis patients (Lee & Molassiotis, 2002). Specifically, remembering to take all the pills as the primary barrier reported in this study is also supported by findings reported from kidney transplants recipients (Orr et al., 2007), and other chronic illness populations such as patients with heart failure (Bennett et al., 2005), suggesting individuals with mild to moderate CKD face similar barriers in managing the medication regimen as those who are in advanced stages of CKD or other illness populations prescribed with similar medications. The finding that perceived barriers was the strongest predictor of medication taking behaviour in mild to moderate CKD is also consistent with what has been proposed in the literature (Janz & Becker, 1984).

This secondary analysis did not support the relationship between other dimensions of health beliefs and medication taking behaviour. One reason why other health beliefs were not found to be statistically significantly associated with medication taking behaviour may be related to the way in which medication taking behaviour was measured in this study. Although self-reported missed doses is commonly used as an indicator of medication non-adherence in the literature, missed dose is measuring only one aspect medication taking behaviour. It is possible that health beliefs may be related to other aspects of medication taking that were not measured in this study, such as counting pills, opening and closing pill bottles, timing dosing frequency, or refilling of medication prescriptions. Examining the relationships between health beliefs and other behaviours associated with medication taking may uncover relationships that were not examined in this study.

A second explanation as to why the relationship between health beliefs and medication taking behaviour was not statistically significant in this study may be attributed to the relative homogeneity of the missed-dose variable. The missed dose variable was positively skewed with

a large proportion of participants reporting they had never missed a dose in this study. This lack of variation could limit the ability to detect differences between those who missed and those who did not miss doses. Furthermore, because the missed dose variable could not be treated as a ratio level of data, parametric correlational statistics could not be used which could limit the ability to detect relationships between health beliefs and medication taking behaviour.

### **Limitations**

The results from this study should be viewed with consideration of several limitations. Due to the exclusion criteria of this secondary analysis, generalizability of the results may not be extended to other individuals who are diagnosed with CKD secondary to other chronic illnesses. In addition, because the majority of this sample primarily spoke English, findings may not be extended to individuals of different ethnic backgrounds or those who are not literate in English. The use of self-report of missed doses may limit the understanding of other behavioural aspects of medication taking. And because the missed dose variable lacked variation in the data, it may have prevented the detection of relationships between health beliefs and medication taking behaviour. The recruitment strategies and setting may also limit the generalizability of study findings due to the fact that participants were recruited from nephrology clinics in acute care settings where they were receiving the state of art management related to their CKD diagnoses. Thus, findings may not apply to other individuals being treated for CKD in other institutions or in the community.

## **Summary of Discussion**

In terms of the representativeness of the sample, sociodemographic characteristics, illness presentation of the sample, as well as the medications being prescribed in this study are fairly consistent with that being described among participants with kidney failure. Management of a complex medication regimen can be particularly challenging for someone living with mild to moderate CKD. However, results from this study revealed that a large number of participants were successful in establishing medication taking behaviour. This higher-than-expected rate of success might possibly be attributed to less frequent dosing regimen, the length of time participants had been living with CKD, as well as the self-reported measurement of medication taking behaviour.

An exploration of health beliefs in this sample demonstrated that women were more likely to believe their kidney function would improve in the future, which may be supported by the observation that women are more likely to discover meanings related to their illness and to engage in spiritual practices (Evangelista et al., 2001; Degner et al., 1997; Rhodes & Bowles, 2002). There were no statistically significant differences in health beliefs between the two age groups in this study and this finding may be attributed to the distribution of age, treatment of the data, as well as the cut off value used to differentiate the two age groups. Only perceived barriers were related with medication taking behaviour, which has been supported by the literature where perceived barriers are the strongest indicator of health behaviours (Janz & Becker, 1984). The homogeneity of the missed dose variable may explain why a relationship was not detected between other health beliefs and medication taking behaviour.

## **Chapter 7 Implications and Conclusions**

This study is the first study to shed light on the complexity of the medication regimen for someone who is living with mild to moderate CKD and highlighted some of the major barriers encountered in managing the regimen. This study is also one of the few studies to explore health beliefs in CKD and further investigated the relationship between sociodemographic variables and health beliefs which may inform and shape medication taking behaviour.

### **Implications for Practice**

Findings from this secondary analysis reveal that perceived barriers were the most important predictor of medication taking behaviour. Therefore, early identification of health beliefs may promote medication taking behaviour by screening for any barriers that patients encounter in taking their medication, or barriers in incorporating the regimen into their daily lives. For example, results from this study identified that most participants were able to manage their medication regimens successfully, but remembering to take all the medications was perceived to be the most difficult. In light of this understanding, assisting patients to establish and implement a regular pattern of medication taking should be beneficial. For example, during follow up sessions, health care providers may assist patients to establish cues for the medication regimen into their daily routines. Cues such as placing pill bottles strategically in areas that are most visible to the individuals, or incorporating the taking of pills with certain daily activities such as before meals were found to be effective strategies among hypertensive patients (Johnson et al.), and these strategies could be introduced and reinforced to patients with mild to moderate CKD in order to minimize the potential barriers in managing their medication regimen.

Moreover, findings from this study also indicated that participants believed taking so many pills at the same time was challenging. Therefore, it is also important for health care providers to assess whether patients experience difficulties in managing and taking all the pills. For example, health care providers may assess patients' schedules and determine whether patients are experiencing challenges in taking medications at certain times of the day or fitting medications into their daily routine. Introducing the use of a pill organizer may be beneficial as it allows patients to allocate pills into separate compartments according to their daily medication regimen, which may minimize the chances of not being able to successfully take multiple pills in a day, or forgetting to take the pills at the right time.

Furthermore, because some of the reported medications in this secondary analysis were associated with bothersome characteristics, it is also important for health care providers to inquire about these adverse effects and assess their implications for medication taking behaviour. For example, some of the bothersome characteristics, which were commonly associated with immunosuppressants, antihypertensives, and diuretics in this study, were that they were difficult to swallow and were reported to cause fatigue and light-headedness. Potential adverse effects with these types of medications may be minimized if health care providers are aware of the problems and interventions are established early to help minimize the side effects experienced.

Differences in health beliefs identified between men and women in this study also suggest that health care providers should be aware that men and women may hold different health beliefs, which may shape their medication taking behaviour differently. In particular, this study identified that a greater number of men than women believed their kidney function would decline in the future. One possible explanation could be related to the ways in which individuals

cope with mild to moderate CKD, suggesting health care providers may need to be aware of the potential differences in coping strategies employed by men and women during follow-up sessions. Because there is an indication in the literature that women express more acceptance of their conditions and are more likely to find meanings in light of their illnesses (Evangelista et al., 2001), different approaches may be required to support men and women to establish coping strategies that are effective. For example, it would be helpful for health care providers to assess and understand the mechanisms patients employ in coping with the diagnosis or the medication regimens during follow up sessions. Moreover, because the finding from this study suggests that it is possible that men may not be as optimistic about their future kidney function as women, it would be helpful for health care providers to better assess male patients' experiences towards adjusting to the demands of CKD and identify those who may be at greater risk for developing ineffective coping strategies.

### **Implications for Research**

This study used self-report questionnaires to obtain data about medication taking behaviour and health beliefs. Future research may choose to combine two methodologies (e.g. self report and objective measure) to gather additional data about medication taking behaviour that have not been examined in this study. Other studies examining medication non-adherence in kidney transplant employed an objective measurement of medication taking, such as the Medication Electronic Monitoring System (MEMS), to provide information about taking and timing of medications, or the opening and closing of pill bottles (Denhaerynck et al., 2005; Shellmer & Zelikovsky, 2007). Although MEMS can offer an objective measurement of non-adherence, using it as a sole indicator of medication non-adherence warrants caution because an

unbiased interpretation of information obtained from the MEMS requires the equipment to function correctly, that patients do not simply open the pill bottle yet skip a dose, or that the MEMS equipment does not disrupt the patient's normal routine in medication taking (McKay & Steinberg, 2010). A comprehensive measure of medication taking behaviour composed of several types of measures (e.g. self report and MEMS) may have the advantage of enriching the interpretation of medication taking behaviour from multiple perspectives (Liu et al., 2001), and may also minimize some of the disadvantages associated with self report or MEMS respectively.

In terms of understanding missed doses, one of the drawbacks of this study is that it was difficult to differentiate whether participants were intentionally or unintentionally missing doses. Because there have been accounts in the literature where participants would intentionally skip doses to test the effectiveness of medications (Johnson et al., 1999), future studies may focus on further differentiating whether participants were missing doses because they wanted to test the effectiveness of medications in reducing the symptoms associated with CKD, or they were unintentionally missing doses for other reasons such as changes in routine.

Future research may also focus on different approaches to measuring health beliefs. Although the MHBQ was a theoretically derived scale, there may be other measurement tools for health beliefs that may offer another perspective. For example, the Champion's Health Belief Model Scale (HBMS) was also developed to test the HBM, with subscales measuring dimensions of health beliefs, including susceptibility, severity, benefits, barriers, and health motivation (Champion, 1984; Tavafian et al., 2009). Although the HBMS has never been tested among CKD populations, it has been used to understand health promoting behaviours such as breast self-examination (Tavafian et al., 2009), compliance behaviours for cardiac patients (Kison,

1992), and medication adherence in diabetes (Hill-Briggs et al., 2005), suggesting the HBMS could be applied to examine medication taking behaviour in CKD.

To broaden the generalizability of the findings, future studies could include individuals diagnosed with mild to moderate CKD secondary to other chronic conditions such as diabetes, lupus, or infections, which were excluded from this research. An examination of the impact of other chronic conditions with CKD in relation to medication taking behaviour may further highlight the complexity of the medication regimen, and may reveal other challenges and barriers experienced by patients living with CKD and other illnesses. With respect to examining differences in health beliefs between younger and older participants, future research may choose deliberate sampling strategies to specifically recruit participants from different age groups, thus facilitating the identification of differences in health beliefs between ages.

### **Implications for Theory**

The current study addresses the complexity of medication taking behaviour and explores domains of health beliefs related to medication taking using the HBM. However, results from this study only supported one dimension of the HBM, specifically perceived barriers. Because medication taking behaviour is a multifaceted concept influenced by multiple factors, future research should examine other constructs within the HBM which may shape medication taking behaviour. Although health beliefs did not appear to differ between gender and age in this study, health beliefs could potentially be shaped by other modifying factors which have not been examined in this study. For example, other modifying factors identified in the HBM may include sociopsychological variables (e.g. peer support or socio-economic status) and structural variables (e.g. knowledge about illness), which may potentially influence perceived susceptibility and

perceived severity, and could be examined in future studies. Another possible explanation for why this study did not uncover any relationships between perceived susceptibility and perceived severity with medication taking behaviour could be attributed to the fact that this study did not take into consideration the influence of cues to action on health beliefs. Cues to action which are a component of the HBM may include physical reminders, advice from friend, and mass media campaigns, which are proposed to influence health beliefs by prompting the individual to be aware of their susceptibility to an illness, or the severity of the illness (Janz & Becker, 1984; Rosenstock, 1984). Although this study did not collect information related to cues to action, future studies may also examine the influence of this domain on health beliefs to determine if these variables play a role in health beliefs and shape medication taking behaviour. For example, studies may examine the effect of cues to action such as physical reminders on perceived barriers to taking medications.

## **CONCLUSION**

Establishment of medication taking behaviour in mild to moderate CKD is an important component of illness management as successful medication taking has been recognized to be important in slowing the progression of the disease (Szromba, Thies, & Ossman, 2002). This study is the first quantitative study to provide an overview of patients' medication taking behaviour, and it is also the first study to examine health beliefs using the HBM in this population. This study supported the proposition that perceived barriers are the strongest predictors of medication taking behaviour. Descriptions about health beliefs revealed from this study are important to health care providers who work in collaboration with patients to design a routine which allows them to incorporate a complicated medical regimen into their daily life. In

conclusion, this study is a preliminary analysis on medication taking behaviour in an area that has not been well researched. Findings from this study shed light on some of the barriers which might impede this population from engaging in medication taking behaviour successfully.

## Appendix A

### *Reported Medications*

Family of medications	Generic Names of Medications
Immunosuppressants	Prednisone
	Cyclosporine
	Mycophenolate Mofetil (Cellcept)
	Azathioprine (Imuran)
Diuretics	Hydrochlorothiazide
	Novohydrzide
	Aldactazide
	Furosemide (Lasix)
	Gen-indapamide
	Novosprioton
	Micardis Plus
Angiotensin II Receptor Blockers	Lsartan (Cozaar)
	Candesartan cilexetil (Antacand)
	Irbesartan (Avapro)
Ace Inhibitors	Ramipril (Altace)
	Enalapril (Vasotec)
	Trandolapril (Mavik)
	Lisinopril

	Fosinopril
	Quinapril (Accupril)
Beta Blockers	Atenolol
	Metoprolol
	Propranolol (Inderal)
Calcium channel blockers	Amlodipine (Norvasc)
	Nifedipine (Adalat)
Statins	Lipitor
	Simvastatin
	Novo pravastatin
	Lovastatin
	Fenofibrate (lipidil)
Anti-coagulative agents	ASA
	Warfarin
Antibiotics	Apo-Sulfatrim
	Sulfamethoxazole
	Trimethorprim
Ant-hyperurecemia	Allopurinol
Proton Pump Inhibitors	Omeprazole
	Zantac
For Bone Disorders	Alendronate (Fosamax)

Vitamins

Multi-Vitamins such as Centrum

Fish Oil

Omega 3

Xelerate

“Stress Tab”

Glucosamine

Vitalux

Iron

Calcium Supplement

Vitamin C

Vitamin A

Vitamine E

Magnesium

Zinc

Over the Counter Medications

Tylenol

Advil

Benadryl

Others

Antioxidants

“Natural Pill”

“Chlorophyll body odour”

Plant enzyme

Probiotics

Seeds (flaxseeds, sunflower seeds)

Allessee

“red pill”

“small pink round”

“pink pill for heart”

“big white pill with heart on it”

“light blue pill”

“dark blue pill”

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## Appendix B

### *Medications and their bothersome characteristics*

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Families of medications	Reported bothersome characteristics
Anti-Hypertensives	Mentally and physically difficult
	Hard to swallow
	Slows heart rate
	“Mental cloudiness”
	Dizziness
	“Sleep mess”
	Nausea
	Need to split pills
	Bitter taste
	“skunk smell”
	“The fact I need to”
	“makes me weak”
	Sleepiness

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Statins	Light headedness
	Broken sleep
	Tiredness
	Drowsiness
	Upset stomach
	“The fact I need to”
Diuretics	Mentally and physically difficult
	Hard to swallow
	An urge to urinate, “makes me want to pee”
	Fatigue
	“The fact I need to”
Immunosuppressants	Mentally and physically difficult
	Hard to swallow
	Headache
	Tremors/ “Gives me the shakes”
	Time consuming

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	Less energy
	“Hard on liver”
Anti-coagulative agents	Upset stomach
	Gives me bruises
	“The fact I need to”
Antibiotics	None
Antihyper-urecemic agents	Nausea/vomiting
Proton pump inhibitors	None
Bone protective medications	None
Over the counter medications	Pills too big

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