

**THE EXPERIENCE OF THE OLDER ADULT WITH END-STAGE RENAL  
DISEASE ON HEMODIALYSIS**

by

Rebecca M. Corrigan

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## Abstract

*Background* The growth in the number of individuals with end-stage renal disease has implications in terms of both the health of individuals, especially older adults (aged 65 years and older), and the capacity of the health care system to provide adequate treatment needed by these patients. Much has been written regarding the pathophysiology of end-stage renal disease as well as how modern advances in technology have contributed to the ‘dialysis world’. However, the literature is sparse in relation to how older adults experience end-stage renal disease and the technological complexity of dialysis in their daily lives.

*Objective* The purpose of this study was to explore the meaning of being hemodialysis-dependent for the older adult living with end-stage renal disease.

*Method* A descriptive method using a qualitative interviewing approach was used. Systematic focused thematic analysis guided by the Crisis of Physical Illness conceptual model allowed for the findings to surface. Data sources included individual interviews, direct observation of participants and the hemodialysis unit, along with field notes. A purposive sample of nine participants was obtained from two different hemodialysis units, both operated by Kingston General Hospital. Data were analyzed using the Colaizzi method.

*Findings* Five themes were identified by the participants: The Will to Live, Recognition of a Lifetime Commitment, Learning to Live with Technology, The Yin and Yang of Hemodialysis, and Transcending Hemodialysis.

*Conclusions* End-stage renal disease and thrice weekly hemodialysis treatment have an impact on the daily life of older adults and their ability to cope with the changes. This study revealed that despite the restrictions of being on hemodialysis, all of the participants had the will to live and some expressed the need for further education using a variety of strategies that would meet the specific needs of this population. A more in-depth understanding of how older adults experience hemodialysis is needed to provide adequate care/resources for this special population.

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## **Chapter 1**

### **Introduction**

Chronic kidney disease (CKD) is growing among all population groups worldwide and the incidence of end-stage renal disease (ESRD) continues to increase. This is reflected in the increasing number of people with ESRD treated by renal replacement therapy (RRT) – be it dialysis or transplantation (Lysaght, 2002).

The incidence and prevalence of ESRD in the world has risen progressively. The Canadian Organ Replacement Register Annual Report, *Treatment of End-Stage Organ Failure in Canada, 2000 to 2009* (2011), revealed that close to 38,000 Canadians were living with kidney failure in 2009 – more than triple the number (11,000) living with the disease in 1990. Of all Canadians living with this disease in 2009, 59% (22,300) were on dialysis and 3,000 people were on the wait list for a transplant, compared with 53% (5,900) on dialysis in 1990 and approximately 1,600 people on the wait list. In 2009 there were 5,400 newly diagnosed patients with kidney failure – more than double the number of people newly diagnosed in 1990 (2,300). Of the 5,400, 78% were receiving hemodialysis (HD) treatment.

The National Kidney Foundation (2002) defines CKD as the presence of kidney damage, or a decreased level of kidney function for a period of three months or more. It can be further divided into 5 stages depending on the severity of kidney damage and the level of decrease in kidney function. Stage 5 of CKD is referred to as end-stage renal disease/failure (ESRD/ESRF). This stage represents the end of kidney function. The kidneys are working at less than 15% of normal. RRT is necessary at this time in order to

sustain life.

There are currently three treatment modalities available for ESRD: RRT – be it HD or peritoneal dialysis (PD) and renal transplantation. Due to the limited number of donor kidneys available for transplantation, dialysis (HD and PD) tends to be the most common method of treatment (USRDS, 2002). For various reasons, which will be expanded upon in the review of the literature, most older adults receive HD treatment.

The aging of the Canadian population is reflected in the demographic profile of new ESRD patients, with 54% of those who initiated RRT being age 65 and older in 2009, compared to 33% in 1990 (CORR, 2011). The largest incidence occurred in older age groups, with prevalence rates escalating by more than 500% for those aged 75 and older. Patients in this age group account for 20% of all those with kidney failure. The average age of new adult patients starting HD – the most common form of dialysis – was 65 in 2009, up from 55 in 1990. The older adult population continues to grow; they experience health differently than their younger counterparts, and therefore require careful attention to their unique concerns.

Such changing demographics in the general population, but most importantly in the older dialytic population, bring forth issues. Older adults are a very complex population who present with a myriad of coexisting diseases. The diagnosis of ESRD is a challenge due to its life-threatening nature and highly technical treatment. The elderly require increased attention while receiving dialysis treatment. Those older adults dependent on HD may be plagued by multiple stressors such as psychosocial adjustment, limited mobility, limited accessibility, visual disturbances, hearing impairments, co-

morbidities, and lack of social support to name some (Calvin, 2004).

The increase in the older adult population in addition to the improvements and progress in nephrology, and most particularly in dialysis treatment, will continue to lead to an increase in the number of older adults receiving hemodialysis.

Given the prevalence of RRT (HD) in the older adult population, it would be important to understand how these individuals experience the illness and its treatment. There are few studies that examine in depth how older adults experience ESRD and its treatment from a qualitative point of view (Hagren, Peterson, Severinsson, Lutzen & Clyne, 2001; Polaschek, 2003). Qualitative approaches not only uncover the realities expressed by patients, but also reiterate the life-altering impact that this disease and treatment regime have on patients' lives. We must not forget who the experts are; those living with this disease and its treatment.

### **Study Objective**

1. To explore the meaning of being hemodialysis-dependent for the older adult.

## Chapter 2

### Literature Review

A review of the current literature was completed in order to determine the state of knowledge related to ESRD in older adults and the meaning this may have for being dependent on HD treatment. Several databases were searched including OVID, MEDLINE and Cumulative Index to Nursing & Allied Health Literature (CINAHL). Books were accessed through the use of Queen's University Library Catalogue (QCAT) search engines. Key words used were: chronic illness, chronic kidney disease, end-stage renal disease, renal replacement therapy, peritoneal dialysis, hemodialysis, older adult, aging, depression, and social support. Combinations of these key words enabled the researcher to narrow the focus of the search. There was little qualitative research found on how older adults experience ESRD (Hagren et al., 2001; Polaschek, 2003). A review of the literature is presented below.

#### *Conceptual Model*

When conceptualizing this study, the meaning of physical illness of older adults, specifically those with ESRD, is explored in the context of Moos and Schaefer's (1984) conceptual model: The Crisis of Physical Illness (Figure 1). With this model, a serious physical illness is understood as a life crisis. Moos and Schaefer believe that, similar to the need for physical homeostasis, there is the need for social and psychological equilibrium. When an individual encounters an event that interrupts their life-style, they utilize habitual problem-solving mechanisms until balance is restored. If these habitual responses are inadequate to cope with a crisis, the individual is faced with a state of

turbulence. It is unhealthy for an individual to remain in a state of extreme disequilibrium, therefore they must establish some resolution. The new balance may represent healthy adaptation, or it can be a maladaptive response. Such a crisis experience can be seen as a transition – a turning point - that can have lasting implications for an individual's adaptation and ability to meet future crises. The Crisis of Physical Illness is described as almost always a serious “upset in a steady state” that may extend over a long period of time and lead to permanent changes for patients and their family (Moos & Schaefer, 1984, p.8). The individual's cognitive appraisal, definition of the adaptive tasks involved, and selection and effectiveness of coping skills are influenced by three determinants: demographic and personal characteristics, factors related to the illness, and physical and social environmental factors (Moos & Schaefer, 1984). Together, these factors will affect the resolution of the initial phase of crisis, and in turn change the ultimate outcome.

The demographic and personal factors include age, gender, socioeconomic status, cognitive and emotional maturity, ego strength, self-confidence, philosophical or religious beliefs, and prior illness and coping experiences. All factors influence the individual's appraisal of an illness and in turn affect the personal and social resources available to meet the crisis. Illness-related factors include the type and location of symptoms. Such factors further identify how the illness impacts their life on a routine basis, along with how they may adapt. Aspects of the physical and social environment affect the adaptive tasks that patients and their families face and the choice and outcome of the coping skills they utilize.

This model is believed to be a good fit for this study as physical, psychological, and social equilibrium may be disrupted by the diagnosis of ESRD and receiving HD treatment. ESRD is a serious physical illness (life crisis) that is often unanticipated, clear information is often lacking, definitive decisions may have to be made quickly, and the ultimate meaning for the individual is ambiguous (Moos & Schaefer, 1984). Not only do those individuals diagnosed with ESRD have to confront the physical illness of ESRD itself, but also the crisis of treatment (HD). There are many demographic and personal factors that influence an older adult with ESRD. This population is already attempting to cope with/adapt to typical age-related changes such as possible cognitive impairment, visual disturbance, change in mobility, and loss. Given that the illness occurs later in the life-cycle, this population may or may not experience the illness differently than their younger counterparts. There are many illness-related factors with ESRD: constant threat of death, potential for reduced life-expectancy, reliance on technology to survive, impingement on time for treatment thrice weekly, dependency on personnel, stringent dietary and fluid-restrictions, the need to follow a complex medical regimen, etc. Finally, there are many physical and social environmental factors at play. For those individuals receiving HD treatment, they spend a considerable amount of their time in a renal unit. Despite the fact that hospitals are designed to deliver care and promote healing, they can be intimidating and dehumanizing places (Moos & Schaefer, 1984) and individuals may or may not benefit from the social support provided in this environment.

All factors will influence how an older adult with ESRD receiving HD treatment experiences their illness.

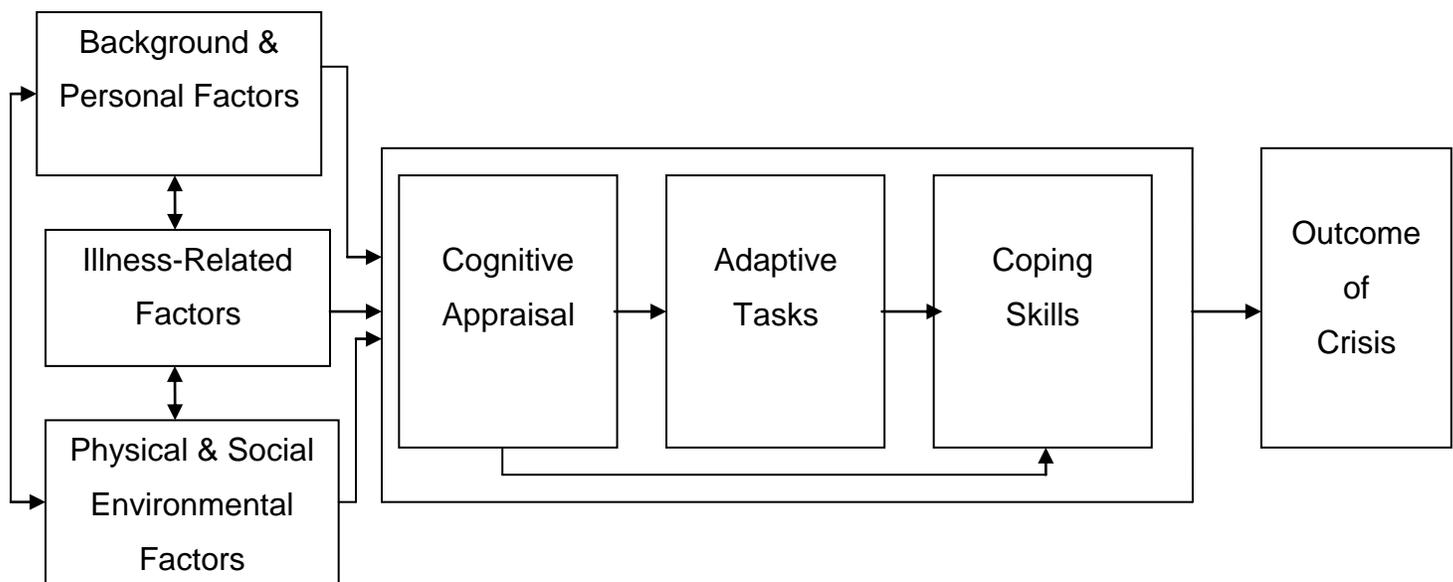


Figure 1. A conceptual model for understanding the crisis of physical illness developed by Moos and Schaefer, 1984.

The following sections of the literature review will address the background and personal factors, in particular of older adults living with chronic illness and chronic illness as it relates to ESRD; illness-related factors, including the treatment regimen for ESRD; the physical and social environmental factors relevant to ESRD, mainly mood and social support; and what is already known about the experience of living with ESRD.

## *Background and Personal Factors*

### *Chronic Illness*

The global burden of noncommunicable diseases continues to grow; tackling it constitutes one of the major challenges for development in the twenty-first century (WHO 2008). Chronic illness is defined as diseases of long duration (greater than three months) and generally slow progression. Heart disease, stroke, cancer, chronic respiratory disease and diabetes are by far the leading cause of morbidity and mortality in the world (WHO, 2008). They caused an estimated 35 million deaths in 2005. This represents 60% of all deaths globally.

Living with a chronic illness has become a reality of the 21<sup>st</sup> century. Living longer with a chronic illness is partly attributable to dramatic strides in medical and surgical interventions (Predeger & Mumma, 2004). Individuals with a chronic illness share common characteristics: illness is not curable, all depend on lifelong treatment and follow-up, and all need to develop their self-management skills so as to improve their health outcomes and avoid acute exacerbations of their illnesses (WHO, 2002). Acute exacerbations are often a key turning point in the illness. The experience of sudden physical illness, extensive or different treatment, along with uncertainty, and intense personal strains can have a profound and lasting impact (Moos & Schaefer, 1984).

Individuals' responses to their chronic illness vary. Some are positive, some negative, while some have elements of both (Martz & Hanoch, 2007). Without action to address the causes and responses to the illnesses, it is predicted that deaths from chronic illness will increase by 17% between the years 2005 and 2015 (WHO, 2008). One

chronic illness which is on the rise today is CKD.

### *Chronic Kidney Disease*

Kidney disease includes a variety of diseases and disorders that affect the kidneys. Most diseases of the kidney attack the filtering unit of the kidneys – the nephrons – and damage their ability to eliminate wastes and excess fluids. The National Kidney Foundation (2002) defines CKD as:

- kidney damage for 3 or more months, as defined by structural or functional abnormalities of the kidney, with or without decreased glomerular filtration rate (GFR), manifested by pathologic abnormalities or markers of kidney disease, including abnormalities in the composition of the blood or urine or abnormalities in image tests
- $\text{GFR} < 60 \text{ mL per minute per } 1.73 \text{ m}^2$  for 3 months or more, with or without kidney damage

CKD can be further divided into 5 stages depending on the severity of the damage. It often starts off slowly and silently and progresses over a number of years. Not everyone progresses from stage 1 to stage 5.

<b>The five stages of chronic kidney disease</b>					
	<b>STAGE 1</b>	<b>STAGE 2</b>	<b>STAGE 3</b>	<b>STAGE 4</b>	<b>STAGE 5</b>
<b>Amount of kidney function remaining at each stage</b>	More than 90%	60 to 89%	30 to 59%	15 to 29%	Less than 15%
<b>Description of each stage</b>	Early kidney damage with normal or even increased function.	Worse kidney damage with reduced function.	Even worse kidney damage with less function.	Kidney damage is so severe with such poor function that the kidneys are barely able to keep the person alive.	End-stage Renal Disease: kidney function is severely impaired. The kidneys are not working well enough to keep the person alive.
<b>Symptoms</b>	No symptoms observed. Urea and creatinine levels are normal.	No symptoms observed. Urea and creatinine levels are normal, or mildly elevated.	Early symptoms occur and may include tiredness, poor appetite, and itching. Creatinine level rises, excess urea is present, and anemia may begin to occur.	Tiredness, poor appetite, and itching may get worse.	Symptoms may include poor sleeping at night, difficulty breathing, itchiness, and frequent vomiting. High levels of creatinine and urea are present.
<b>eGFR (estimated Glomerular Filtration Rate)</b>	90 ml/min or more	60 – 89 ml/min	30 – 59 ml/min	15 – 29 ml/min	15 ml/min or less
<b>Treatment options*</b>	Identify cause and try to reverse it.	Monitor creatinine level, blood pressure, and general health and well-being. Try to stop or slow the worsening kidney function.	Continue to try to stop or slow the worsening kidney function. Patient learns more about the disease and treatment options.	Plan and create access site for dialysis. Receive assessment for possible transplant.	Start renal replacement therapy: dialysis or transplantation.

Table 1 The Five Stages of Chronic Kidney Disease (Kidney Foundation of Canada, 2009).

CKD can arise from both inheritable and acquired conditions. The two most common co-morbid diseases are diabetes and hypertension. Approximately 2/3 of all CKD cases have an associated diagnosis of diabetes and hypertension, with diabetes being the most predominant underlying cause (CORR, 2011). For the purpose of this study, I have chosen to study stage 5, ESRD.

#### *End-Stage Renal Disease*

ESRD is the 5<sup>th</sup> stage of CKD. It is a state when the kidneys do not function properly or sufficiently. When the kidneys fail, wastes and fluids accumulate in the body causing potentially permanent and irreversible damage to body cells, tissues and organs. The Canadian Organ Replacement Register Annual Report, *Treatment of End-Stage Organ Failure in Canada, 2000 to 2009* (2011), revealed that close to 38,000 Canadians were living with kidney failure in 2009 – more than triple the number (11,000) living with the disease in 1990. In 2009 there were 5,400 newly diagnosed patients with kidney failure – more than double the number of people newly diagnosed in 1990 (2,300). Once kidneys function below 20% of their requested capacity, RRT is required in order to sustain life. The incidence and prevalence of ESRD continues to grow worldwide.

#### *The Older Adult with End-Stage Renal Disease*

As a result of the normal aging process, older adults present with a variety of physiological, psychological, and sociological changes. Some of these changes include change in vision, mobility, and social network to name a few. Thus, older adults with a chronic disease such as ESRD present with myriad challenges and complexities. The aging of the Canadian population is reflected in the demographic profile of new ESRD

patients, with 54% of those who initiated RRT in 2009 being age 65 and older compared to 33% in 1990 (CORR, 2011). One of the most dramatic changes over the past 10 years has been the increase in the incidence and prevalence of the older population receiving dialysis treatment. Such an increase is multi-factorial and may be partly related to an increased prevalence in CKD, aging population with longer life expectancy, more liberal acceptance into dialysis programs, and earlier initiation of dialysis treatment. The greatest increase in both incidence and prevalence has been among those 65 years and older. It is possible that an older adult will experience ESRD differently than their younger counterparts due to the timing of the illness in the life cycle. Co-morbidity associated with aging also has important implications for this population, with the number of co-morbid conditions shown to have a major influence on survival rates for older adults with ESRD.

Such changing demographics in the general population, but most importantly in the older dialytic population highlights the need to focus on this particular population to provide them with appropriate support and resources.

#### Illness-Related Factors

#### *Treatment Modality*

For an individual with ESRD to sustain life, a form of RRT is necessary. There are two forms of dialysis: HD and PD. HD means “cleaning the blood”. Blood is withdrawn from the body by a machine and passed through an artificial kidney called a dialyzer (Kidney Foundation of Canada, 2009). This treatment is often required three times per week for four to five hour sessions. It is typically offered for the more ‘acute’

dialysis patients in a hospital or satellite unit where medical personnel are available. PD is very similar to HD, however with this treatment, blood is cleansed while still inside the body. The peritoneal cavity is filled with dialysis fluid through a surgically inserted catheter in the abdomen. This exposes the blood vessels in the peritoneum to the dialysis fluid. The peritoneum functions like an artificial membrane in a dialyzer where excess water and wastes pass from the blood through the peritoneum into the dialysis fluid (Kidney Foundation of Canada, 2009). The dialysis fluid is then drained from the body and discarded. The process is repeated 4-6 times in every 24 hour period. This treatment is usually reserved for those who can participate in their own treatment at home, independently or with the assistance of family (i.e. spouse) and for those, less acute, dialysis patients. For the purpose of this study, the focus will be on HD treatment due to the age of the population and the challenges of carrying out dialysis in the home environment.

HD has allowed for longer survival of patients with ESRD, thus increasing the incidence of patients on dialysis throughout the world (Miles & Friedman, 2001). At the end of 2009 there were 37,744 Canadians receiving RRT – more than triple the number in 1990 (CORR, 2011). Of these, 22,310 (59%) were on dialysis and 15,434 (41%) had a functioning kidney transplant. Among the 22,310 patients on dialysis, 18,267 (82%) were on HD (CORR, 2011). The main factor in the selection of dialysis modality has been patient choice (Krishnan, Lok & Jassal, 2002). However, co-morbid conditions also play a role. Despite the efficacy and safety of renal transplantation in adults, it appears to be the least used for those age 65 and older due to a shortage of cadaver/donor kidneys,

presence of co-morbidity in recipient, and a misconception that advancing age is a limiting factor for success in transplantation (Ismail, Hakim & Helderman, 1994). PD is preferred in those with peripheral vascular disease, cardiac disease associated with hypertension or arrhythmias, and to avoid disequilibrium syndrome (Dharmarajan, Venkatasamy & Russell, 2003). It also allows the individual to receive their treatment in their home environment. Unfortunately, physical and psychological factors influence the choice of therapy. Psychosocial factors which may negatively influence PD are poor caregiver support, presence of dementia or depression, and visual or physical handicaps – all of which are common in the older adult population (Dharmarajan, Kaul & Russell, 2004). As a result, in both Canada and the United States, HD has been the most popular modality of RRT in the older adult population. There are both strengths and limitations to HD treatment. Some strengths include: relieves the symptoms of uremia; works quickly and efficiently; most individuals have suitable blood vessels for establishing an access site; and it provides a social setting for those who may be lonely and suffering from depression (Kidney Foundation of Canada, 2009). Limitations include: having to follow a strict medication and nutrition regimen; obtaining and maintaining vascular access which can cause discomfort; and planning life around a HD schedule (Kidney Foundation of Canada, 2009).

HD has transformed the prognosis of patients with ESRD by improving their life expectancy. However, individuals must still contend with the sequelae of treatment. The aim of RRT is to maintain kidney function and to enable the older adult to live with dignity and independence and with an acceptable quality of life. As a consequence of this

treatment, compounded with the normal aging changes, individuals may have difficulty coping with the many restrictions.

### *Restrictions & Adverse Effects*

As patients with ESRD are dependent on life-long HD treatment, their quality of life may be impinged by the many restrictions imposed by their intense medical regime (Hagren et. al, 2001). In an effort to improve nutritional status, reduce uraemic toxicity and delay renal deterioration, individuals must comply with a strict treatment plan. Dialysis and the complexity of the treatment plan include rigid diet and fluid restrictions, the need for vascular access, lifestyle modifications, and the need to develop close relationships with the health care team (Devins et al., 2001; Hailey & Moss, 2000; Welch & Austin, 1999). The amount of time invested into the treatment plan is also a factor, as not only do these individuals commit to thrice weekly HD treatment for approximately four hours per session, but they also spend time traveling back and forth to the dialysis unit (Welch & Austin, 1999).

Unfortunately the effectiveness of treatment is often compromised by non-adherence to this strict regime. As a result, HD permeates all areas of life and affects physical and psychosocial health (Hagren, Peterson, Severinsson, Lutzen & Clyne, 2005). Patients' beliefs about illness are important as they influence adherence and adjustment (Krespi, Bone, Ahmad, Worthington & Salmon, 2003).

## *Physical and Social Environmental Factors*

### *The Impact of End-Stage Renal Disease on Emotional Status*

The existence of a chronic illness is a very stressful life event and creates significant psychological problems among these patients. For ESRD, HD is an unpleasant and restrictive treatment. Mood change and depression are generally accepted to be the most common psychological problem encountered in those with ESRD (Kimmel et al., 2000), however little work has been done to explore the variables associated with depression (Welch & Austin, 2001). Depression is characterized by both cognitive and somatic features. A number of the somatic characteristics of depression are similar to the symptoms of uremia such as anorexia or sleep disturbances, fatigue, and gastrointestinal disorders. Such similarities make the determination of the role of an association between depression and ESRD potentially problematic in the older adult.

The impact of psychosocial factors on the outcome of patients with ESRD has been receiving more attention lately (Kimmel et al., 2000; Nevi et al., 2011; Plantinga et al., 2010; Rambodi & Rafii, 2010; Spinale et al., 2008). One factor potentially affected by the changes associated with a chronic disease such as ESRD with mood changes and possible depression is that of social support.

### *Social Support*

The relationship between human beings and their social milieu is dynamic and exceedingly complex and can contribute to differing health outcomes (Burton, Kline, Lindsay & Heidenheim, 1988). Social support is a concept generally understood in an intuitive sense as the help from other people in a difficult life situation. One of the first

definitions was put forward by Cobb (1976). He defined social support as ‘the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations’.

In comparison to other chronic illnesses such as cardiovascular disease and cancer (Greenwood, Muir, Packham & Madeley, 1996; Oxman & Hull, 1997), there is a paucity of research addressing the association between social support and quality of life/functionality in older adult HD patients.

Patients with ESRD must confront challenges daily from chronic fatigue, dietary and fluid restrictions, changes in economic status, and the high cost of health care, as well as embarrassing disfigurement, dependence on others, and loss of family role, self-esteem, and family dynamics (Clarkson & Robinson, 2010). All of these can potentially impair social relationships and would benefit from support.

Several studies have shown an association between survival and perception of social support in ESRD patients (Christensen, Wiebe, Smith & Turner, 1994; Kimmel et al., 2000; McClellan, Anson, Birkeli & Tuttle, 1991; McClellan, Stanwyck & Anson, 1993; Thong, Kaplein, Krediet, Boescholen & Dekker, 2007).

Treatment adherence is a major issue in the effective management of patients receiving HD (Kutner, Zhang, McClellan & Cole, 2002). Studies have been conducted to evaluate the association of social support and treatment adherence. Several studies have shown that social support is associated with improved adherence to treatment (Kimmel et al., 1996; Kugler, Vlaminck, Haverich & Maes, 2005; Kutner, 2001). Studies have been conducted to identify a relationship between social support and adherence to dietary

restrictions (Oka & Chaboyer, 1999). All studies supported the proposition that dietary adherence improved with levels of social support. It has also been noted that elderly subjects require more social support for dietary management behavior than younger individuals (Oka, Munakata, Tomura & Tsuchiya, 1996).

Social support is positively associated with higher quality of life in HD patients (Kimmel et al., 1995; Parkerson & Gutman, 2000; Tovbin, Gidron, Granovsky & Schnieder, 2003). Patients perceptions of social support were suggested to moderate the adverse effects of ESRD on depression and survival (Kimmel et al., 2000). Religious beliefs and spirituality (other forms of support-personal) have also shown to be important to a patient's overall sense of well-being (Kimmel et al., 2000; Patel, Shah, Peterson & Kimmel, 2002).

Social support is an understudied, yet important, modifiable risk factor in a number of chronic illnesses, including ESRD (Cohen et al., 2007). The need exists to explore the nature of and type of support on older adults coping with ESRD who are receiving HD treatment. A better understanding of such social, non-medical factors will hopefully identify the future targets of the multidisciplinary management of ESRD.

### *Summary*

The majority of studies which evaluate quality of life for the older adult living with ESRD are quantitative in nature and translate patients' subjective experiences into objective quantifiable data (Lok, 1996; Welch & Austin, 1999). There have been studies conducted recently regarding the experience of patients living with maintenance dialysis (Hagren et al., 2001; Hagren et al., 2005; Polschek, 2003), however these studies did not

focus specifically on the older adult receiving HD treatment. Therefore there is the need to evaluate the experience of life on hemodialysis through a qualitative lens, and in particular to explore the perceived experience of being on maintenance hemodialysis for those older adults aged 65 and older.

Given that previous studies were based on a younger population and thus a population with potentially less co-morbidities, less life experience, and at different stages developmentally, the experience may be very different for the older adult population. Their background, illness, and psychosocial factors may/could contribute to a different experience and different outcomes from those of older adults.

The purpose of this qualitative study was to explore how older adults living with ESRD experience their illness and its associated treatment. It is hoped that this information will enable the healthcare team to better advise them and support their needs.

This review of the literature revealed that there is much information available on the technical advances, and pathophysiology of HD; however, little is written about how older adult HD patients experience their illness – a very subjective experience. There is the need to understand the experience of HD for the elderly population.

## **Chapter 3**

### **Methodology**

To address the study objective a descriptive, phenomenological study using a semi-structured interview guide was employed to collect and analyze qualitative data regarding how older adults experience hemodialysis. The systematic focused thematic analysis was guided by the Crisis of Physical Illness conceptual model. This chapter addresses the data sources, sample, study settings and the data analysis and trustworthiness methodology.

The researcher's goal was to capture the lived experience, to find meaning that may or may not be known to the person who experienced it, and to describe the phenomenon through the composite narrative. Through the collection of qualitative data, the researcher was able to provide intricate details about the thoughts and feelings expressed by those receiving hemodialysis.

#### *Phenomenology*

Phenomenology is defined as a science whose purpose is to describe particular phenomena, or the appearance of things, as lived experience (Speziale & Carpenter, 2007). Phenomenology continues to be an integral part of inquiry that cuts across philosophic, sociologic, and psychological disciplines (Speziale & Carpenter, 2007). This rigorous, critical, systematic method of investigation is a recognized qualitative research approach applicable to the study of phenomena important to the discipline of nursing. Professional nursing is enmeshed in people's life experiences, therefore phenomenology

as a research approach is well suited to the investigation of the phenomena important to nursing (Speziale & Carpenter, 2007). Phenomenology was therefore the selected method for this study as the researcher was investigating how older adults diagnosed with ESRD, receiving hemodialysis, experience this chronic illness.

### *Hermeneutic Phenomenology*

Hermeneutic phenomenology uses the lived experiences of people as a tool for better understanding the social, cultural, political, and historical context in which those experiences occur (Polit & Beck, 2004). Such inquiry often focuses on meaning – how socially and historically conditioned individuals interpret the world within their given context. The phenomenologist believes that the lived experience gives meaning to each person's perception of a particular phenomenon (Polit & Beck, 2004). The goal of utilizing this particular approach was to describe fully, lived experience and the perceptions to which it gives rise. This research design was especially useful as the topic at hand was fundamental to the life experience of humans – living with a chronic illness (ESRD). In order to interpret the lived experience of the participant, it was necessary that the researcher have a previous understanding of the human action being studied (Polit & Beck, 2004). As such, the researcher attempted to understand the lived experience of those older adults aged 65 years and older who were receiving maintenance hemodialysis treatment. Highlighting this experience allowed the researcher to explore the thoughts and feelings of these individuals, so as to gain a better understanding of the experience as a whole.

### *Sample*

A purposive sample with the criterion of dialysis-dependency was used. Both males and females aged 65 years of age and older who had been on HD for a minimum duration of two years as an outpatient were sought. Purposive sampling is most commonly used in phenomenological inquiry. This method of sampling selected individuals for study participation based on their particular knowledge of a phenomenon (experience of hemodialysis) for the purpose of sharing that knowledge.

### *Inclusion Criteria*

Additional criteria that guided the nomination and selection of the hemodialysis participants are listed below:

1. Able to speak and understand the English language
2. Living within the Kingston, Frontenac, Lennox, Addington (KFL&A), Lanark, Leeds or Grenville counties/communities (home or assisted living)

### *Exclusion Criteria*

1. Cognitive deficit
2. Severe hearing deficit
3. Kidney transplant recipient
4. Resident in a long-term care facility

According to Polit & Beck (2004), phenomenological studies often involve a small number of study participants, ten or less. Participants were determined to have met the

outlined inclusion criteria following completion of the demographic information form (Appendix C) collected prior to the interview. The information obtained was specific enough to ensure that the target participants who were interested would be captured and be general enough so that variety in the phenomenon would be captured. Once saturation was met via rich descriptions with numerous comments and examples provided by participants, data collection ceased.

### *Setting*

A dialysis program operated by an acute care teaching hospital was used. Semi-structured interviews were conducted in each participant's home dialysis unit, a safe, non-threatening environment as expressed by the participants. This environment was chosen as this is where these individuals spend a large part of their time and experience this part of their life (Speziale & Carpenter, 2007). In addition, this allowed the researcher to maintain the natural setting where phenomena occur (Speziale & Carpenter, 2007).

### *Recruitment Process*

Prior to recruitment, the researcher approached the Clinical Manager and Director of the Renal Program at KGH. The researcher then approached the Charge Nurse for each HD unit to see which individuals met the outlined inclusion criteria. Based on this, the researcher approached each participant and provided a detailed explanation of the purpose of the study and the data collection process (Appendix A). The first nine individuals approached, agreed and were included in this study. For those who indicated

that they were interested, a demographic form (Appendix C) was completed, and for those who ‘qualified’, verbal and written consent was obtained (Appendix B). In addition, posters were utilized (posted in dialysis units) as a method to present information regarding the study in hopes of gaining the interest of potential participants (Appendix E). The recruitment period was approximately four weeks. The researcher (R.C.) had difficulty recruiting 9 participants who were 65+ and had been receiving HD for a minimum of two years. Therefore, with permission from the thesis advisor, the researcher interviewed two participants who had only been receiving HD treatment for just over a year. All participants seemed more than willing to share their stories.

### *Participants*

In total, there were nine participants involved in the study, aged 67 to 83. Three females and six males consented to participate. Out of all nine participants, one individual received post-secondary education. All nine participants had co-morbidities. Four of the participants were married, while five were widowed. The length of time on HD ranged from 1-8 years, for an average of 3.4 years on HD.

### *Data Collection*

A brief socio-demographic questionnaire (Appendix C) was completed prior to each interview in order to collect preliminary information. Face-to-face focused interviews served as the primary method of data collection for this study. This method allowed the researcher the opportunity to gain entrance into the informants’ world and to have access to their experiences as lived (Polit & Beck, 2004). A semi-structured interview guide was

utilized which listed the topics to be covered in the interview (Appendix D). This written topic guide was used to ensure that all topic areas were covered. Given the methodology with phenomenology, it is common to pose an open-ended question that allows a participant to share their experience in relation to being on HD when they have ESRD. The semi-structured interview guide included questions that were selected in order to facilitate the individual to elaborate on their experience. The open-ended interview provided participants with the opportunity to fully describe their experiences. The introductory question was: “Can you share your story with me from the time leading up to your diagnosis of end-stage renal disease until now?”. In most instances the participants answered the questions listed in the guide. If they did not, the guide was used to prompt the discourse. The function of the interviewer was to encourage participants to speak freely about all of the topics listed in the guide (Polit & Beck, 2004).

While participants were offered the opportunity to be interviewed in a private room, they all elected to be interviewed in the dialysis unit while receiving HD. Each interview lasted approximately 60-90 minutes. Each interview was recorded using a digital voice recorder. The researcher not only gathered information, but also made an effort to experience the phenomenon in the same way through participation, observation, and introspective reflection (Polit & Beck, 2004). Field notes were recorded within one hour of each interview. Such notations described observations, assumptions about what was being heard or observed or personal narrative about what is being felt by the researcher during each encounter. Such notes also described the participants’ expressions, changes in position, and other observations that could not be captured by voice recordings in an

interview (Speziale & Carpenter, 2007). They provided validation for important points made by the participants and facilitated appropriate emphasis on emerging themes (Speziale & Carpenter, 2007).

### *Data Analysis*

The Colaizzi Method of Phenomenological Analysis was utilized to interpret the data. The 7-step procedure is outlined below.

#### *Colaizzi Method of Phenomenological Analysis*

Colaizzi's method involves a stepwise process:

1. Read all protocols to acquire a feeling for them.
2. Review each protocol and extract significant statements.
3. Spell out the meaning of each significant statement.
4. Organize the formulated meanings into clusters of themes.
  - a. Refer these clusters back to the original protocols to validate them.
  - b. Note discrepancies among or between the various clusters, avoiding the temptation of ignoring data or themes that do not fit.
5. Integrate results into an exhaustive description of the phenomenon under study.
6. Formulate an exhaustive description of the phenomenon under study as unequivocal a statement of identification as possible.

7. Ask participants about the findings thus far as a final validating step.

(Colaizzi, 1978 as noted in Polit & Beck 2012, p.566)

The purpose of using this method was to describe the experience of the phenomenon. Following data collection, an extended period of immersion took place. This allowed the researcher to identify and extract significant statements made by the participants. Thematic content analysis was then conducted in order to illuminate patterns and insights that filtered into themes. Tape-recorded interviews were transcribed verbatim by the researcher. Field notes were made by the researcher within one hour of the interview to provide validation for important points made by the participants and facilitated appropriate emphasis on emerging themes during data analysis (Speziale & Carpenter, 2007).

The first step of the analysis involved a line-by-line review of each transcript extraction and classification of interview items into categories. These categories were then examined and collapsed into major themes. The categories of items and reduction of items into themes were validated independently by my research supervisor, Dr. Diane Buchanan. After comparison and discussion, consensus was reached and revisions were made.

### *Ethical Considerations*

The research proposal was submitted and approved by the Queen's University Review Ethics Board. The ethics protocol as outlined in the consent form was followed. Participants were ensured by the researcher that the information provided by them would

remain confidential and would not be personally identified at any time during or following the study. Privacy was respected during the interview process by allowing the participants to decide where they would like the interview to take place. Possible risks and benefits involved in the study were outlined by the researcher. The researcher advised all participants that although they may not benefit personally from the study, their involvement may assist others coping with the disease and the health care team in the development of appropriate interventions.

#### *Ensuring Trustworthiness/Rigor*

Rigor in qualitative research is demonstrated through researchers' attention to and confirmation of information discovery (Speziale & Carpenter, 2007). The goal of rigor in qualitative research is to accurately represent study participants' experiences. Lincoln and Guba (1985) have identified operational techniques supporting the rigor of the work: credibility, dependability, confirmability, and transferability. Through the current study, trustworthiness was practiced in a variety of ways. It was enhanced through the strategies detailed below.

Credibility is an evaluation of whether or not the research findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data (Lincoln & Guba, 1985). It includes activities that increase the probability that credible findings will be produced. Prolonged engagement with the subject matter – older adults who are on hemodialysis, was completed. The technique of 'member checking' allowed the researcher to see whether participants recognize the findings of the study to be true to

their experiences. Such “member checks” sought feedback from the participants regarding the accuracy of the interpretation by the researcher. If there was discrepancy, the researcher returned to the data for further analysis and interpretation. The researcher also had those who have lived the described experiences validate that the reported findings truly represented their experiences. Regular meetings with my thesis supervisor, Dr. Diane Buchanan were scheduled. She posed questions regarding the research question, methodology, ethics, trustworthiness, and other research issues. She pointed out observations and suggestions and posed questions throughout the process. Her role was generally consistent with that defined in the literature (Lincoln & Guba, 1985).

Dependability is an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation. It is met once researchers have demonstrated the credibility of the findings. Dependability cannot exist without credibility.

Confirmability measures how well the inquiry’s findings are supported by the data (Lincoln & Guba, 1985). It is a process criterion. In order to ensure confirmability, the researcher will document all findings so as to leave an audit trail (Lincoln & Guba, 1985). This required recording the activities that occurred during the study so that another individual can follow. The objective was to illustrate as clearly as possible the evidence and thought processes that led to the conclusions. An independent audit from my thesis supervisor allowed for examination of original transcripts, data analysis documents, field notes, comments from member checks and the text of the dissertation itself allowed for confirmability.

Transferability refers to the probability that the study findings have meaning to others in similar situations. This was achieved by providing rich detail related to the context of the study. Whether the findings are transferable rests with the potential users of the findings rather than with the researcher. Access to the researchers paper trail allows fellow researchers the opportunity to transfer conclusions of this inquiry to other cases so as to repeat the procedures used in this study as closely as possible.

These four criteria are crucial for judging the rigor of qualitative research. They define for external audiences the attention qualitative researchers render to define their work (Speziale & Carpenter, 2007).

## **Chapter 4**

### **Findings**

This chapter describes the stories of the experiences of nine older adults, 6 men and 3 women aged 67-83 years with ESRD who had already been on HD for 1-8 years. Their descriptions were analyzed using Colaizzi's method. Out of this, 5 themes emerged that depicted the experience of learning to live with a chronic disease on top of a pre-existing disease. In this chapter, I discuss the five themes that arose in this study along with rich text to highlight their experience: The Will to Live, Recognition of a Lifetime Commitment, Learning to Live with Technology, The Yin and Yang of Hemodialysis, and Transcending Hemodialysis (Figure 2). In the following descriptions of the themes, categories, and quotes from participants, pseudonyms have been used to protect confidentiality.

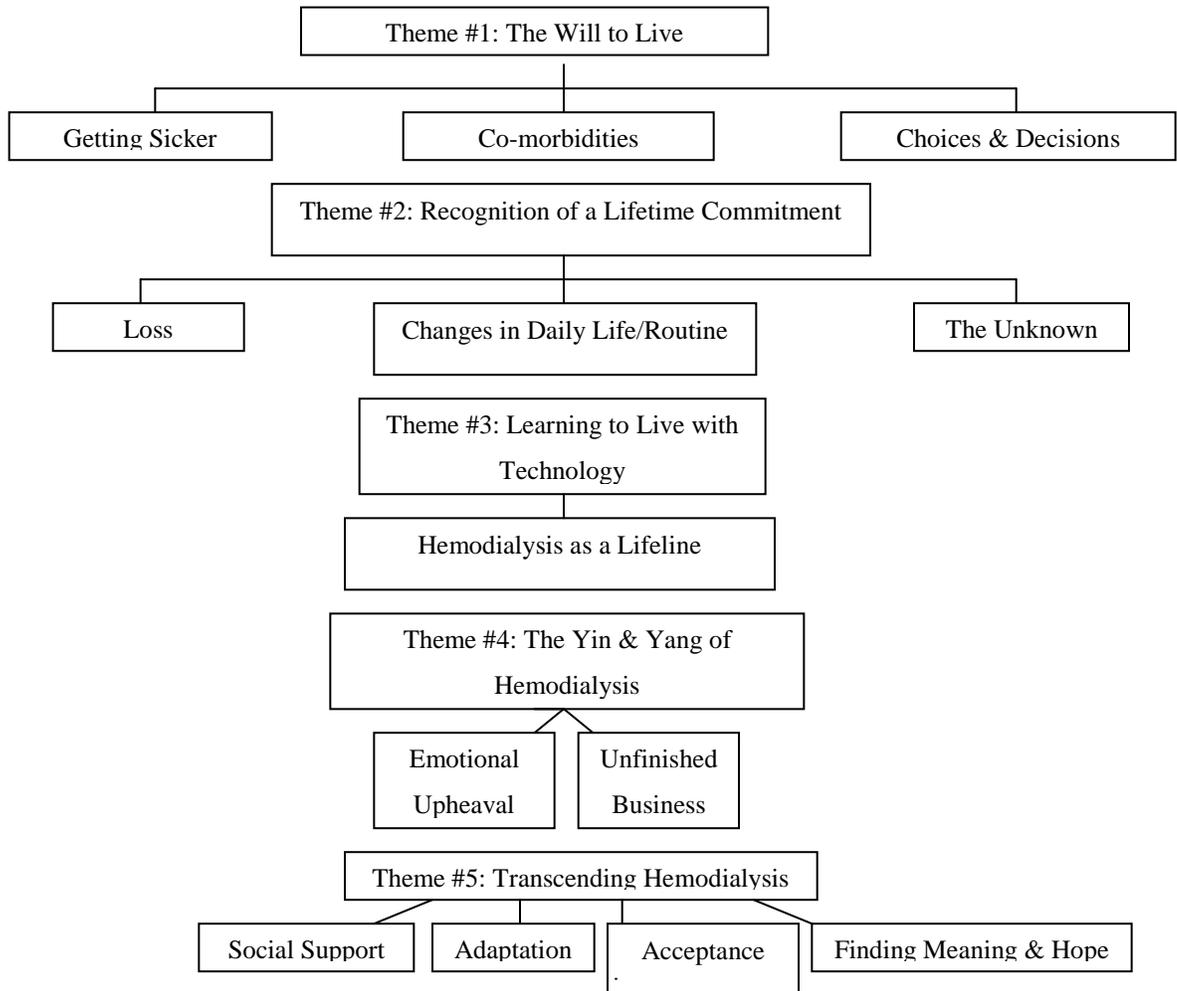


Figure 2 Themes and Categories

*The Will to Live*

The will to live was apparent in each participant. All spoke of wanting to continue with HD treatment so as to continue living life. One individual stated “*Well I know I*

*gotta be here if I want to keep livin'”* (Herb). Another participant stated *“I’m still not ready to die”* (Mary). Robert, explained his thoughts/feelings quite simply: *“Because if you don’t, you’re dead. It’s that simple”*. Ralph demonstrated a very positive approach in his statement *“Because I’m going to make it”*.

When talking about being diagnosed, all participants spoke not only of their will to live but also of what occurred with the illness trajectory and the process of being diagnosed; they spoke of getting sicker, co-morbidities, and their choices and decisions.

### Getting Sicker

All nine participants spoke of their change in health prior to being diagnosed with ESRD. They each described the signs and symptoms that they experienced. For some of the participants, their diagnosis was somewhat of a gradual process. Mary describes her frustrations leading up to her diagnosis: *“I just kept getting sicker and sicker and uh pain and everything going off whack...and it took me 4 years of complaining... So I kept getting worse and worse and I got to the point I knew I was dying”*. Ralph was aware that he had deteriorating renal function years prior to his diagnosis of ESRD: *“Well my doctor told me back in 199(pause) 7 or 8, somethin’ like that. And he said in the future you’re going to be havin’ trouble with your kidneys”*.

There were 4 participants for whom the diagnosis of ESRD was sudden. Ernie had to have cardiac surgery (repair of a valve). One week following his discharge home he became unwell and immediately returned to hospital. He spoke about this experience: *“They sent me home and I seemed to be normal but uh I just after a period of about 5 or 6 days I just blew up like a balloon...So I went back to the hospital. Right away they put me*

*on dialysis and I didn't know why I was on dialysis...I didn't know it was my kidneys – and nobody ever told me”.*

### Co-morbidities

In discussing the experience of being diagnosed, participants identified a number of conditions that potentially led to their kidney failure and their understanding of how it affected their situation. One participant attributed his loss of renal function to infections that developed following cardiac surgery: *“Well, I was never diagnosed with kidney disease and I don't have kidney disease. A disease per se. Uh, my kidneys just failed due to infections that I went through after heart surgery”* (Ernie). One participant in describing his co-morbid condition also demonstrated how the two diseases were having an impact on one another through his inability to exercise: *“It gets ridden (bike) when I feel like it, but hey like I mentioned before if the heart says no you're tired today – you don't go”* (Ernie). Another participant, Herb stated *“I got...I got a bad knee”*. This prevents him from exercising and therefore impacts on his diagnosis of ESRD and its treatment. Ed not only attempts to cope with ESRD and its treatment, but also the diagnosis of diabetes and its treatment: *“Oh gosh I've been a diabetic for quite a number of years...it must be...it's a good 10 anyway...maybe a little more than that”*.

### Choices and Decisions

Being diagnosed with any chronic illness has implications for an individual's choices and decisions. However, being diagnosed with ESRD, the choices are limited to one of two treatment options, RRT or not to take action at all, which would eventually

result in death. All nine participants spoke of learning about their choices and of making their decisions to initiate HD. Mary spoke of not being ready to die and leaving her family: *“Because I didn’t want to die and my kids weren’t ready – they’re adults and they’ve got children but they weren’t ready to give up their mommy either. My husband wasn’t ready to give up a wife so I thought...why not, I’ll try it and maybe I’ll get over the fear of the machine...”*. Robert woke up in ICU on dialysis. When asked if he was able to make the decision to initiate HD, he responded: *“Well, you don’t make that decision...they [doctors] make it”*. When speaking about making the decision to initiate HD another participant replied *“It’s not – when you’re on dialysis and you’ve had kidney problems and you have to be on dialysis you don’t have any choices – die or don’t die”* (Ernie). In one instance, when the participant was unconscious, the participant’s power of attorney (wife) made the decision for him: *“I was shocked the first time. They have the cord running out of your neck...that’s where they hook you up to the emergency hemodialysis when it starts. I was feeling it. My wife was there luckily and she told me to leave it alone. She told me what it was and I said oh...”* (Robert). In some cases, the illness process was longer and the individual had time to consider their options.

#### *Recognition of a Lifetime Commitment*

ESRD is a chronic disease requiring a lifelong commitment to a strict treatment regimen in order to sustain life. While the decision to initiate HD has the benefit of sustaining life, such commitment does not come without its restrictions. All participants spoke of the various losses they experienced as a result of the diagnosis and initiation of

HD. Under this theme related to having made the lifetime commitment to HD, the challenges and thus the categories included loss, change and the unknown.

### Loss

All participants spoke of the various losses they experienced throughout the course of receiving HD. These losses include loss of independence, freedom and control and loss related to their social network. When Herb was asked how it made him feel to be on hemodialysis, he commented on time lost: *“Well, it’s taken most of my life away...I mean, four hours a day...three days a week.... I can’t do whatever I want...ties me down”*. Robert spoke about how he has lost his independence as a consequence of the illness and its treatment: *“...my biggest problem I have is I have to depend on people now to help me out which I never had before...I was always independent. My wife and I were independent people. Now I have to depend on her for everything...”*. Herb commented on his loss of independence and how he would rather drive himself to his HD sessions: *“I still got my car...it’s already insured. I’d sooner get in my own car and drive”*.

### Changes in Daily Life/Routine

All participants spoke of the changes related to being on HD in their day-to-day life. In order for the HD process to be successful, it calls for a strict dialysis regimen and changes in daily routines and family dynamics. Some of the restrictions that these individuals face include fluid, dietary, inability to travel far from a hemodialysis unit, exercise, and changes to their past social activities (i.e. going for a drink).

With regards to diet, there are mainly fluid restrictions which are a major change and can complicate therapy. Some spoke of the challenge of limiting their fluid intake so as to follow the treatment protocol. When Ernie was asked how his life had been impacted since starting HD, he responded “*Well, there’s one thing I really miss..really really miss and that’s a cold bottle of beer*”. He also spoke about the fluid restrictions and how he copes: “*Yep – you get used to it and then it becomes routine...*”. Robert identified fluid restrictions as his biggest problem: “*Trying to control the amount of liquid I drink...oh, it’s the biggest problem*”. Ed spoke about how he enjoys going to Tim Horton’s to visit with his friends, but finds it difficult with the fluid restrictions: “*But you see I don’t like goin’ there [Tim Horton’s] too much because you’re drinkin’ again...so, but I do go there...I’ve went to Tim Horton’s and never bought nothin’*”. Ruth shares the same difficulties: “*I try. Oh yeah...weekends kill ya you know and uh if you go out to some place well you just have to hold your drink, whatever you have in your hand...you’re there two hours – it’s gotta be there. You just sip away...yeah...and a soft drink, which I used to love – they’re gone*”. Finally, Ruth also spoke of how she copes with the fluid restrictions: “*So I’m careful. Like we have soup...mushroom soup, but I’ll only have just about a scoopful*”. While individuals attempted to be compliant with treatment, they also indicated the need to ‘treat themselves’ sometimes. Three participants spoke honestly about ‘cheating’: “*Diet doesn’t bother me...they say don’t eat that and don’t drink this – what the hell...I want a hotdog, I’m gonna eat it*” (Ernie). When talking about following the dietary and fluid restrictions, Herb responded with: “*I don’t like to do what I’m told*”. Ed admitted that he cheats and that the nurses get ‘mad’

about it: *“I cheat a little bit and then the nurses get mad at me...”*. Some spoke of how the consequences of treatment affect their day-to-day lives: *“...it’s affected my life, that’s...we used to do a lot of traveling and that’s sorta stopped now. It can be arranged but we haven’t really tried it. So we just hang around at our summer trailer. You know, everything in our life now...the wife and I is – pretty much done around dialysis and the fact is that if you don’t do it that way you do die”* (Ernie). Robert also commented on how treatment has impacted on his life: *“So, here I am today...the sad part is I can’t go away on holidays...uh, if I go some place there would have to be a dialysis unit close by...but that wouldn’t be fair to my wife if I have to go to dialysis in some other city three days a week”*. Individuals spoke about how they plan their life around their HD: *“’Cause our grocery shopping day is on Thursday which I don’t have any dialysis”* (Mary). One participant thought of his thrice weekly dialysis schedule much like his routine when he used to work. This approach seemed to help him cope with the restrictions of the regimen: *“It’s like going to work”* (Ernie).

### Learning About the Unknown

Participants spoke of making the decision and commitment to HD without a full understanding of the effects it will have on life and their day-to-day activities. This was in part due to not being fully educated or informed prior to the initiation of HD. Ernie spoke about when he woke up on HD: *“I don’t know what the hell I’m doing on dialysis and then they tell me ‘your kidneys have failed’...why would my kidneys fail?”*. Several of the participants spoke of the unpredictable nature of the disease, the fact that a decision has been made and their life sustained but it is still unknown for how long.

Many of the participants spoke of their limited knowledge and how they became educated about the illness and HD. As they became educated about ESRD and HD, they became actively involved and knowledgeable about the disease as it related to themselves and how it affects them. The individuals learned to become experts on their own health. Ernie spoke about how he reacted when he woke up on HD: *“Well, they put me on dialysis and I started askin’ a whole bunch of questions – why am I hooked up to this machine?...Really, I didn’t get a lot of answers”*. As a result, he took the initiative to educate himself: *“...but the fact of asking questions and stuff like that really didn’t satisfy me. When I went home I pulled it all up on the computer and I asked the computer questions and got the answers from there”*.

#### *Learning to Live with Technology*

Receiving HD treatment means relying on technology to sustain life. For older adults, trusting technology can be challenging, scary, and anxiety provoking. The participants in this study voiced their concern with relying on a machine to sustain life along with their loss of control. The dialyzer becomes their lifeline. In time, after educating themselves and through ongoing treatment, while they don’t trust the machine 100%, they do see it as effective.

#### Hemodialysis as a Lifeline

Individuals spoke of HD being their access to sustaining life and providing said life with the best quality. In saying this, they live with an underlying fear, should technology fail, this life-saving treatment would be compromised. Most of them spoke of

their feelings about having to rely on a machine: *“I know in my mind, it means my life. But I’m still scared of it because things can still go wrong while you’re on the machines”* (Mary). Mary also commented on how HD treatment was a better treatment modality for her and her family in comparison to PD treatment: *“Because that way we have to learn how to hook it up and everything and (husbands name) has a bad heart and his breathing is gone too. We need some place like the dialysis unit with the machines, where you can come in...the nurses keep track and do the work... I rather have the security of the hospital and the machine and the nurses”*.

Over time, participants spoke of accepting what HD has to offer them and coming to terms with living and relying on a machine. This in part may be due to their being more knowledgeable as they became accustomed to being on dialysis and the routine. It may also be due to them feeling better. An example of this is: *“Well I put it down to technology and if it wasn’t for the machine I’d be dead...like they used to die years ago but now it’s different...they hook you up, fix you up, you go home”* (Ernie). Mary who was initially quite frightened by the dialysis machine, began to accept it: *“Yep. And uh, like I said, I’ve accepted the machine now”*.

### *The Yin and Yang of Hemodialysis*

Learning to live with a chronic disease requires acceptance and adaptation to the losses and changes that have occurred as a result of the disease and its process. This applies to ESRD and HD for older adults. The participants all spoke of their emotional responses, both negative as well as positive.

## Emotional Upheaval

In learning to cope with having ESRD and being on HD, participants spoke of their emotional responses to this disease process. Their emotions changed based on how they were feeling physically, along with their understanding of the illness and how to live with it. Robert spoke of his emotions: *“I’m on mood pills. After my lungs collapsed...uh, when we sold our house I would sit here and I’d start to cry and I would say ‘what the hell am I crying about?’”*. When Mary was asked how she felt on the days that she received dialysis she stated: *“They’re like a depression day”*. Herb stated that he would rather be somewhere else rather than receiving HD treatment: *“Well I’d sooner be home with my wife...or something else”*. One participant spoke of the adverse effects of treatment, but also how they allow him to feel better: *“Go for it. It’s a tough life. You’re very confined to what you can and what you can’t do. Like I spend uh from 10:00 to 7:00 at night...that’s 9 hours a day, three days a week I spend here and that’s a lot of time, but I relax for a better word and when I’m here on dialysis...I can get through the next day. And then on weekends, I have trouble with my weight problem because I drink too much on the weekend, and uh I have a lot of problems on that, but I know by Wednesday I’m back to my normal weight”* (Robert).

## Unfinished Business

Participants spoke of some of the positive aspects of the opportunity to be on dialysis and to continue with life. It appeared to provide some of them with a wake-up call and the opportunity to pursue some unfinished business. This is evident in Ernie’s

statement: *“I got things to do and places to go...and I haven’t finished with this world yet”*.

### *Transcending Hemodialysis*

For anyone diagnosed with a chronic and life-threatening disease, coming to terms with the body-mind disease relationship results in the healthiest outcome for the individuals and those in their life. Older adults diagnosed with ESRD and on HD are faced with this challenge and the benefits that result from coming to terms with or transcending the experience of living with ESRD and HD.

Achieving transcendence with the chronic disease of ESRD and the dialysis process calls for social support, adaptation, and acceptance of HD as a life extender, and having that acceptance provides meaning and hope.

### Social Support

Many of the participants who had a spouse, children or grandchildren spoke of the importance of these individuals not only in helping them cope with HD, but also in strengthening their will to live. Mary was considering terminating her dialysis treatment, but her children, grandchildren, and husband made her change her mind. A part of social support for some of them was their faith and how this helped them: *“It takes the stress off me. I am alive today because of the blessed Virgin Mary. Simple as that. When you walk into a doctors office and he says I have been reviewing your file and he says ‘you should be dead’...you know there has been miracles going on”* (Robert).

The regimen of thrice weekly dialysis sessions and requiring assistance often brought family members together. Also, because of the need to be on dialysis three times a week, four hours a day, relationships are formed with staff and others coping with ESRD. This was noted when participants referred to fellow HD recipients as their family: *“Everybody in here is just...it’s my family!”* (Ruth). Ralph also spoke about those others who are receiving HD treatment: *“Small group but you make a lot of friends”*.

### Adaptation

All of the participants spoke of the need to adapt to the chronic illness in order to have a positive outcome. Ruth stated: *“Sure! Well, if you want to be well and you want to stay with your family – you gotta go that way. It’s a time in my life, I feel just like I was going to work but not getting paid [laughs]”*.

### Acceptance of Hemodialysis as a Life Extender

Most participants spoke of coming to terms with HD and it being a life extender. Despite being on HD, they still experience symptoms and often feeling unwell immediately following dialysis, but in spite of this, they are able to accept the downside of dialysis in order to reap the benefits. When referring to ESRD and its treatment, Mary stated: *“No this...you gotta...if you want to live, whatever your reasons for living are, you just gotta accept it”*.

### Finding Meaning & Hope

Several participants spoke of coming to terms with living with ESRD. They spoke about how having accepted HD allowed them to find meaning and hope again in their

life. They were also able to put 'life with HD' in perspective in relation to others. For Ralph, he was faced with other co-morbidities which led to hospitalization and poor health, but despite this he kept a positive attitude: *"Well I'm not going to give up"*. Ernie spoke about how difficult it was to adjust to the HD treatment initially, but how in time he developed a new meaning for his illness: *"When it first started it really kicked me in the butt...but you uh, you start to uh look around in your travels through dialysis and other people and friends that are dying of cancer, etc. and you got nothing to complain about at all, you know?...You just...you just go with the flow"*. Mary spoke about how following her diagnosis with ESRD, she appreciated life more: *"No, I do! Like some people say they never notice the sunsets or anything or like that until they got really sick like on kidney machine or something...then they appreciate it and notice it more"*.

### *Summary*

The interviews with the nine older adults who have been living with ESRD and receiving HD treatment seemed quite willing to share their stories regarding their experience of living with this chronic disease. Out of these discussions, the five themes: The Will to Live, Recognition of a Lifetime Commitment, Learning to Live with Technology, The Yin and Yang of Hemodialysis, and Transcending Hemodialysis arose. The following chapter will discuss these findings in relation to the conceptual model and other research.

## Chapter 5

### Discussion

This chapter addresses the findings of this study and links these with the literature. The five themes that arose out of the interviews with the nine participants who were diagnosed with ESRD and receiving HD were: The Will to Live, Recognition of a Lifetime Commitment, Learning to Live with Technology, The Yin and Yang of Hemodialysis, and Transcending Hemodialysis. The chapter will also address the findings in relation to the conceptual model, the limitations of the study as well as similarities and differences between my findings and the literature and implications for practice and future research.

#### *Related to the Literature*

Consistent with the literature, the older adults spoke to the length of time until they were diagnosed. The study conducted by Martin-McDonald (2003) with primarily a younger population (aged 22-68) had similar findings to the current study conducted with an older population. In Martin-McDonald's qualitative study, themes identified by the ten participants included 'Freedom-Restrictions', 'Hope-Despair', and 'Support-Abandon'. These are similar to the themes *Recognition of a Lifetime Commitment* and *The Yin and Yang of Hemodialysis* identified in this current study.

Hagren et al. (2001), conducted a qualitative study with 15 participants aged 50-86 examining the experience of suffering from ESRD. The themes and subthemes arising from their study support some of the themes and categories of the current study. A major theme within their study was 'the hemodialysis machine as a lifeline'. This is similar to

the theme *Learning to Live with Technology* in the current study. The subthemes of ‘loss of freedom’, and ‘disrupted marital, family and social life’ are consistent with *Recognition of a Lifetime Commitment* in this study and the categories of loss and change. Their second major theme was called ‘alleviation of suffering’ and its two subthemes were ‘gaining a sense of existential optimism’ and ‘achieving a sense of personal autonomy’. This is similar to *Transcending Hemodialysis* and the categories found in this study of social support, adaptation, acceptance of HD as a life-extender, and finding meaning and hope.

Another study by Molzhan, Bruce, and Shields (2008), explored how people with CKD described the experience of liminality, defined as occupying a position at, or on both sides of, a boundary or threshold (Oxford English Dictionary, 2011). The findings of this qualitative study were based on 100 narratives provided for a book on living with kidney failure; the participants ranged in age from 21-88 years and spanned a range of treatment modalities. Six themes arose from this study. The first, ‘Living/Not Living’ reflected the themes, *The Will to Live*, as well as *Learning to Live with Technology* in the current study. Their second and third theme ‘(In)Dependence’ and ‘Restrictions/Freedom’ were in keeping with our theme of *Recognition of a Lifetime Commitment*. Their themes of ‘Not Normal/Normal’ and ‘Worse Off/Better Off’ were also similar to our themes *Learning to Live with Technology* and *The Yin and Yang of Hemodialysis*. One difference noted between these two studies, which may reflect the older population of the current study, was their theme of ‘Alone/Connected’ in which participants did not seem to reach the level of acceptance reflected in our theme of

*Transcending Hemodialysis*. While individuals in their study voiced that they felt alone within their circle of support, this did not seem to be the case in the current study. The theme of *Transcending Dialysis* which was found in the current study in which all of the participants were 65 years or older is in keeping with the concept of Gerotranscendence identified by Erikson (1997) and now recognized as the ninth stage of development. Erikson states "...that is elders can come to terms with the dystonic elements in their life experiences in the ninth stage, they may successfully make headway on the path leading to gerotranscendence" (p 114). Transcendence in the older adult reflects a positive spiritual experience, the ability through wisdom to discover the freedom in going beyond the limits imposed on us in our world (Erikson, 1997).

#### The Crisis of Physical Illness Conceptual Model

The findings of this study reflected the ability of older adults to live with the diagnosis of a chronic illness, ESRD, and its subsequent impact on their lives. The participants who volunteered for this study were ones who displayed successful outcomes in their decision-making and learning to live with the day-to-day consequences.

In the study conducted by Davis and Magilvy (2000), regarding *The Experience of Chronic Illness by Rural Older Adults*, they found themes which were in keeping with our study examining ESRD in older adults. The main findings included 'Managing Daily', 'Support from Faith and Family', 'Balance Through Negotiation', 'Self-Care', and 'Belonging to Community'. The first four themes were in keeping not only with the themes identified in the current study, but also are a good fit with the Crisis of Physical Illness conceptual model chosen for the current study. Furthermore their final theme,

‘Finding Meaning in Life’, also reflects a positive outcome and the fifth theme of the current study, *Transcending Hemodialysis*.

Thus the conceptual model selected to guide this study was reflected in the stories shared by the nine participants. Their stories conveyed their cognitive appraisal of learning about an additional chronic illness and its restrictions on their life. They found ways to adapt and cope while on HD treatment and learning to live with these restrictions. They were then able to describe what the positive outcomes were in their own lives.

#### *Limitations of the Study*

In this study the participants were primarily males. They were all Caucasian and from the same geographical region. None of the participants were over 83 years of age. This may reflect that there are not many old-old adults receiving HD; this may change over time as a result of the aging population. This study did not bring forth participants showing signs of clinical depression as noted in previous studies. All participants seemed to describe and perceive social support from family and friends, which may be linked to less presence of depressive symptoms. This may also be because the participants shared their stories while receiving HD, which may have masked depressive symptoms. All participants seemed to enjoy having another individual to ‘visit’ with and talk to during part of their HD treatment session (4 hour long session). Studies where depression was noted tended to be quantitative. Also those who are depressed may be less liable to initiate HD or volunteer to take part in a research study.

### *Implications for Practice*

There is evidence to support the increasing proportion of the older adult population receiving RRT today. Despite such knowledge, there is sparse literature available which portrays how this older adult population copes with being dialysis-dependent. This study illuminates the thoughts and concerns with this specific population. This information will further allow the health care system to provide adequate support so as to allow this population to experience a life of high quality.

It is important for clinicians to understand the different factors and stages involved in the crisis of a physical illness along with its treatment. A strength of this study was the understanding of the way in which older adults come to understand what the chronic illness means to them, its implications for their life, and the possibilities provided through the HD treatment.

As clinicians, we need to recognize that older adults do still have the will to live. They need information to understand the illness, the impact on daily life, the support that they will require, and the psychosocial response to ESRD and its treatment. There is the need to develop a variety of age appropriate strategies and to give them sufficient time, given that they are dealing with not only ESRD and HD, but also one or more co-morbid diseases. Likewise, if clinicians understand the developmental stages for older adults, they are more inclined to support their patients learning to cope with and transcend dialysis.

It became apparent through the individuals' stories that there is a gap in provision of adequate education at a level that is comprehensible by the older adult. We need to somehow bridge this gap in order to identify individual educational needs.

### *Implications for Research*

This qualitative study added support to previous studies, in particular, as it relates to older adults with a chronic illness such as ESRD, and relying on a highly technical treatment regimen. As well as the benefits from the pathophysiological aspect, we need to provide technology support otherwise. This technology support could provide an avenue of diversionary activity which will equate to a more positive outcome. Future research could utilize technology to assist with the psychosocial aspect of those with ESRD. With the aging population, people will be more comfortable with computers. For example, research could include looking at interventions such as internet education sessions and online support groups. For a disease such as ESRD, where social networks are possibly limited and where they need to be physically dialyzed for approximately four hours thrice weekly, the use of computers would potentially enhance their understanding and social network.

It may be beneficial for future studies to focus on the illness trajectory from the time an older adult is diagnosed with ESRD and initiates HD treatment. Based on the current study, conducting a similar study soon after being diagnosed and initiating HD treatment could be beneficial in helping us to better understand the experience immediately following diagnosis. In addition, a descriptive study identifying the current education strategies available and being utilized could identify whether the needs of the

older adult population are being met. If not, the development of new educational strategies along with tools to measure their effectiveness could bridge this gap.

## **Chapter 6**

### **Conclusion**

In conclusion, this qualitative study explored the meaning of being on HD treatment for the older adult with the chronic illness, ESRD. Nine participants shared their stories revealing five themes: The Will to Live, Recognition of a Lifetime Commitment, Learning to Live with Technology, The Yin and Yang of Hemodialysis, and Transcending Hemodialysis. A key finding of this study was the understanding that older adults can accept technology as a lifeline and not only can they learn to adapt to the losses and changes that occur with this disease, but that they are also able to achieve transcendence through accepting social support, HD as a lifeline and as a life-extender and through finding meaning and hope in spite of the changes.

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## Appendix A

Project Title:

The Experience of the Older Adult with End-Stage Renal Disease on Hemodialysis

Investigator: Rebecca Corrigan, RN

Information Sheet: The purpose of this study is to gain a further understanding of the lived experience of those older adults who are on maintenance hemodialysis.

Taking part in this study will involve answering questions in an interview which will take approximately 45 minutes to one hour to complete. This can take place during/following your hemodialysis session, or I will be happy to interview you in your home. During this study you will talk to the nurse researcher, Rebecca Corrigan, who is conducting the study for 45 minutes or longer if you wish to continue talking about the topic being discussed. If you become tired or want to stop the interview for any reason at any point in time, you may do so. The researcher may ask you to speak with her again to ensure that she has understood the information which you have shared with her. With this study:

Your decision to take part in this study is entirely your own. Your decision will in no way affect the care you receive from the doctors, nurses, or the hospital. You are free to change your mind and withdraw from the study at any time. You may refuse to answer any specific question and will be free to stop the interview at any time. If you decide to participate in the study and wish to be interviewed following your dialysis session, you will be reimbursed for your parking costs.

If you do decide to take part, your name will be kept strictly confidential and will not be recorded with your answers in the interview. Your responses will not be discussed with any of the doctors, nurses, or hospital staff. You will not be personally identified in any discussion or publication of the research report.

There are no expected risks to you, but some questions may be of a personal nature which may make you uncomfortable (sensitive issues). While you may not benefit directly from taking part in this study, the information which you provide may help others who are living with hemodialysis.

Do you have any questions about the study? Would you be willing to take part in the study?

- a. The talk will be tape recorded.
- b. Anything you say will be kept confidential.
- c. Your name will not appear in any report of the study.
- d. There are no known risks to taking part in this study. If you find you are upset due to

talking about sensitive issues, the nurse researcher will assist you with an appropriate referral.

e. You may or may not directly benefit from being involved in this study. The information which you share may help others.

You may withdraw at any time by contacting Rebecca Corrigan at 613-548-8589 or Dr. Diane Buchanan at 613-533-6000 X 78907; your withdrawal will not affect any care you are receiving from the KGH Dialysis Program.

## Appendix B

Name of project:

The Experience of the Older Adult with End-Stage Renal Disease on Hemodialysis

Investigator: Rebecca Corrigan, RN

Consent form: The Experience of the Older Adult with End-Stage Renal Disease on

Hemodialysis.

I have been provided with a description of the study along with any possible risks or benefits that may be associated with this study (Appendix A).

I have also been provided with an opportunity to ask questions which pertain to this study, and any questions which I have asked have been adequately answered.

I have been informed that I can withdraw my consent and stop my participation in this study at any point in time and for any reason. I have been told that my identity will be kept confidential.

I understand the information that I have been provided, and I voluntarily consent to participate in this study.

\_\_\_\_\_  
(Signature of Participant)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature of Researcher)

\_\_\_\_\_  
(Date)

### Appendix C

#### Demographic Information

Subject Number \_\_\_\_

1. Gender: male \_\_\_\_\_, female \_\_\_\_\_
2. Date of birth: \_\_\_\_ day, \_\_\_\_ month, \_\_\_\_ year
3. Marital status: \_\_\_\_ single (never married), \_\_\_\_ married, \_\_\_\_ separated, \_\_\_\_ divorced, \_\_\_\_ widowed
4. Years of education:  
\_\_\_\_ 7 years or less  
\_\_\_\_ 7-9 years  
\_\_\_\_ 10 or 11 years

- High school graduate
- 1-3 years of college (including business school)
- Completed professional degree (i.e. MA, M.D, PhD, etc.)

5. What is your current home situation?

- Live in your own home, on your own
- Live in your own home, with your spouse
- Live in home, with other family/friends
- Live in a seniors center
- Live in a nursing home
- Other, please specify \_\_\_\_\_

6. Do you have another physical disorder, such as heart disease, diabetes, respiratory disease in addition to chronic kidney disease?

- Yes       No

If yes, please specify: \_\_\_\_\_

Researcher will gather demographic data from participants.

## Appendix D

### Semi-Structured Interview Guide

1. Can you share your story with me from the time leading up to your diagnosis with end-stage renal disease until now?
2. Can you share with me what it is like to be on hemodialysis?
3. What is a typical day like on a non-dialysis day?
4. What is a typical day like on a dialysis day?
5. Are there particular things you like/find challenging?
6. How has your life changed since starting hemodialysis?
7. Who are your supports currently?
8. Have these supports remained the same since pre-hemodialysis?
9. How/has being on hemodialysis affected your mood?
10. What helps you through the difficult days?

## Appendix E

The Experience of the Older Adult with End-Stage Renal Disease on Hemodialysis

### VOLUNTEERS NEEDED

WOMEN AND MEN, AGED 65 and older

I am a registered nurse in the Master of Science (Nursing) program at Queen's University. I am interested in learning about the process experienced by older adults as they cope with being dependent on hemodialysis. This information may help health professionals to better understand how older adults experience being hemodialysis-dependent.

Would you like to share with others what it is like to live with end-stage renal disease and receive hemodialysis treatment? If so, I would appreciate the opportunity to include you in this study. If you agree to assist me with this study, you will take part in an interview session with me.

FOR INFORMATION, please contact:

Rebecca Corrigan RN, BScN, MSc(c) at 613-548-8589

or

Dr. Diane Buchanan RN, BScN, MSc, PhD at

613-533-6000 x 78907

LOCATION of interview: a location convenient for you

TIME of interview: a time convenient for you

If you wish to receive a copy of the final results, please provide the name and mailing address to which you would like the report sent.

Name:

Address: