

Patient's Experience with Home Hemodialysis: A Qualitative Study

By

Christopher Stephen Purves

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF HEALTH SCIENCES IN COMMUNITY HEALTH

In

THE FACULTY OF HEALTH SCIENCE PROGRAM

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

March / 2015

© Chris Purves, 2015

Abstract

As the number of chronic kidney disease patients increases so does the need for a renal replacement therapy (RRT). Increasing patient age, medical complexity, and a shortage of organs for transplantation are contributing factors to the rise of patients starting a RRT known as dialysis. The purpose of this research was to explore the patient experience using home hemodialysis (HHD) and identify common benefits and barriers that exist. Twenty HHD patients from a community based hospital participated in a semi-structured interview. The interviews were audio recorded and transcribed by the principal investigator. By utilizing the constructs of the Health Belief Model as a template, four overarching themes were identified: perceived benefits, perceived barriers, perceived severity and self-efficacy. Patients indicated they benefit from HHD as it allows them to customize their treatment schedule and promotes autonomy while improving their overall health. Reported barriers of HHD were self-cannulation, troubleshooting alarms and travel restrictions. Above all, managing and storing heavy supplies was the most common barrier. All participants realized the severity of their situation and perceived HHD necessary for survival. Patients reported different mindsets towards HHD and its impact on their lifestyle. Varying levels of self-efficacy were reported however, confidence through experiential learning and type of vascular access were underlying factors for improving self-efficacy. The consensus for enhancing the HHD experience was the desire for a smaller more portable machine that would allow patients to perform treatments away from their home and ultimately eliminate travel restrictions. This combined with smaller or fewer supplies were the most prominent experience enhancing suggestions. This study identifies key elements of the HHD patient experience and provides a basis for improving HHD programs.

Keywords: Health Belief Model; home hemodialysis; experience; benefits; barriers; perceived severity; self-efficacy.

Acknowledgements

This work is dedicated to the loving memory of my grandfather, William Morgan, whom was burdened with juvenile diabetes and dialysis.

First and foremost, I would like to thank my loving girlfriend Angie for being my rock. I could always count on you for suggestions and you offered an open ear to my countless justifications. Thank you for helping me through the tough times but also for being a great friend in celebrating the achievements. I would like to thank my entire family, especially my parents for their belief in my ability to succeed academically and for their continuous support over the years both financially and emotionally.

Secondly, I acknowledge the participants of my study. Without their cooperation and willingness to share their experiences with me, this research would not be possible. I want to thank you for taking the time to speak with me during your busy schedules. Your enthusiastic responses provided valuable information, benefiting the study outcomes. It was a pleasure meeting you all and I hope I have represented you well.

To the Lakeridge Health staff, I want to extend my gratitude for your corporation and support throughout my research. Your involvement with the recruitment process was very helpful and allowed me to maximize my time with the participants. Honorable mentions go out to Christina Vaillancourt, Emily Harrison and Tracey Burton. You have all been instrumental in the development of my thesis from the early stages of my literature review right up to my data collection in the clinic. Your assistance throughout the years does not go unnoticed and I want to thank you for your service.

To my committee members Dr. Robert Weaver and Dr. Natalie Ceccato, your expertise was second to none as your astute advice steered my research in a productive direction. Your in-depth reviews and comments not only enhanced the structure of the thesis but also enriched the fine details. The time and effort you both contributed was greatly appreciated.

Finally, I would like to extend my greatest thanks to my supervisor, Dr. Manon Lemonde. I want to start by thanking you for accepting me as your student and giving me the opportunity to pursue research in dialysis. Not only were you an educator, but you were also a role model. Whenever I needed advice or reassurance you were always there for me. I have the upmost respect for you and proud to say you are my supervisor and friend.

Table of Contents

ABSTRACT..... i

ACKNOWLEDGMENTS..... ii

TABLE OF CONTENTS iv

LIST OF TABLES viii

LIST OF ABBREVIATIONS ix

CHAPTER 1: INTRODUCTION..... 1

1.01 INTRODUCTION 1

1.02 PURPOSE..... 2

1.03 RESEARCH QUESTION..... 2

1.04 BACKGROUND 2

1.05 REFLECTIVE EXPERIENCE 4

1.06 THEORETICAL FRAMEWORK: HEALTH BELIEF MODEL 5

1.07 COMMUNITY BASED HOSPITAL DIALYSIS PROGRAMS..... 7

1.08 CURRENT DEVELOPMENTS 8

CHAPTER 2: LITERATURE REVIEW 10

2.01 INTRODUCTION 10

2.02 SEARCH PROCESS 10

2.03 LITERATURE REVIEW 11

 MODALITY SELECTION & SETTING..... 11

 COST ANALYSIS..... 16

 BENEFITS 18

 BARRIERS 21

2.04 GAPS IN LITERATURE 25

2.05 THEORETICAL FRAMEWORK: HEALTH BELIEF MODEL 27

HEALTH BELIEF MODEL CONSTRUCTS	27
HEALTH BELIEF MODEL LIMITATIONS	28
THEORETICAL FRAMEWORK JUSTIFICATION	29
2.06 SUMMARY OF MAJOR FINDINGS	31
CHAPTER 3: METHODOLOGY	33
3.01 INTRODUCTION	33
3.02 ETHICAL CONSIDERATION & RESEARCH APPROVAL	33
3.03 SAMPLE POPULATION & RECRUITMENT STRATEGY	34
3.04 DATA COLLECTION	35
OBSERVATION REPORTS	35
INTERVIEW SETTING	36
INTERVIEW PROCESS	36
INTERVIEW CREDIBILITY	38
3.05 DATA ANALYSIS	39
TRANSCRIPTION OF DATA	39
ANALYTICAL PROCESS	39
3.06 ACHIEVING TRUSTWORTHINESS	40
CHAPTER 4: RESULTS	44
4.01 INTRODUCTION	44
4.02 SOCIO-DEMOGRAPHICS OF PARTICIPANTS	44
4.03 INTERVIEW RESULTS	45
4.04 HEALTH BELIEF MODEL CONSTRUCTS	58
4.05 PERCEIVED BENEFITS	59
PERSONALIZED AND FLEXIBLE TREATMENT SCHEDULE	59
AUTONOMY AND PSYCHOLOGICAL BENEFITS	60

PHYSICAL HEALTH BENEFITS	62
4.06 PERCEIVED BARRIERS	63
MANAGEMENT OF SUPPLIES	63
SELF-CANNULATION.....	64
TRAVEL RESTRICTIONS.....	64
TROUBLESHOOTING ALARMS	66
4.07 PERCEIVED SEVERITY	67
COMPULSORY FOR SURVIVAL	67
MINDSET.....	68
4.08 SELF-EFFICACY.....	69
CONFIDENCE WITH EXPERIENCE	69
CAREGIVER SUPPORT	71
VASCULAR ACCESS.....	72
4.09 SUMMARY OF RESULTS	73
CHAPTER 5: DISCUSSION	76
5.01 INTRODUCTION	76
5.02 SOCIO-DEMOGRAPHICS OF PARTICIPANTS	76
5.03 PERCEIVED BENEFITS.....	77
5.04 PERCEIVED BARRIERS	79
5.05 PERCEIVED SEVERITY	81
5.06 SELF-EFFICACY.....	83
5.07 HEALTH BELIEF MODEL.....	85
5.08 SUMMARY OF DISCUSSION	86

CHAPTER 6: CONCLUSION.....	88
6.01 INTRODUCTION	88
6.02 STUDY CONCLUSION	88
STUDY STRENGTHS	88
STUDY LIMITATIONS	90
POTENTIAL BIASES.....	90
RISKS & BENEFITS	91
6.03 RESEARCH IMPLICATIONS	91
THEORETICAL IMPLICATIONS.....	91
PRACTICAL IMPLICATIONS	92
6.04 FUTURE RESEARCH.....	93
6.05 CLOSING REMARKS.....	95
REFERENCES.....	96
APPENDIX A: LAKERIDGE HEALTH STANDARDIZED HEALTH CHECKLIST	101
APPENDIX B: TCPS: CORE	102
APPENDIX C: UOIT REB APPROVAL	103
APPENDIX D: LAKERIDGE HEALTH REB APPROVAL.....	104
APPENDIX E: CONSENT FORM	110
APPENDIX F: CONSENT FORM FOR AUDIO RECORDINGS	116
APPENDIX G: STUDY NOTIFICATION POSTER.....	118
APPENDIX H: RECRUITMENT LETTER/VERBAL SCRIPT	119
APPENDIX I: INTERVIEW QUESTIONS.....	120
APPENDIX J: CLINIC AND EDUCATION OBSERVATION REPORT.....	122

List of Tables

TABLE 1. Health Belief Model (Austin, et al., 2002, p.124) 28

TABLE 2. Trustworthiness Criteria 41

TABLE 3. Participant Socio-Demographics 45

TABLE 4. Summary of Emerging Themes 74

List of Abbreviations

AVF- Arteriovenous Fistula

AVG- Arteriovenous Graft

CAD- Canadian Dollar

CKD- Chronic Kidney Disease

CVC- Central Venous Catheter

ESRD- End Stage Renal Disease

HD- Hemodialysis

HHD- Home Hemodialysis

NHHD- Nocturnal Home Hemodialysis

PI- Principal Investigator

PD- Peritoneal Dialysis

REB- Research Ethics Board

RRT- Renal Replacement Therapy

SCDT- Self-Care Deficit Theory

SCT- Social Cognitive Theory

UOIT- University of Ontario Institute of Technology

Chapter 1: Introduction

Section 1.01

Introduction

As the number of chronic kidney disease (CKD) patients increases so does the need for renal replacement therapy (RRT). Increasing patient age, medical complexity, and a shortage of organs for transplantation are contributing factors in the rise of patients starting RRT in the United States and Canada which continues to increase by 5%-7% each year (McLaughlin, Manns, Morris, Hons, & Taub, 2003). Most patients with kidney disease eventually require a RRT known as dialysis. Dialysis is a CKD treatment that filters a person's blood to compensate for lost kidney function. Dialysis treatments can be performed at an in-centre location (hospital or satellite location) or at home. In-centre dialysis comprises of strict weekly treatments performed by nurses while home dialysis consists of a more flexible treatment schedule performed in the patient's home. Not all patients are suitable candidates for home-based dialysis as there are certain barriers preventing them from adopting this modality. This study focuses on home hemodialysis (HHD) patients and explores their experiences. More specifically, this study will identify common benefits and barriers¹ through the collection of semi-structured interviews. Findings from this study can support identifying strategies for improving attrition rates and increasing the prevalence of HHD. Recognizing the benefits and barriers of HHD from a patient's perspective will provide a foundation for renal program improvements. This introductory chapter begins with the purpose and research question, followed by background information and a reflective experience piece. The theoretical framework, community based hospital and current developments will then be introduced.

¹ The words barriers and challenges are used interchangeably throughout this study.

Section 1.02

Purpose

The purpose of this research is to explore the experience of HHD patients and identify common benefits and barriers. Interviewing the patients individually offers a unique perspective into their experience at home. Emerging themes will be reported to provide insight for describing and improving the HHD experience.

Section 1.03

Research Question

What are the common benefits and barriers that emerge through the exploration of the HHD patient experience?

Section 1.04

Background

Dialysis is a procedure used to filter a person's blood by eliminating excess fluid, potassium, phosphate and waste products (e.g., creatinine and urea) when the kidneys are in a state of renal failure. This form of RRT is often required for individuals that have acute damage to their kidney(s) or suffer from CKD, which is the progressive loss of renal function over a period of months or years. CKD is often the result of high blood pressure, diabetes or glomerulonephritis. The progression of CKD is classified into five stages based on the severity of the disease. Stage 1 is the least severe where Stage 5 is the most severe and commonly known as end-stage renal disease (ESRD). ESRD means the kidneys are working less than 15% of normal and are no longer able to keep functioning to the level needed to survive. Therefore, if a

renal transplant is not an option, dialysis is the alternative RRT. Although dialysis can be used as temporary treatment option for inpatient care, most dialysis patients require treatments several times a week for the rest of their life.

Peritoneal dialysis (PD) and HD are two different types of RRTs for ESRD patients. Deciding between these two dialysis treatments involves the collaboration between the patient and the healthcare professional. In PD, blood is filtered inside the body at the peritoneal membrane, located in the abdomen. This requires a catheter incursion into the abdominal cavity where dialysate is introduced to allow blood to be filtered across the peritoneum (semipermeable membrane). Although CKD is irreversible and renal function continues to deteriorate over time, the kidneys continue filtering blood (at their own capacity) with PD treatment. This is a more natural blood filtration process and thus is the ideal method for initial dialysis. PD also allows the patients to perform dialysis independently and while travelling because treatment supplies can be packed in a vehicle. In most cases the PD process loses its effectiveness over time and complications arise (e.g., access point infection). Eventually the PD patients must switch to HD as their permanent form of RRT.

The HD process involves filtering of the blood externally into a machine called the dialyzer. The blood from the patient and a solution called dialysate enter the dialyzer in opposite directions for reverse osmosis to occur. This counter current flow allows maximum concentration gradient of solutes across the semipermeable membrane, increasing the dialysis efficiency. Fluid removal is controlled by creating a pressure gradient in the dialysate compartment (hydrostatic pressure). HD has three primary access points, all of which require surgical procedures: 1) central venous catheter (CVC); 2) arteriovenous fistula (AVF) or; 3) arteriovenous graft (AVG). The CVC is inserted in the chest and gains access to a large vein

(i.e., vena cava) to allow for a high blood flow. An AVF involves joining of an artery and vein (usually in the arm) and bypassing smaller blood vessels to promote high blood flow. Two needles are then inserted into the fistula to draw and return blood. AVG's are similar to AVF's except they use an artificial vessel to join the artery and vein. Grafts are used as an alternative to fistulas when a patient's vasculature does not permit or develop into a suitable fistula.

Dialysis can be performed in-centre (hospital or satellite location) or at home, each offering a distinct experience for the patient. Various factors such as a patient's health status and level of support are considered when determining the location for dialysis treatment. HD remains the most prevalent type of dialysis in Canada, particularly at the in-centre locations at 79% (Ontario Renal Network, 2011). Although HD can be done at home, the majority of treatments still occur in a hospital setting. When HD is employed, HHD proves to be the superior modality choice because of the frequency of treatments and the convenience of a flexible schedule. The reason why HHD has not become the dominant dialysis modality is because of the barriers that deter patients from choosing this treatment method. According to Agar, Hawley, and Kerr (2011) most HHD barriers are perceived and relative, rather than real and absolute. These perceived barriers are generally why patients are restricted to in-centre HD. Limiting these barriers will open doors for patients to choose their preferred RRT modality and ultimately provide an improved dialysis experience.

Section 1.05

Reflective Experience

Dialysis has been an area of interest for many years. In 2011, I was a volunteer at the Lakeridge Health Whitby in-centre HD clinic. As a volunteer I would chat with patients in the

waiting room, assist them on the weigh scale and help them to their chairs. Awaiting their connection to the dialyzer I would fetch warm blankets, ice chips or pillows for patients that had established stringent routines. Above all I was there to socialize and engage in friendly conversation. Little did I know that most patients would open up to me about their dialysis experiences. I quickly became a trusting ear for them to share their views about the clinic, healthcare professionals, other patients, and life in general. It was fascinating to see how excited they were to speak with me on a weekly basis and how much they wanted to share. I saw the impact of such a strict regimen and the strain that three in-centre treatments had on their lives. This exposure stimulated my inquiry to investigate the HHD patient experience. I wanted to see both sides of the fence and developed a genuine interest in dialysis. Creswell (2003) suggests that there is undoubtedly a strong personal stimulus to pursue topics that are of personal interest related to marginalized people and an interest in creating a better society for them and everyone. This accurately depicts my rationale in choosing to focus my research on dialysis. Although my experience as a dialysis volunteer initiated my curiosity and provided me with an understanding of the in-centre HD clinic, I felt it was necessary to observe the HHD patient journey. Therefore I attended three observation days: two days at the independent dialysis clinic; and one day at an independent dialysis education session. These observation reports can be found in (Appendix J) and are discussed later in *section 3.04*.

Section 1.06

Theoretical Framework: Health Belief Model

The Health Belief Model (HBM) was chosen as the theoretical framework for this study. Originally, the model was designed to explore why people didn't utilize preventative health

services and screening programs. It was first introduced introduced in the 1950's by social psychologists to understand screening programs for Tuberculosis. The failure of large numbers of eligible adults to participate in Tuberculosis screening programs triggered the inquiry to illuminate those factors that were facilitating or inhibiting positive responses (Rosenstock & Strecher, 1997). In 1974 the HBM received a comprehensive review and was modified to understand why individuals choose to engage in a health related action or not. In more recent years the model has been used to predict more general health behaviors and how patients respond to symptoms of disease. The HBM postulates that individuals are likely to perform preventive health behaviors if they perceive the existence of a threat to their health (Wiebe & Christensen, 1997). The approach encompasses the belief in a personal threat combined with the belief in the effectiveness of a proposed behaviour to predict the likelihood of that behaviour. Therefore an individual's compliance to a health action is based on their perception of the outcome.

The HBM is a well-established theoretical framework that has been used for more than sixty years. It continues to be used in health research to examine an individual's perception of their own health. "It is entirely consistent with the HBM that interventions will be more effective if they address a person's specific perceptions about susceptibility, benefits, barriers, and self-efficacy" (Champion & Skinner, 2008, p. 57). To better understand the behavioural response to treatment one must understand how the experience is perceived by the patients. More specifically it is important to identify common benefits and barriers that exist for HHD patients. The constructs that make up the HBM (see Table 1 in *section 2.05*) include perceived benefits and perceived barriers and align with the purpose of this study.

Section 1.07

Community Based Hospital Dialysis Programs

The community based hospital situated in Eastern Ontario comprises of an in-centre HD program and an independent dialysis program offering both PD and HHD modalities:

In-Centre HD

In-centre HD occurs at two sites within the community based hospital where patients are scheduled to receive routine treatment three times a week: Monday, Wednesday, and Friday or Tuesday, Thursday, and Saturday. A total of 138 patients receive HD daily. Patients arrive before their scheduled times and sit in the waiting room until their nurse calls them to be weighed. The patients each have their own target weight and are weighed prior to treatment so the nurse can determine how much fluid should be removed from the blood for that particular treatment. Once the patients are successfully connected to the dialyzer some may choose to sleep while others are occupied with television, reading, or other routines. The patients are closely monitored by the nurses and are not required to perform any self-care of their own. Various healthcare professionals (physician, pharmacist, and dietician) also visit the patients during treatment to discuss health matters. These prearranged consultations allow the healthcare professionals to collaborate and make the appropriate changes to each patient's disease management.

Independent Dialysis

The community based hospital offers independent (at home) HHD and PD to their patients. When a new dialysis patient attends their pre-dialysis education session they are presented with both modalities. A healthcare professional (typically a nurse) provides

educational materials detailing the differences between HD and PD. The patient is usually accompanied by a family member or friend who will act as their primary caregiver and/or support person. Once the RRT decision is made, the patient and caregiver begin dialysis training for approximately six to eight weeks. Patients who perform HHD have the option of a short daily treatment schedule (five to six days a week) or nocturnal treatment schedule (five to six nights a week during sleep). Once established at home the patients are still required to return to the clinic. They are expected to follow-up every eight weeks for a full assessment from the interdisciplinary team consisting of a nurse, dietician, pharmacist and physician. HHD patients are also required to submit their blood work on a monthly basis. The blood tests can either be dropped off in person or results can be sent directly from the laboratory. Prequalified patients may also call or email the clinic a “report card”. In some cases the lab technician, whom services their dialysis machine monthly, can bring back their blood tests to the clinic. The patients have several options, and choose whichever one is more convenient for them. This study will focus on the HHD population from the community based hospital.

Section 1.08

Current Developments

The Ontario Renal Network (ORN) is a provincial leader for managing and delivering renal services across Ontario. They have developed a strategic plan called the Ontario Renal Plan to reduce the burden of CKD and improve the quality of care and treatment. Specific priorities for independent dialysis are to provide standardized, easy-to-understand education; adequate support for patients to carry out their decision; and minimize attrition rates (ORN, 2014). The ORN has set targets to be achieved by 2015:

- 40% of all new dialysis patients will be on an independent dialysis option within 6 months of initiating dialysis. (ORN, 2014)
- 100% of dialysis patients seen in a pre-dialysis clinic for at least one year will have been assessed for independent modalities before starting dialysis (ORN, 2014)

The ORN (2014) recognizes an opportunity to enhance autonomy, quality of life, and outcomes for patients with CKD, while reducing costs to the overall healthcare system through increased uptake of independent dialysis. This study explores the experiences of HHD patients with a focus on identifying common benefits and barriers. This qualitative research will provide contextual insight to support the objectives of the Ontario Renal Plan. Results from this study will create opportunity for the ORN to expand on their strategic plans.

Chapter 2: Literature Review

Section 2.01

Introduction

A critical analysis of multiple peer-reviewed articles and grey literature provided informative knowledge to help shape this study. The purpose of the literature review is to consider current findings for this particular topic and to report relevant experimental and observational works. This chapter begins by defining the search process and lists key words used in the search. The literature review is organized by content and presents available evidence based on the search parameters. Gaps in the literature will be identified followed by a theoretical framework review and a summary of major findings.

Section 2.02

Search Process

The majority of research papers were found using the University of Ontario Institute of Technology (UOIT) Library, PubMed and Pro Quest search engines. Original key words used to search in the databases were as follows: “dialysis”; “hemodialysis”; “home hemodialysis”; “patient experience”; “benefits”; “barriers”; “challenges”; “renal replacement therapy”; “qualitative” or a combination of these were searched by using Boolean operators (AND/OR).

A variety of studies were included (i.e., prospective and retrospective cohort studies, sociological studies and epidemiological studies). Government and association websites (i.e., Health Canada, Ontario Renal Network, and Lakeridge Health) provided information on current policy, developments, and surveillance reports.

Publications over ten years old were excluded unless they were useful in defining terms or concepts, or presented meaningful background information. Therefore publication dates ranged from 1984-2014. Many of the older articles were critical reviews of the Health Belief Model (HBM) framework and more current literature focused on home hemodialysis (HHD) cohorts.

Section 2.03

Literature Review

This review provides an in-depth analysis of current literature and has been organized into four themes:

- Modality Selection & Setting
- Cost analysis
- Benefits
- Barriers

Modality Selection & Setting

While investigating the different types of dialysis modalities it is clear that hemodialysis (HD) is the most commonly used renal replacement therapy (RRT). “HD is virtually always used as initial therapy when patients present with acutely discovered chronic kidney disease (CKD), primarily because of the availability and suitability of the central venous catheter for immediate HD access” (Holly & Sinnakirouchenan, 2011, p. 429). Patients that require immediate dialysis treatment generally do not have extensive knowledge of the various modalities and therefore are unable to make an informed decision. In this case the physician generally makes the initial

modality decision for them. Physicians choose HD because of the vascular access options and the relative simplicity of their surgeries for earlier treatment. Patients unsure about the type of modality they wish to use can receive in-center HD while deciding on long-term RRT (i.e., peritoneal dialysis [PD], in-centre HD or HHD).

Initial therapy choice is important, but not as significant as the long-term treatment plan. Once selected, dialysis usually lasts for the duration of one's life and therefore it is important to determine which setting best suits each patient. A 2010 study focused on 'end-of-life decisions' (referring to RRT modality decisions) for end stage renal disease (ESRD) patients. Davison (2010) found that although patients want to primarily involve family and friends in end-of-life discussions, nephrologists and family physicians are considered integral to the process, and a substantial proportion of patients reported that they would rely on their nephrologist to make medical decisions on their behalf should they become incompetent to make decisions for themselves. Davison (2010) found that many elderly patients in this study seek support from their family and their physician when choosing a long-term modality. Hines, Glover, Holley, Babrow, Badzek and Moss (1999) conducted face-to-face interviews with 400 HD patients in community based dialysis units. The study examined HD patients' preference for involving physicians and family members in advanced care planning. Among the 400 HD patients, 36% wanted to include a physician, 91% wanted to include their caregiver and 88% wanted to include additional family members (Hines et al., 1999). This suggests that patients prefer family members to be involved in the decision making process, especially their caregiver. Henriques, Anes and Sardo (2014) focus on 29 HD patients empowerment and assess the importance of the learning experience using a survey. This cross sectional study concluded that healthcare educators have an extraordinary role by redirecting and focusing their energies on assessing

individual learning styles, motivation, relative past experiences, level of engagement, and willingness to apply the learning (Henriques et al., 2014). HHD enables self-care dialysis and puts the patient in control of their treatments which requires proper education.

The purpose of CKD education is to provide an informed transition to RRT and to help patients cope with barriers associated with starting a form of RRT. After receiving CKD education, patients are more likely to identify advantages of self-care dialysis (autonomy and lifestyle benefits) (Rioux, Cheema, Bargman, Watson, & Chan, 2011, p. 802).

Education helps patients realize the advantages to HHD and collaboration between the educator and learner will maximize long-term success with this independent modality.

Focusing on in-center HD, current literature suggests that patients adopting this type of RRT share similarities such as age, comorbidities (the co-occurrence of two or more chronic conditions) and lack of caregiver support. Generally, it is the older ESRD population who require in-center HD as it provides high level acuity for patients with multiple comorbidities who require on-site medical and nephrology care (Agar et al., 2011). In a hospital environment the nurses do all the work for the patient. They record weights, prepare the dialyzer and supplies, acquire vascular access, closely monitor the patient and disconnected them after treatment. Everything is done for the patients from start to finish. This conventional in-centre HD is the dominant form of RRT in North America (Cafazzo, Leonard, Easty, Rossos, & Chan, 2009). Patients are required to travel to the hospital for conventional in-centre HD three times a week. According to Cafazzo et al. (2011) this type of care is the most expensive, has the poorest environment and uses a rigid schedule. Conventional HD patients following this strict weekly schedule must arrange their own

transportation to and from the hospital. The costs and quality of life associated with in-centre HD will be discussed later in the literature review.

Generally, older patients have more comorbidity, both physical and cognitive, which decreases their ability to self-manage. As older patients predominantly receive in-centre HD, patients adopting independent dialysis tend to be younger (Rioux et al., 2011). It may be argued that younger healthier patients are able to perform dialysis at home while elderly patients with more comorbidity are best suited for in-centre HD. “Additional support was required for patients choosing in-center HD, which may be a marker of frailty rather than a direct reflection of choice of renal replacement modality” (Rioux et al., 2011, p. 802). This marker helps explain why in-center HD continues to be the leading RRT since the implementation of independent dialysis modalities in the late 1970’s. Further research is required to measure the impact of comorbidities on modality selection.

Home dialysis or independent dialysis is currently being promoted as the superior RRT however; HHD remains the least prevalent modality according to the ORN (2011). This contradicts what 105 pre-dialysis patients and 73 caregivers would actually prefer from a 2012 five month prospective study: “When patients and caregivers are given comprehensive pre-dialysis education and a choice, a much greater proportion of patients would choose a home-based modality” (Morton, Snelling, Webster, Rose, Materson, Johnson & Howard, 2012, p. 109). Given the option more patients chose HHD as their preferred modality, as did their caregiver. “Home-based dialysis (either peritoneal or home hemodialysis) was chosen by patients in 65% of choice sets; in-centre dialysis, in 35%; and conservative care, in 10%. For caregivers, this was 72%, 25%, and 3%, respectively” (Morton et al., 2012, p. 102). The caregivers supported home dialysis because it would enable the entire family to travel with minimal restriction. Both the

patient and the caregiver did not want to commit to the rigid in-centre schedule. These results represent preference rather than actual choice and whether patients ended up with their preferred modality is unknown. The patient-caregiver relationship is important for successful HHD and will be discussed further in the barriers section of this review.

Overall, current findings indicate that HHD offers more flexibility, autonomy and privacy for patients. HHD provides the opportunity for more frequent and/or longer dialysis sessions than would otherwise be for in-centre HD (Mowatt, Vale, & Macleod, 2004). Patients are not restricted to a rigid weekly schedule and can undergo dialysis daily, allowing their blood to be filtered more often. Standardized pre-dialysis education is fundamental for increasing the patient's success by elevating self-efficacy. "Self-efficacy involves the perceived likelihood that one can personally perform the preventive behavior successfully and experience expected positive outcomes" (Fisher & Fisher, 2000, p. 6). The preventative behaviour in this case is independent dialysis. Increasing a patient's perceived self-efficacy in performing HHD will in turn increase attrition rates and promote the uptake of independent dialysis (a priority in the Ontario Renal Plan). When patients receive sufficient HHD education they develop the confidence to take on this home-based therapy. An adequately resourced dialysis education program is an essential requisite for CKD patients who need to make choices about their treatment and their new lifestyle (Henriques et al., 2014).

HHD is not restricted to daytime/conventional treatments, as a more intensive type of HHD has emerged. Nocturnal home hemodialysis (NHHD) was developed in Toronto in 1993 at the Humber River Hospital and is the world's first and largest program (McFarlane, Bayoumi, Pierratos, & Redelmeier, 2003). Patients place themselves on dialysis at night, receive treatment while they sleep, and disconnect themselves the following morning. A typical NHHD treatment

lasts 6 to 8 hours, and is performed 5 to 7 nights a week. This modality allows patients to receive more frequent treatments which results in more controlled fluid and waste reduction from the blood compared to conventional HD. As outlined in the benefits review below, NHHD improves patient's overall health compared to in-centre HD.

Cost Analysis

It is important to understand that all forms of dialysis are expensive but HHD is a more cost efficient modality choice than in-centre. "In-center HD, the most common dialysis modality in North America, costs between \$60,000 CAD and \$95,000 CAD annually per patient. Hospital-based treatments are generally more expensive than home-based treatments (\$88,585 CAD for in-center hemodialysis vs. \$26,048 CAD for home conventional hemodialysis)" (McFarlane et al., 2003, p. 1004). This study shows that moving dialysis into the home can cut over \$60,000 each year per patient. Considering there are over 23,000 patients receiving HD in Canada there is a significant monetary incentive to increase the uptake of independent dialysis and cost savings will be more marked over time. The annual growth rate in the incidence and prevalence of dialysis is considerable and will present a growing challenge to the healthcare system (Quinn, Laupacis, Hux, Moineddin, Paterson & Oliver, 2009).

As the prevalence of dialysis patients continues to rise finding ways to control costs associated with dialysis is paramount. Increasing the proportion of HHD among ESRD patients proves to be a viable opportunity for controlling these costs. Since ESRD poses a hefty financial burden on healthcare systems, appropriate ESRD management, either by a conservative approach or the most appropriate RRT modality, will have a major impact on available healthcare

resources (Somma, Trillini, Kasa & Gentile, 2013). Determining cost-effective strategies for treating the ESRD population may contribute to the sustainability of the healthcare system.

According to Zhang et al. (2010) HHD is a cost-effective RRT and is associated with better quality of life in patients with ESRD. McFarlane, Pierratos and Redelmeier (2002) conducted a one-year descriptive costing study at two centers in Toronto, Ontario and found cost savings in staffing, overhead and support, admissions and procedures. These savings overcame the cost increases for direct HD materials, laboratory tests, imaging, and the cost of depreciable items at home (McFarlane et al., 2002). Cost reductions were primarily driven by a lower requirement for nursing staff. These findings suggest that HHD may also help alleviate the pressure of nursing shortages, however this requires further investigation.

Literature consistently demonstrates that costs associated with home-based dialysis are lower than in-centre dialysis. Moreover, the Toronto experience (Humber River Hospital) determines lower costs associated with NHHD than in-center HD (\$56,394 CAD vs. \$68,935 CAD) despite the more frequent and intensive treatments (McFarlane et al., 2003). One would assume that a more intensive form of dialysis to be the more costly option, however the costs associated with hospital HD remains the highest of all options. “Total health care costs for the home nocturnal hemodialysis group compared to the in-center hemodialysis group were significantly lower” (McFarlane et al., 2003, p. 1008). Numerous findings are consistent with these results and reveal that in-centre HD is by far the most costly form of RRT. However these studies focused primarily on running costs of each program. HHD and NHHD are not available for everyone and programs have not been established universally. According to McFarlane and Komenda (2011) these programs are expensive and require adequate funding and resources for start-up:

Up-front capital costs remain a significant barrier to starting programs. Dialysis programs that find the reduced operating costs to be attractive may not be able to afford the start-up costs of a new home HD program, or the marginal capital cost as the program grows.

(p.683)

A financial plan must be in place to allow HHD programs to succeed before they are launched. Still, many dialysis facilities cannot afford the start-up costs for a new HHD program and therefore continue running the in-centre care instead.

Benefits

ESRD is an irreversible chronic disease and is associated with poor quality of life and specifically dialysis patients report a strikingly poor quality of life, making it among the worst for any chronic medical condition (McFarlane & Komenda, 2011). ESRD decreases a person's length and quality of life and different forms of treatment for ESRD offer particular benefits that lead to different levels of quality of life. For example, according to McFarlane et al. (2003) HHD and kidney transplantation have been associated with a higher quality of life than in-center HD. This section will report the benefits associated with home-based dialysis.

The importance of pre-dialysis education to increase the uptake of independent dialysis was discussed earlier in this review. We revisit this discussion with a quality of life and clinical outcome focus. Woods, Port, Stannard, Blagg, and Held (1996) performed a prospective study over one year with 4,892 RRT patients to explain how independent dialysis is linked to and improved patient experience:

Independence is best encouraged by allowing patients to take responsibility for their own well-being. This is maximized by training patients to perform self-care HD at home. We

would speculate that home dialysis removes patients from the dialysis center where nurses and physicians tend to create dependence, and where the presence of other patients with serious medical problems lead them to develop an image of themselves as ill. As a result of doing their own dialysis, HHD patients may become more knowledgeable about their illness and treatment and so are more likely to receive adequate dialysis and therefore live longer than patients dialyzing in a center (p. 1470).

The responsibility of managing HHD gives the patient's autonomy; however Woods et al. (1996) can only speculate that removing patients from the in-centre environment is beneficial.

Associating HHD with living longer is a bold statement, however Woods et al. (1996) statistically support this relationship as those patients with evidence of training for self-care HD had a 22% reduction in the risk of death after adjustment for the effects of age, sex, race and diabetes as a cause of ESRD. HHD therefore shows an association in reduced mortality risk.

More recent studies have also confirmed that independent dialysis increases survival rates. Rioux et al. (2011), investigated time of death since dialysis initiation (in years) in patients treated with independent dialysis (PD and HHD) and in-center HD. In this retrospective observational cohort study lower death rates were found when patients began dialysis at home. Independent dialysis is associated with long-term health benefits and therefore, HHD and PD are grouped as the superior RRTs.

Research also focused on evaluating cannulation (needling) strategies for improving the dialysis experience for patients. Verhallen, Kooistra, and van Jaarsveld (2007) prospectively examined 33 HD patients with arteriovenous fistula (AVF) using rope-ladder¹ and button-hole²

¹ Cannulation sites are rotated along the length of the vascular access.

² Needles inserted into exact same site.

techniques. They found that adequate vascular access is an essential factor in successful HD and the button-hole method contributes to cannulation ease, thus improving the quality of life of self-cannulating patients. A similar study by van Loon, Goovaerts, Kessels, van der Sande and Tordoir (2009) compared 75 HD patients using the button-hole technique with 70 patients using the rope-ladder technique and found that the button-hole method is a valuable technique with fewer complications such as haematomas, aneurysm formation and the need for interventions. The literature suggests that the button-hole technique is most beneficial for self-cannulating patients with AVF access.

More modern research has shifted to the benefits and clinical outcomes of HHD, and specifically the benefits of NHHD. McFarlane et al. (2003) conducted a one year prospective study at two dialysis centres in Toronto, ON – *St. Michael's Hospital* and *Humber River Hospital*. A total of 30 NHHD patients and 20 in-centre HD matched cohorts were included by the end of the study period. Results showed improved clinical outcomes for patients using NHHD modality and identified the benefits of more frequent therapy. NHHD was associated with improved biochemistry (balanced blood chemistry), blood pressure, cardiac function, and sleep patterns (McFarlane et al., 2003). A more recent study also found that NHHD improves cardiovascular health, sleep quality, and eliminates the need for dietary restrictions (Cafazzo et al., 2009). Strict diets are part of ESRD management however, NHHD is a more frequent and intense form of dialysis which can reduce or eliminate dietary restrictions. There is consistency in findings associating improved clinical outcomes with NHHD compared to short daily HD.

Now that we have explored the practical benefits of HHD we shift to literature focusing on the benefits from a patient perspective. A qualitative study by Morton, Devitt, Howard, Anderson, Snelling and Cass (2010) used thematic synthesis of patient views about RRT. The 90

participant study included in-centre HD, HHD, PD and transplant patients. From the data collected in the semi-structured interviews, Morton et. al (2010) concluded that patients preferred RRTs that enhanced their freedom and autonomy and were convenient, effective, and simple. Again these emerging themes were devised from patients using different types of RRTs. These findings suggest that patients prefer an independent modality treatment (PD or HHD) over in-centre HD. According to Morton et. al (2010) the participants prefer a modality which embodies particular characteristics that minimize impact on their lifestyle. Now that we have covered the benefits of HHD, both actual and perceived, we look at the barriers associated with this home RRT.

Barriers

The terms ‘barriers’ and ‘challenges’ were both key search words utilized for reviewing current literature. Several articles provided a thematic analysis of the barriers that surfaced within their data. Articles that looked at both the benefits and barriers associated with independent dialysis sometimes discussed the relation between them.

According to Thodis and Oreopoulos (2011) the major barriers to HHD were patients disinterest and lack of family support. Although these were not the only barriers to keep patients using conventional in-centre HD, they were the most recurrent. Zhang et al. (2010) conducted an observational cohort study examined 486 patients with CKD attending the University Health Network in Toronto for renal management between 2001 and 2007. Zhang, et al. (2010) found the majority of these patients (61%) transitioned to a home-based modality for their RRT and the remaining 39% of the patients transitioned to an in-centre location:

Among the patients who did not choose home dialysis, patients' and their families' disinterest in home dialysis (25.4%) and lack of social support (12.1%) constituted the main barriers to home dialysis adoption. Inadequate space for home dialysis (5%), communication barrier (5%) and inability to perform their own dialysis (3%) represented other perceived barriers. In addition, 11% had a medical contraindication for home dialysis (p. 761).

If patients are not interested in changing their dialysis routine then clearly they will not be inclined to change modalities. Ultimately, the patients must be willing to make the change and actually want to adopt a home-based RRT. The majority of disinterested patients were single men and Zhang, et al. (2010) found that the lack of interest of these patients may imply that additional resources and innovative strategies are required to empower patients who otherwise perceived a lack of confidence toward HHD. This lack of confidence in self-care otherwise known as low self-efficacy is a very common barrier. The disproportion of single men did not want the added workload at home and felt more comfortable in the hospital setting. They also enjoyed socializing with people that were in the same situation (receiving dialysis). Patient lack of interest to adopt independent dialysis requires more in-depth research to better understand the underlying factors. It should also be noted that the barriers identified by Zhang et al. (2010) were not specified as perceived barriers or actual barriers and were only generalized as barriers.

Many patients feel they are not capable of HHD and are afraid to lose the hospital support, especially for unexpected situations (Cafazzo et al., 2009). Many patients who are not capable of performing HHD independently lack caregiver support and therefore are restricted to in-centre care. Even if there is support at home for the patient, the willingness and availability of the caregiver must be taken into account. "Home dialysis can place considerable ongoing

emotional and financial burdens on caregivers, particularly if they are unable to maintain employment” (Morton et al., 2012, p. 103). The caregiver may feel burdened by the added workload and have schedules that conflict with their new role. Home dialysis must be a collective decision between patient, caregiver and physician to ensure lasting success at home.

There are number of barriers linked to self-care dialysis, but more research has been aimed at increasing the uptake of HHD and overcoming the barriers. Mclaughlin et al. (2003) concluded that changing behavior, in this case, switching from in-center HD to self-care dialysis, requires changing knowledge, attitudes, and then skills. Overcoming these challenges one step at a time will allow more patients to be eligible, eager, and capable for HHD (Mclaughlin et al., 2003). This may also be true for new dialysis patients. In fact, HHD training occurs in-centre for approximately six to eight weeks where these patients undergo HD treatment with the support of a nurse in a hospital environment. During this transitional phase, the patient and caregiver are educated by the nurse and learn how to conduct their own dialysis treatments at home.

Since HHD (especially NHHH) shows improved clinical outcomes and improved quality of life, the barriers must be well understood so that more patients feel comfortable changing modalities. The longer patients remain on conventional in-centre HD, the less likely they are to adopt independent dialysis (Cafazzo et al., 2009). Barriers must be eliminated early in RRT so patients are more likely to embrace the opportunity to use a home-based modality. Limiting the barriers associated with independent dialysis means a greater proportion of patients can adopt this modality and succeed. However not all patients qualify for HHD, especially ones with comorbidities. An inverse relationship between additional comorbidities and quality of life was identified. The more comorbid conditions a patient has the poorer their quality of life may be (Boateng & East, 2011). One individual’s health status will vary from another’s because of the

complexity and various complications related to ESRD. Therefore, physicians must treat each case uniquely to determine the best treatment option for each individual. There is no simple ‘yes’ or ‘no’ answer to the question of which dialysis modality promises a better quality of life. Each one of the modalities should not be considered as a stand-alone treatment but as an integrated approach to treating ESRD (Boateng & East, 2011).

The specific barriers associated with NHHD were investigated and presented very similar findings. In the Cafazzo et al. (2009) study a cross-sectional survey, study-specific questions, and ethnographic interviews were used to determine patient perceive barriers. 56 NHHD patients and 153 conventional (in-centre) HD patients were included in the survey. This mixed method approach focused on identifying barriers associated with the adoption of NHHD. The main themes identified in the qualitative components were burden on family members, fear of self-cannulation, fear of a catastrophic event, and low self-efficacy (Cafazzo et al., 2009). Family members (or caregivers) might be fearful when presented with this complex home therapy. Fear of self-cannulation was perhaps the most common perceived barrier. This fear included more than just the perception of pain, but also the potential occurrence of mishaps and complications. Patients also expressed a fear of life-threatening events associated with NHHD. When there is no nursing support patients assume there is a loss of safety, and worry that if something went wrong they would lack the ability to fix the problem. Overall patients felt they were not capable of HHD and were afraid to lose the hospital support especially for unexpected situations. This lack of confidence in self-care otherwise known as low self-efficacy is a very common barrier. Since NHHD shows improved clinical outcomes and quality of life, these barriers must be well understood so that more patients feel comfortable changing modalities. Patient’s perceived

barriers must be eliminated early in RRT adoption so patients are more likely to embrace the opportunity to use a home-based modality.

Section 2.04

Gaps in Literature

Limited studies have determined the willingness of conventional HD patients to convert to any form of HHD. Optimal strategies to teach and learn about NHD and self-cannulation have not been studied and a gap exists with specific home-based supportive care issues. These include supply management, plumbing issues, troubleshooting support, equipment maintenance and the impact of caregiver emotional support. Patient preferred vascular access requires further clarification while also considering the risk-benefit ratio (e.g., infection rates). Understanding the patient's dialysis experience qualitatively was never thoroughly assessed and most studies drew results from surveys and various quality of life tools (i.e., WHO quality of life questionnaire [WHOQOL-BREF]; kidney disease quality of life; Spitzer QL-index; Euro QoL [EQ-5D]). There was limited control in observational studies which failed to reveal direct cause-effect relationships. Random allocation of patients was another challenge because of ethical issues. The majority of researchers mentioned that data was sometimes difficult to collect because of the busy lives of patients, caregivers and healthcare professionals; however this is not a gap but rather a limitation worth noting.

All of the longitudinal studies only used a sample cohort from a single renal program and results may not be a strong representation of the entire dialysis population as patients may have varying experiences in different regions. Many studies reviewed were performed in Toronto, Ontario where the population resides in an urban setting and have easy access to public

transportation to various dialysis clinics. Several studies were performed at the Humber River Hospital Nephrology Program, which is a world-renowned dialysis centre and is one of Toronto's largest dialysis programs. Many of these studies focused on the clinical benefits and the quality of life for patients using NHHD. With all the previous research stemming from a Toronto based hospital it is surprising there have been no studies focusing on the HHD population from the community based hospital in the Durham Region. This community based hospital serves a mix of urban and rural residents in a large geographic area. This study will be the first of its kind to explore the HHD experience within the Central East Local Health Integration Network, specifically in the Durham Region.

Among the reviewed studies only two -- Wiebe and Christensen (1997) and Cafazzo et al (2009) -- utilized the HBM as their theoretical framework to apply to their dialysis based studies. Other studies did not apply any theoretical framework which suggests the HBM is most utilized in dialysis research. Wiebe and Christensen (1997) recruited 70 in-centre HD patients and performed a hierarchical regression analysis to assess four perceived constructs of the HBM: susceptibility; severity; benefits; and barriers (see Table 1). These authors also suggest the need for a reliable, valid and standardized measure for HBM constructs in the dialysis context and thus conclude that the lack of standard measure limits the generalizability of their results. This thesis utilizes the HBM constructs as a means for coding data and grouping themes. Therefore low generalizability is not a limitation for this study. Cafazzo et al (2009) used a mixed method approach to identify barriers for NHHD adoption and offers a detailed discussion on emerging barriers however only uses the perceived barriers and self-efficacy constructs from the HBM.

Section 2.05

Theoretical Framework: Health Belief Model

Since its establishment in the 1950's numerous articles have analyzed the HBM to measure its 1974 transformation. In a systematic review, Janz and Becker (1984) explored 46 studies that used the HBM and found that prior to 1974 it appeared that perceived susceptibility was the most powerful dimension of the HBM and few of these studies attempted to measure perceived barriers. Studies conducted post-1974; perceived barriers yielded the highest significance to the HBM (Janz & Becker 1984). The shift of significance from perceived susceptibility to perceived barriers remains consistent in today's HBM framework. More emphasis is now aimed at understanding and reducing the barriers to a health related action rather than the susceptibility of acquiring the disease or condition.

Health Belief Model Constructs

The HBM consists of six fundamental constructs. A study by Austin, Ahmad, McNally and Stewart (2002) defines these constructs and outlines the application in practice for each (see Table 1). Self-efficacy was only added to the HBM in 1988 to help increase its explanatory power. According to Fisher and Fisher (2000) self-efficacy involves the perceived likelihood that one can personally perform the preventive behavior successfully and experience expected positive outcomes. To promote higher self-efficacy one must develop confidence in their ability to perform a health action. This can be acquired through proper education and training for the desired action. While these constructs are viewed as the primary determinants of health behaviour, demographic, sociological, psychological and structural variables can affect each construct and thus indirectly affect an individual's conscious decision.

Table 1		
Health Belief Model		
Constructs	Definition	Application
Perceived susceptibility	One's opinion of chances of getting a condition	Define populations(s) at risk, risk levels; personalize risk based on a person's features or behavior; heighten perceived susceptibility if too low
Perceived severity	One's opinion of how serious a condition and its sequel are	Specify consequences of the risk and the condition
Perceived benefits	One's opinion of the efficacy of the advised action to reduce risk or seriousness or impact	Define action to take; how, where, when; clarify the positive effects to be expected
Perceived barriers	One's opinion of the tangible and psychological costs of the advised action	Identify and reduce barriers through reassurance, incentives, assistance
Cues to action	Strategies to activate readiness	Provide knowledge, education, promote awareness, reminders
Self-efficacy	Confidence in one's ability to take action	Provide training, guidance in performing action

Table 1 Health Belief Model (Austin et al., 2002, p.124)

Health Belief Model Limitations

The HBM, the grandparent of all health behavior change models, has been accepted uncritically by many health researchers and probably has been used more than any other health behavior change model over the past decades (Fisher & Fisher, 2000). However there does appear to be some limitations with this prevailing theoretical framework. Wiebe and Christensen (1997) suggest there is a need to refine and standardize the tools used to measure the HBM components. According to Wiebe and Christensen (1997) the lack of consistency in the measurement tools reduces the reliability and validity of the HBM. These authors also discuss

how the scope of the constructs is too limited to fully explain the complex problem of non-adherence. Cummings, Jette and Rosenstock (1987) suggest that the HBM does not presuppose or imply any specific strategy for change, but knowledge of the problem is a necessary step in developing a rational and an effective solution.

There are many factors that may directly or indirectly influence an individual's health action and therefore makes it very difficult to quantify reason and predict the outcome. Christensen, Benotsch and Smith (1997) note that such a purely cognitive model not only assumes perfect rationality on the part of the patient, but also a close link between intentions and adherence behavior. With their research focusing to the adherence in renal dialysis regimens Christensen et al. (1997) found that neither of these conditions may necessarily hold true, especially with a very demanding self-care regimen with dialysis.

Theoretical Framework Justification

As mentioned in *section 2.04* only two articles in the literature review applied the HBM to their studies. Wiebe and Christensen (1997) used components of the HBM in their study assessing 70 in-centre HD patients in a hierarchical regression analysis to examine variance in weight gain associated with adherence to fluid restriction, diet and medication. This study incorporated the perceived severity construct from the HBM to associate with patient adherence. Cefazzo et al. (2009) used the HBM to develop an interview guide and then used the constructs to code data. The HBM was the only theoretical framework applied to dialysis research within the literature review. This thesis will use the constructs of the HBM to organize transcribed data for analysis. Since the HBM was the only theoretical framework discovered in the initial search process the principal investigator (PI) conducted a secondary search of various theoretical

frameworks to justify the HBM applicability. Two most notable theoretical frameworks were the Social Cognitive Theory (SCT) and the Self-Care Deficit Theory (SCDT). Both frameworks share similarities with the HBM; however upon further review the HBM was selected as the most appropriate model for this study.

As cited by Rosenstock, Strecher and Becker (1988) the SCT (previously labelled Social Learning Theory) was developed in 1941 by Miller and Dollard and used to observe an individual's behaviour based on social contexts. Before a person makes a choice to engage in a new behaviour they consider the past experiences of an individual choosing that same behaviour (Rosenstock et al., 1988). Both the HBM and SCT can be utilized to predict behavioural outcomes. Differences are found when comparing their constructs. According to Rosenstock et al. (1988) the SCT expectations about outcomes does not explicitly include costs or barriers nor does it focus on self-efficacy in its constructs. Since this study uses a thematic analysis approach, barriers and self-efficacy were considered valuable themes for discussion and therefore the HBM proved to be more relevant than the SCT which lacked these constructs.

As cited by Wilson, Mood, Risk and Kershaw (2003) the SCDT was first introduced in 1959 by Dorothea Orem and is frequently used to analyze patient self-care and offers nurses and other healthcare professionals a comprehensive conceptual framework for judging the appropriateness of the teaching materials they use. It has been used in rehabilitation and primary care settings where patient independence is encouraged. There are three major concepts within Orem's (1991) theory including the self-care agency (patient's ability to engage in self-care activities), basic conditioning factors (background and health status information), and therapeutic self-care demand (the sum total of activities needed to meet the requirements to self-care). Orem (1991) uses the term 'basic conditioning factors' to signify distinguishing features of individuals

and their environment to address those internal or external factors that affect one's capacity to care for self. This theoretical framework would be ideal for assessing independent dialysis education programs and the relationship to the number of patients choosing a home-based modality. Although this thesis touches on pre-dialysis education programs, the central focus remains to identify common benefits and barriers HHD patients face by interpreting their lived experience. The majority of studies that utilize the SCDT seek measurable quantitative data rather than the rich qualitative data collected in this study.

Section 2.06

Summary of Major Findings

There are a number of studies that investigate the various types of dialysis modalities. HD is the most prevalent modality in North America because of the simplicity of surgical access sites, whereas PD is more prevalent in other countries (i.e., China). Both modalities provide distinct benefits but further research is needed to compare their risk factors for patients requiring urgent unplanned dialysis. The NHHD method has been regarded as the most beneficial RRT and although is a more intense form of dialysis, it is still cheaper than in-centre HD. NHHD is linked to improve clinical outcomes (phosphate and potassium levels, blood pressure, cardiac function and sleep patterns) and quality of life. Performing dialysis at night gives patients more time during the day to live normal lives. All independent dialysis eliminates frequent travelling to the hospital and can be performed more frequently in a home environment by utilizing a flexible treatment schedule. Prospective studies before and after changing modalities should be employed in the future to support these findings.

Moving dialysis treatment to the home environment often requires the support of a caregiver. If a patient is willing to begin HHD, they might lack this support and are forced to continue with in-centre HD. The lack of a caregiver support is only one barrier that prevents the transition to HHD. The modality choice is not simply a reflection of an individual's psychosocial attributes, but rather a complex interplay between the patient's health state and the perceived benefits and barriers to adopting the chosen therapy (Cafazzo et al., 2009). Several qualitative studies mentioned "perceived barriers", "perceived benefits" or "self-efficacy" in their research. This was taken into consideration when selecting the HBM as the theoretical framework for this study. The HBM constructs outlined in Table 1 can exhibit HHD patient perspectives (perceived severity, perceived benefits, and perceived barriers) and confidence (self-efficacy). The HBM framework will help demonstrate how perception and knowledge play a role in personal responsibility.

According to Quinn et al. (2009) between 1998 and 2005, the average annual growth in the incident dialysis population was 4.9% while the growth in the prevalent dialysis population outpaced incidence, growing an average of 7.2%. The increasing number of elderly dialysis patients may result in fewer HHD candidates and an increased in-centre HD population. Literature shows that HHD (especially NHHD) is a cost-effective modality that offers benefits such as improved quality of life and clinical outcomes to the patient. There is a need to explore the benefits and identify current barriers as perceived by HHD patients. Reporting these benefits and barriers will provide insight into the patient experience using HHD. An in-depth qualitative study will provide information to highlight benefits and help overcome the challenges of HHD. Renal programs can then use these findings to develop improvement strategies for independent dialysis programs.

Chapter 3: Methodology

Section 3.01

Introduction

This qualitative research study examined home hemodialysis (HHD) patients from a community based hospital in Eastern Ontario. The objective was to examine the HHD experience and identify common benefits and barriers reported by the patients. As previously discussed the Health Belief Model (HBM) represents the theoretical framework. This well established framework has often been used in many qualitative studies for studying and promoting the uptake of health services by predicting a patient's health behaviour choice. However, the HBM will was not used to predict a specific behaviour but rather the constructs, perceived benefits and perceived barriers were utilized for a thematic analysis. The methodology was designed to allow patients to discuss the benefits and barriers of HHD while exploring their lived experience. Data collected was analyzed and organized into these predetermined constructs. This chapter begins identifying ethical considerations, followed by a discussion of the sample population, recruitment strategy, data collection process and the analytical approach.

Section 3.02

Ethical Consideration & Research Approval

This research involved human subjects and therefore the principal investigator (PI) required successful completion of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2: CORE) (Appendix B). Ethical approval was required and successfully granted from both the University of Ontario Institute of Technology (UOIT) Research Ethics Board (REB) (Appendix C) and the Lakeridge Health REB (Appendix D). The HHD observation sessions at the community based hospital were approved by Lakeridge Health

and the Ministry of Training Colleges and Universities. This study will not include the collection of sensitive retrospective data from the Lakeridge Health databases (i.e., access to patient health records). Once REB and administrative approvals were granted, a notification letter for the research study to commence was electronically emailed to the PI (Appendix D).

All participants involved in this study provided informed consent by reading or being read the Consent Form (Appendix E), initialing each page, printing their name, signing and dating the document. The interviews were audio recorded and participants printed their name, signed and dated the Consent Form for Sound Recordings (Appendix F). Participation was purely voluntary and participants could refuse to answer any question they wish, and could terminate the interview at any time. If the participants wished to withdraw from the study they were instructed to verbally inform the PI or provide a written notification to have their data withdrawn. A participant's decision to withdraw from the study will not affect their care at the community based hospital. Interviews were conducted in a private room between the PI and participants. The autonomy and confidentiality of the participants were of the utmost importance and protected at all times.

Section 3.03

Sample Population & Recruitment Strategy

Participants were recruited from a population of approximately 50 patients in the HHD program. The inclusion criteria for participation were current HHD patients from the community based hospital and had functional literacy in English. Participants were not excluded based on age, race, gender, or religion. Participant recruitment occurred at the community based hospital during Wednesday clinic days. Upon arrival to the clinic, patients had the opportunity to view a

Study Notification Poster (Appendix G) which briefly described elements of the study (who; what; when; where; and why). Multiple Study Notification Posters were posted around the HHD clinic. Recruitment took place on Wednesdays during regular clinic hours (8:00am-2:00pm). The registered nurses personally screened their patients and identified eligible patients for the study based on the inclusion criteria. The nurses also screened patients based on their cognitive ability. If they felt their patient would have difficulties participating in the interview, they did not introduce them to the PI. When the patients finished their consultations their nurse briefly explained the study to them and asked if they were interested in participating. Interested patients were then introduced to the PI who explained the research purpose and participation requirements using the Recruitment Letter/Verbal Script (Appendix H). All patients that were introduced to the PI chose to have the interview immediately in a private room. Participants were recruited until data saturation was acquired (no new themes or concepts evident in the data). Data analysis occurred concurrently with data collection and therefore the PI was able to determine when data saturation had been reached. According to Guest, Bunce and Johnson (2006) data saturation has become the gold standard by which samples sizes are determined in health science research.

Section 3.04

Data Collection

Observation Reports

Prior to the interviews the PI performed three observation reports (Appendix J) to become familiar with; a) the clinic environment; b) the HHD patient consulting process with various healthcare professionals and; c) the pre-dialysis education session. The first observation allowed the PI the opportunity to become acquainted with the clinic staff and become

comfortable in the setting where the interviews took place. On the second observation day, the PI observed a HHD patient consult with multiple healthcare professionals. This gave the PI first glimpse of the HHD patient experience. The third observation report occurred during a pre-dialysis education meeting between a healthcare professional, patient and their caregiver. There were no criteria in choosing this particular education session, and its purpose was to acquire a general understanding of the pre-dialysis experience. These observation reports increased the trustworthiness of the thesis (see *section 3.06*).

Interview Setting

The interviews all took place at the community based hospital where patients have regular clinic visits. According to Kvale (1996) it is important for the interviewer to establish an atmosphere in which the subject feels safe enough to talk freely about his or her experiences and feelings while maintaining a delicate balance between cognitive knowledge seeking and the ethical aspects of emotional human interaction. Data collection occurred at the HHD clinic so participants would feel comfortable in a familiar environment. Furthermore, the interviews were held in a private room to encourage full disclosure.

Interview Process

Before each semi-structured interview the PI provided participants with the Consent Form and explained the entire document to them. The PI provided clarifications when needed and answered any questions or concerns participants had. The PI explained that participation in the study is entirely voluntary and participants may choose to withdraw from the study or refuse to answer any question at any time without any consequence. Once the participant provided consent (Consent Form and Consent Form for Audio Recordings) the PI turned on the audio

recording device and reminded the participants that there would be no identifying information collected. As described by Kvale (1996) the PI used himself as a research instrument, drawing upon an implicit bodily and emotional mode of knowing that allows privileged access to the subjects lived experience and communicated not only with words, but by tone of voice, expressions, and gestures in the natural flow of a conversation. The PI provided a participant code (01-20) and assigned each participant a nickname. Nicknames were cross-referenced with actual names of participants to ensure there were no matches. The interview process then began and participants were asked questions from the Interview Questions document (Appendix I). Socio-demographic information was collected on the first page (i.e., gender, age, marital status, highest level of education included, etc.). The second page had five themed questions the PI asked the participants one at a time. There was no time limit for responses and participants were not interrupted if they deviated from the central theme of the question. As outlined in the Consent Form, participants had the right to refuse to answer any question or terminate the interview at any time; however all of the twenty participants fully completed the interview. The average duration of an interview lasted approximately fifteen minutes. Upon completion of the semi-structured interview the recording device was turned off and the PI verbally thanked each participant for their involvement. Debriefing continued after the recorder was turned off and information regarding access to the final thesis was discussed. After each interview the PI composed interview blurbs. The purpose of these brief summaries was to allow the PI to reflect back on each interview before transcribing ensued. The interviews were audio recorded to ensure accuracy in transcriptions. The recordings were stored on a password protected computer and deleted from the audio recording device by August 31, 2014.

Interview Credibility

The literature review suggests a gap in the use of semi-structured interviews for studying dialysis as most studies used standardized quality of life questionnaires. This study employed a semi-structured interview as the primary data collection tool. The PI personally conducted each semi-structured interview to increase content validity. According to Brod, Tesler and Christensen (2009) the most appropriate way to support content validity is by conducting qualitative research entailing direct communication with patients to adequately capture their perspective on issues of importance. The themed questions were reviewed and revised multiple times by the PI and committee members to capture the experience of HHD from the beginning (initial treatment) to present day. The questions were developed to allow the participants to share their dialysis story by utilizing open ended questions. The questions were also designed for the data to be categorized to match the HBM constructs; perceived benefits and perceived barriers. Since the purpose of this study was to explore HHD experiences by focusing on the benefits and barriers, participants were not directly asked about perceived severity or self-efficacy. Perceived susceptibility and cues to action (remaining constructs of the HBM) do not align with the HHD experience because; a) all participants already have CKD and therefore susceptibility does not apply; and b) all participants receive HD and therefore are not preparing for a new treatment or behaviour.

Section 3.05

Data Analysis

Transcription of Data

Transcriptions were performed by the PI to ensure accurate representation of the data and to retain a better understanding of its context. According to Bowling and Ebrahim (2005) when transcription is performed by an audio-typist (external from the research) the researcher loses the opportunity to absorb the data, and need later to check to ensure that the transcriptions are accurate. Thus, the PI transcribed the interviews, providing a greater opportunity to absorb the rich qualitative data. Before transcription occurred each interview blurb was reviewed to become familiar with the corresponding interview. Interview recordings were replayed three times over before the PI transcribed the next. Once the data set were transcribed the text files were imported to the NVivo10 qualitative data analysis software; QSR International Pty Ltd. Version 10, 2012. This computer software program was used to facilitate the analysis of the content by sorting and classifying the data into Nodes (NVivo10 coding frame). The qualitative data was thoroughly examined and text segments were sorted into the appropriate Nodes.

Analytical Process

The analytical process encompassed a combination of the template approach and a thematic analysis. The template approach was described by DiCicco-Bloom and Crabtree (2006) as using codes from a codebook for tagging segments of text and then sorting text segments with similar content into separate categories for a final distillation into major themes. This approach has been described as a 'template approach' as it involves applying a template of classifications based on prior research and theoretical perspectives. Thematic analysis is a method for

identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006). In this case, HBM constructs acted as the templates for Node classification and each Node underwent a thematic analysis.

The interview questions were analyzed separately (e.g., all twenty participant responses for Q1 were analyzed together) and therefore five Nodes were created to represent each question. After the analysis of all five interview questions, “perceived barriers” and “perceived benefits” were created as Nodes. Initially, these were the only constructs from the HBM expected to be utilized, however “perceived severity” and “self-efficacy” were later added as Nodes to interpret the entire data set. Therefore four constructs from the HBM were used to represent the data and corresponding text segments were organized into their respective Node category (template approach). The PI then carefully reviewed the data within each Node to identify emerging themes (thematic analysis).

Section 3.06

Achieving Trustworthiness

According to Lincoln and Guba (1985) trustworthiness of a qualitative research study is important to evaluating its worth and involves a series of techniques that can be used to achieve credibility, transferability, dependability, and confirmability. Definitions of these criteria, as described by Lincoln and Guba (1985), are represented in Table 2 along with the techniques used in this study for establishing these criteria.

Table 2		
Trustworthiness Criteria		
Criteria	Definition	Techniques
Credibility	Confidence in the “truth: of the findings	<ul style="list-style-type: none"> - Prolonged engagement - Persistent observation - Peer debriefing
Transferability	Showing that the findings have applicability in other contexts	<ul style="list-style-type: none"> - Thick description
Dependability	Showing that the findings are consistent and could be repeated	<ul style="list-style-type: none"> - External audits
Confirmability	A degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest.	<ul style="list-style-type: none"> - Audit trail - Reflectivity

Table 2 Trustworthiness Criteria

To maximize credibility the PI experienced prolonged engagement with various dialysis patients and became familiar with the HHD processes. The PI worked seven months volunteering at an in-centre HD clinic, attended two observation days in a HHD clinic, and one pre-dialysis education session (as outlined in Appendix J). The PI also spent several months in the community based hospital meeting with stakeholders, speaking with healthcare professionals and conducting patient interviews. According to Lincoln and Guba (1985) spending sufficient time in the field to learn or understand the culture, social setting, or phenomenon of interest will allow the researcher to become oriented to the situation so the context is appreciated and understood. In an effort to maximize content validity the PI interviewed the patients first hand with prolonged engagement and persistent observations in the dialysis field.

The third credibility technique was also used as the supervisory committee members providing peer debriefing. Mays and Pope (2000) identify that personal and intellectual biases

need to be made clear to enhance the credibility of the findings. The constant reviews of the supervisory committee allowed the PI to uncover own biases, perspectives and assumptions. Included in this thesis is a reflective piece in *section 1.05* and a discussion of potential biases in *section 6.02*.

Transferability, the next principle of trustworthiness was met by using a thick description technique. Thick description refers to the detailed account of field experiences in which the researcher makes explicit the patterns of cultural and social relationships and puts them in context (Holloway, 1997). The extensive field experience the PI gained provided a strong foundation for understanding the HHD patient journey. This combined with a thorough literature review detailing various dialysis modalities and settings, cost analysis and associated benefits and barriers strengthened the PI's ability to analyze the data and extract its context. When analyzing the data, the PI exhibited results in two ways: a) results for each interview question and; b) thematic analysis to identify emerging themes for each HBM construct. Providing an in-depth analysis and a thorough description of the results increases this study's transferability. Lincoln and Guba (1985) state that when describing a phenomenon in sufficient detail one can begin to evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people. This research provides a thick description of the HHD experience for patients from a community based hospital in the Durham Region. Although results can be applicable to other HHD populations it is the responsibility of the reader to determine its transferability to a different context.

Dependability was achieved by using external auditors. According to Lincoln and Guba (1985) external audits involve having a researcher not involved in the research process examine both the process and product of the research study to evaluate the accuracy and evaluate whether

or not the findings, interpretations and conclusions are supported by the data. The supervisory committee conducted many reviews and offered feedback to the PI throughout the development of the study. These reviews challenged the PI to continuously revise the process and results of the study to ensure they were dependable.

Confirmability was met by using an audit trail and reflexivity. As described by Lincoln and Guba (1985) an audit trail is a transparent description of the research steps taken from the start of a research project to the development and reporting of findings. The PI included raw data from the observation reports, field notes from interviews (interview blurbs) and process notes for the methodology. This thesis includes a reflective piece in *section 1.05* which allows the reader to grasp the PI's past experiences with dialysis and identifies the motive in choosing this field of research. According to Mays and Pope (2000) reflexivity means sensitivity to ways the researcher and research process have shaped the collected data, including role of prior assumptions and experience. Comprehending all four criteria with validated techniques gives this thesis a high degree of trustworthiness and strengthens its methodology. The next chapter will discuss the results collected for each interview question and identify emerging themes.

Chapter 4: Results

Section 4.01

Introduction

This chapter provides an overview of the results obtained from the participant interviews. Participant recruitment results will be discussed followed by a summary of the socio-demographic information collected. Results of the qualitative data collected from the interviews will then be individually summarized for each question. Health Belief Model (HBM) constructs and their corresponding themes will then be identified and discussed. This chapter will conclude with a summary of results and includes Table 4 which outlines the HBM constructs, emerging themes and participant quotes.

Section 4.02

Socio-Demographics of Participants

The socio-demographic information was verbally collected before the interview questions were asked. Among the 20 participants there were 13 males (65%) and 7 females (35%). The age of the participants ranged from 31 to 85 years with an average age of 56 years. The majority of the participants reside in the Durham Region (5 Whitby; 5 Oshawa; 2 Ajax; 1 Pickering; 1 Brooklin; 1 Courtice; 1 Bowmanville; 1 Newcastle; ; 1 Port Perry; 1 Little Britain; 1 Port Hope) and all live in houses. Fifteen participants are married and the remaining were single (2), divorced (1), common law (1), or widowed (1). Participant's level of education included High School (8), College (8) or University (4). Participant average personal income was \$44,000 and their average household income was \$95,111. 3 participants mentioned they collect Canada

Pension Plan (CPP) disability benefit and 6 participants collect CPP retirement pension.

Therefore 9 participants (45%) have a personal annual income less than \$30,000. Table 3 summarizes the socio-demographics of the 20 participants:

Table 3	
Participant Socio-Demographics	
Gender	13 males; 7 females
Age	
Range	31-85
Mean	56
Median	51
Living Arrangement and Location	20 house - 5 Whitby; 5 Oshawa; 2 Ajax; 1 Pickering; 1 Brooklin; 1 Courtice; 1 Bowmanville; 1 Newcastle; ; 1 Port Perry; 1 Little Britain; 1 Port Hope
Marital Status	15 married; 2 single; 1 divorced; 1 common law; 1 widowed
Level of Education	8 High School; 8 College; 4 University
Annual Personal Income	
Range	\$10,000 - \$120,000
Mean	\$44,300
Median	\$30,500
Annual Household Income Range	
Range	\$16,000 - \$250,000
Mean	\$95,111
Median	\$72,500

Table 3 Participant Socio-Demographics

Section 4.03

Interview Results

Once the socio-demographic information was collected the participants were asked five themed questions. The questions were transcribed in Heading 1 format to separate and organize participant responses within the NVivo10 software program. The following is a summary of participant response to each themed question:

1: Share with me how you came to start home hemodialysis therapy and your transition experience to home dialysis? Was there anything or anyone that had an influence in your decision?

The large majority of participants accredited their decision for HHD transition to the hospital staff. Either the nurse or the physician recommended HHD to them and explained the benefits over in-centre dialysis. Participants felt supported by the nursing staff during their transition to HHD. Some described the nurses as “absolutely fantastic”; “instrumental”; and “a big information source”. Most participants received an eight week training period where other younger and more eager participants had a compressed training period. This was due to participants desire to move treatment to their home as quickly as possible in an effort to get back to a relatively normal lifestyle. Marj describes it as: “It was something I really wanted to do really quickly because I wanted to get back to the same lifestyle as before”. When Marj was in-centre her children were very active and she was not able to participate in their sports like she use to. Marj felt separation from her children and for her, HHD brought back her ability to be involved with her kids again. Marj embraced the opportunity to transition to HHD and was determined to be more involved with her family activities again. Similarly, Eric wanted to get back to his normal routine; however his work was his motivation: “I wanted to be able to do this at home so I could be done this training session and hopefully get back to work. I wouldn’t say it was rushed I just had a target I wanted to meet”. Vickie also mentioned that coming in-centre for treatment was interfering with her work schedule which influenced her decision to adopt HHD: “I use to run a few restaurants and it was just getting tougher and tougher. So I decided to do it at home”. Few participants felt there was no influence in their decision and HHD therapy was entirely their choice, however, at some point all participants received a HHD information session

and this may have incidentally influenced their decision. Heather had a unique perspective on HHD because of past experiences she had with her father:

Well they fought me tooth and nail to even go on dialysis because my father was on dialysis and I watched him do it and it sucked. He lasted three years and passed away. He had a bad fall and it was just too much weight on his heart. So like I said I didn't want to do it at all. My doctor talked me into it and told me these are your choices; you can live or you can die. So we chose life.

Heather experienced her father's dialysis and watched his health decline over time. She had developed a poor outlook towards dialysis long before she required it. She associated HHD with a decreased quality of life and poor health outcomes. This experience made Heather reluctant to commit to any form of dialysis until it was absolutely necessary for survival.

2: What is it about this type of therapy that has a positive effect in your life? What do you like about it? What makes it easy?

For this question there were different mindsets on how participants construed their HHD. There were favorable and unfavorable perspectives towards HHD depending on how participants made sense of their realities. Some participants reported that they dislike dialysis in general and there is nothing easy about it. Eric expresses his negative thoughts towards dialysis: "Nothing's easy about it. I never expected to be so tired. Like even when I had 10% function I felt I had more energy than I do on dialysis. It just totally drains you and I'm stunned by that". Participants who initially discussed the negative experience with dialysis would later admit they are thankful to be able to survive with dialysis. Paul states: "I don't really like anything about it but I like it

because it keeps me alive. I think it's a marvelous thing, I really do". Likewise Drew articulates his appreciation for his second chance in life:

It's not easy. It changes your lifestyle and what I mean by change your lifestyle you have to look at being on the machine, your diet changes and your social life gets changed around. You can get depression being on the machine because you're now stuck with that lifestyle. But then you got to look at being on the machine as a second wind of life because without the machine you wouldn't be around.

Drew takes the good with the bad and accepts the new lifestyle because it means he is able to live on. Although some participants, at first, label HHD as an undesirable nuisance they also realize its significance in their life and expressed their appreciation for it.

Given that some participants expressed their undesirable views, the majority of the participants spoke positively about HHD when asked this question. Nick answers:

I would say the biggest advantage to doing home is not having to travel to the hospital and then having your own schedule whenever you want to do it, whenever you want to start it and it's up to you. So just having more control of your treatments is a big advantage to me.

Many of the participants shared this same view. They are ecstatic they don't have to travel to the hospital and adhere to a strict schedule. They can perform treatment in the comfort of their own homes surrounded by family. They have the option to postpone treatments if it conflicts with their social life or personal preference. HHD can also improve how they feel as Kyle explains:

Well you're generally feeling a lot better. I can't feel this well on 3 days a week. My body does just not like 4 hour treatments. I get bad headaches, the sweats, all kinds of stuff...the shakes. Really, really bad. On eight hours I don't have any of that.

Kyle can notice health improvements with more frequent, slower treatments. Pam also expressed how she felt, not only physically but psychologically: "there's such a feeling of power there like you feel really good because your taking good care of yourself and you learn...and it's fun actually". Pam feels in control of her disease management which empowers her and improves her psychological outlook on dialysis. Essentially participants compared HHD with in-centre dialysis and felt that HHD is a more convenient, flexible and empowering RRT.

3: What are the challenges you have found or continue to face with home therapy?

What makes it hard?

There was a variety of different responses to this question. Many participants discussed challenges pertaining to the dialysis procedure itself such as set-up and take down of the machine, self-cannulation and managing supplies. Neil answers:

Challenges I find are ordering the materials and keeping on track with all that. And then the storage and carrying it back and forth and there's some heavy bottles involved and that's the part that I don't like about it.

Many participants felt overwhelmed with all the required supplies and the ordering process. They are required to keep track of their inventory and manage supply orders. This, along with storing and carrying supplies from one room to another was the most common challenge reported.

Another challenge commonly reported was devoting time for disease management. Larry: "The only challenge is the commitment I have to give to it like time wise. You know you're always

thinking I have to go home I have to this I have to do that". Reports from Question 2 suggest that many participants feel liberated with HHD's flexibility and convenience however, some participants like Gary still feel burdened with HHD scheduling and preparation:

Based on the work that I do and the different hours that I keep I always have it in the back of my mind that I have to do four treatments a week based on eight hours a day. So that becomes a challenge sometimes. So I just have to adjust my schedule or adjust my schedule at work or adjust the schedule at home to have the treatment stuff. Or if I have to travel I have to do additional treatments and if I'm going out of town I have to make arrangements at the other end if I'm going to be gone for an extended period of time.

Many participants recognize that HHD has changed their lifestyle. Given that dialysis is a recurrent long-term RRT, adopting any type of dialysis modality (i.e., HHD, PD or in-centre HD) will notably change one's lifestyle. Some participants compared their HHD regime to a past lifestyle without dialysis which makes this reported challenge difficult to gauge. Participants each have a unique lens on the impact HHD had on their lifestyle. Therefore, this lens may have influenced these reported challenges. Most participants, who discussed lifestyle changes associated with HHD, also communicated their successful adaptation. Drew:

The other bit is the kind of restrictions you personally do. Like I was saying, going swimming with my daughters you can't do stuff like that. The food that you love to eat changes. It's more that you have to adapt or accept those items. So once you do, you don't have many issues.

Drew understands his restrictions and deals with them well. Psychologically, accepting the HHD lifestyle puts him in a better state of mind. This is particularly evident when compared to other participants like Vickie who find it harder to accept:

The challenge for me is seeing it there every day because it's in my room. It's in my bedroom so I feel like I can't get away from it. So that's tough sometimes because it's there all the time. And the challenges when you run into an issue, there's nobody there to help you. Like you can phone in and page somebody but they don't answer right away. So you're stuck trying to troubleshoot yourself and then you get anxious because it's your blood and you're hooked up to it and what if it clots or whatever.

Vickie seems to have psychological difficulties accepting HHD as part of her life and has problems troubleshooting alarms. It should be noted that all other participants reported feeling supported by the nurses at some point during the interview. Other notable challenges reported were plumbing issues and difficulty travelling for longer than two days away from their home. These are actual issues that inhibit their experience rather than perceived technical issues that can potentially be overcome.

4: Who or what helps you deal with the challenges? Do you rely on a caregiver?

What could help you continue this home therapy?

Nine male participants said their wife was their primary caregiver. The majority of them relied heavily on their wives to aid with dialysis treatments while others only required minimal support. These male participants reported a high dependence on their wives at home while utilizing their nurses for additional telephone support. They could contact them on a pager any day except for Sundays. Drew describes the different levels of support he has:

Wife at home and nurses you can page 24 hours except for Sundays and keep track of your health and want you to check in of how he is feeling, social worker for psychological support, physician watch out for you and make changes to the health plan. Essentially there's always somebody for support.

Not only does Drew look to his wife for support but also recognizes the support structure offered by the clinic. Similarly, other participants like Larry recognized their nurse as a backbone for support:

My nurse is my go-to person. She's the one who trained me during my dialysis training here and she's just been totally helpful [to me] and my wife. My wife has a lot of issues with it. She's not as easy going with it as I am but my nurse helps her out a lot. The nurse knows she needs more assistance so she coaches her on quite well. I wouldn't say that to my wife or the nurse but I know she's very good with my wife and helps her out a lot. My wife hasn't taken to it to good. It's a pain in her lifestyle too.

Although Larry's wife is the primary caregiver, Larry knows that she hasn't adapted well to the lifestyle change as a primary caregiver.

As for the female participants three labeled their husbands as their primary caregiver.

Heather:

I rely on my husband one hundred percent. Other than my doctor, my husband is my guiding influence. If I were just looking after me I probably would have taken the other route. But I have a family you know.

Without the support of her husband Heather may not have chosen HHD and instead be in-centre. Alexa also relies on her husband because she recently injured her leg and requires assistance. She actually feels relieved from conducting treatments on her own and is enjoying the hands on support from her husband. She even mentioned that she wouldn't mind if he continued performing dialysis with her after she recovers from her leg injury. Deena requires assistance from her daughter (primary caregiver) and her friend (secondary caregiver). Deena's daughter is very knowledgeable and skilled at performing dialysis however when her daughter is unavailable to conduct a treatment her friend fills in. Deena was the only participant to report having two trained caregivers. For Marj, her husband is the primary caregiver but is not always available for support:

My husband did come with me to get trained but he has chosen not too really assist me. Not because he doesn't want to but because he has a hard time visualizing the blood that makes him very squeamish. so he has a hard time with that though he has come to my rescue a couple times when he's been home and things have happened. He's very technical so he can actually figure out the machine a little bit more than I can because he understands mechanics a little bit more than me so he's actually helped me that way but when it comes to the actual treatment I'm pretty much on my own.

Her husband has helped in emergency situations but stays away from actually overseeing the treatment being performed. Marj also says it is her senior parents that are at home when she performs dialysis. Her husband is often at work and technically her untrained parents are there for emergencies.

Other participants did not rely on a caregiver to conduct dialysis and were confident and capable enough to perform treatments independently. James in particular had a fascinating response to this question:

If you do decide to do HHD its best to be equipped with two things: one is a personality that wants control of their life and the second thing is a little bit of help from a partner. A girlfriend, a wife or someone that can help you out. My wife was trained with me at the same time and she hardly does anything with it. She literally leaves me alone with it but if I do need emergency help with anything she's there. But that has never happened.

James does not require assistance from his wife and he performs dialysis on his own. His wife has been trained and is there for emergency backup. James feels that having an autonomous personality and adequate caregiver support are the main ingredients for a positive HHD experience. James realizes that each HHD patient is different and requires a certain level of support to be successful at home. His comments were indicative from his own experience with HHD.

5: In your opinion what could enhance your dialysis experience at home?

Six participants wished their dialysis machines were smaller and more portable to travel with. Moreover five of those participants would want smaller or fewer supplies because storing and carrying the supplies is challenging. In essence these participants want the freedom to travel. They want to bring the dialyzer and supplies along with them. Marj discusses her desire for a portable dialysis system:

More portable, yeah because then that would allow me to travel cause right now I can't really travel. You know if I go away I can only go away for two days because I can only

go off the machine for two days. I mean you push it if you go three and you start feeling not well if you go three days without dialysis. So basically I'm stuck with two days so I'm only really allowed to go away for a weekend. Which hinders you right...because I haven't been away since 2006 because of my situation. So a portable machine would be amazing I mean that would allow me to travel because I can do my treatments anywhere I am, so that would enhance it. And if they could come up with a different way of cannulating without having to stick eighteen inch gauge needles that would really be a good thing too because regardless of how use you get to it it's never easy and it's never not pleasant. Like I've been doing it for almost seven years and I still get very anxious every time I have to stick a needle in my arm and I have to do that five days a week. It never gets better. I don't care what anybody says, you never get used to it and it never feels good. That's the hardest part I think is to get your needles in.

Since Marj cannot travel with her large dialyzer she has been denied the freedom to travel for longer than two days. Marj later reports that self-cannulation with large needles is very challenging. She wishes she didn't have to self-needle or at least use smaller needles for easier access. In total three participants complained about the needles used for self-cannulation. Furthermore two participants wished there was a simpler and faster process for connecting and disconnecting to the machine, three participants desired shorter treatments and one participant sought fewer treatments per week with the same results.

Three participants discussed the importance of caregiver support. Gord reported that he relies on his wife and it would be tough if he had to do it himself. This remark is not a suggestion for enhancing his dialysis experience but a reflection to the value of caregiver support. Gord

recognizes that his dialysis experience would diminish without the support from his wife. Deena discusses her experience with caregivers:

Having relief for the caregivers in the home rather than having to pack up and go someplace else. That's why I wanted to make sure that it was in there...and it's a little bit nervous when my secondary caregiver is there rather than my daughter because she has problems she can't solve so she just tears down the machine and leaves it for another day.

The secondary caregiver is not as skilled at performing dialysis and at times Deena feels more comfortable coming in-centre to receive treatment when her daughter is not available. The secondary caregiver relieves Deena's daughter once a week (usually Sundays). However if her daughter is away for a week Deena's friend drives her in-centre instead of performing all four treatments at home. Deena wished that her secondary caregiver was fully capable and confident in assisting with dialysis treatments at home for complete caregiver support.

In Vickie's case, she has encountered plumbing issues in her home and was forced to return in-centre for treatment while her water treatment system was being repaired. Vickie reports that her plumbing has been an on-going issue since day one:

Like right now there are water issues in my house. The water tester is failing so I have to come in-centre until they figure it out. But I don't usually come in-centre to do it unless I'm like feeling really overwhelmed because of a lot of personal stuff going on or whatever. I'm in-centre right now because my water keeps failing the tests. And they are trying to figure that out.

Vickie is frustrated because between her water and health issues she always finds herself back in-centre more than she would like. With no caregiver support at home she finds it hard to

constantly manage HHD on her own. Vickie's lack of caregiver support will be discussed in more detail in *section 4.08*.

James had an interesting thought on the administrative process involved with HHD. HHD patients are required to maintain log reports for each treatment and submit these reports to their nurse. He believes in our modern world there should be access to an electronic database that records treatment information and tracks progress:

Like actual documentations of writing down recording stuff and that just to me it's a nuisance because I'm growing up in a world where I'm doing everything by my phone and electronics it doesn't make sense to me. Having the new machines if they had WiFi on them, if they an Ethernet connection...If I could easily email a monthly report of my blood pressures and my treatment log sheets. If I was able to just hit a button and email that to my nurse and she could easily review that that would be something that would definitely change the world in dialysis for sure especially when younger people like myself are coming on to dialysis. I think that is something that really responds to them as opposed to all the paper work that is done now. That doesn't make sense to me. The paper work gets stored and just sits there in piles of paper. But electronically having that information, even for the patient, is useful. If I can easily import that information into an Excel sheet or something and create a graph of where my blood pressure goes up or down. Visually a lot of patients respond to that. You can see where your potassium levels go up and down and things like that. Something along the lines of removing all this unnecessary written paperwork every single night and having the machine electronically record that and then send that in. Now a day it's definitely possible. It's a simple, simple thing. I see doctors using iPhones now. So something along the lines of that would be

amazing to use. I've even researched to see if there is an APP that can be used... that patients at home can easily use their iPhone to record all that information and there is no such thing. So something like that even attached to machine, because the machine is Microsoft based. So if it had an addition or software that could record the information of the patient that would be revolutionary.

James' suggestion is unique from the interviews. He is the only participant to discuss the paper work involved with log sheets and the desire for an automated electronic database system.

Many participants shared personal opinions about enhancing their HHD experience however ten (50%) of the participants started by saying they love HHD regardless of the challenges they encounter. Several began by expressing their appreciation of HHD before sharing thoughts for improvement. Statements such as: "I'm thankful", "not much can improve it", "as good as it gets", "it's fairly simple", "nothing really could enhance it" and "not much improvement" are examples of opening remarks for this question.

Section 4.04

Health Belief Model Constructs

The remaining sections in this chapter are summaries of the node classifications from the NVivo10 software. The nodes include perceived benefits, perceived barriers, perceived severity and self-efficacy all of which derive from the HBM. Perceived benefits and perceived barriers were constructs expected to be used based on the design on the interview tool. However, throughout the interviews participants also discussed their perceived severity and self-efficacy with HHD. The PI added these constructs as nodes in the NVivo10 software and common themes

were identified within each node. In total there were four HBM constructs each with several emerging themes.

Section 4.05

Perceived Benefits

Personalized and Flexible Treatment Schedule

Although question 2 was specifically aimed at unveiling the benefits of HHD as perceived by the participants, many positive comments about the HHD experience were made throughout the entire interview. As previously mentioned in *section 4.03* the majority of participants compared their HHD experience with their in-centre experience. The predominant benefit for participants is the flexibility to manage and personalize their treatment schedules. This is especially valuable for participants with greater accountability to work and family. Although some participants are retired and others have very busy lifestyles, all participants benefit in some way or another from the HHD flexibility. Patrick comments on HHD and how it suits his lifestyle:

This is perfect for my lifestyle and the way I do things right. If I was ninety and had all the time in the world to come into the hospital...sure. I need that time during the day to be able to do normal things.

Patrick is 41 years old and the ‘normal things’ he is referring to include his career, family and social commitments. Older patients also reap the benefits of a personalized schedule with HHD. Larry, a 65 year old, discusses the feeling of freedom to modify treatments: “There’s no schedule. It’s my schedule. I can do it as much as I want or as little as I want if my needs change

you know around my family”. Even though Larry is retired, he enjoys the flexibility HHD can offer. No matter the lifestyle, participants young and old have an appreciation for a personalized and flexible treatment schedule.

Autonomy and Psychological Benefits

Since HHD is an independent RRT, several participants felt rewarded with autonomy by successfully conducting their own treatments. Sandra states that HHD encourages autonomy: “It’s on my own time and I guess you could say it gives the patient autonomy. I can do what I want, when I want”. Participants like Sandra feel more independent because she is very hands-on with her disease management. This responsibility ultimately improves her dialysis experience through autonomy. Cindy is another participant who embraces her role as a self-governing care provider:

Just the fact that you get to do your own therapy. You’re like your own nurse. You get to do all the...you string up your machine and there’s such a feeling of power there like you feel really good because your taking good care of yourself and you learn how to. It’s not as hard as people think. You learn and it’s fun actually.

Cindy enjoys the challenge of continuous learning to build her confidence. She retains control of her dialysis and feels empowered in the driver seat. This attitude is shared by other participants like James who developed a treatment schedule that he can feel good about. James performs dialysis three days in a row, takes a day off, then follows with two more treatments and another day off. This system works well for James and he explains why:

I’ve broken it up so it kind of, in my mind, it helps because psychologically I’m not stuck five nights a week in a row. I’m doing three nights. I think psychologically it plays a

game on your mind and it kind of tells you that you have that freedom. You have three nights on the machine and the fourth night you're on your own and you had a really good night sleep and you're refreshed. You do two nights again and another rest and you're refreshed again. I have a feeling if I go to a schedule that most patients are on which I think is five nights a week I think I would be more exhausted. I think the three break and the two works really well in my scenario. Psychologically it really makes me feel like I'm independent.

Over time James was able to customize a treatment plan that delivers psychological benefits and gives him an improved experience with HHD. Heather shares her views on an improved environment when compared to in-centre HD:

You see them sitting in the hospitals and it's just a life, it's just to keep them going. When I started I was at the hospital, and don't get me wrong the nurses and everything are great at the hospital. They are doing all they can. Most of the people at the hospital are older as well and you just see them wasting away and it's depressing when I'm sitting there going, is that me? And now I'm at home and it's like no, that's not me. It's making a difference.

This is a very powerful statement from Heather as she differentiates between the in-centre HD and HHD populations. She sees a predominance of elderly patients using in-centre HD and feels good about using the more autonomous modality. Heather reports psychological benefits by disassociating herself with in-centre HD patients. The independence that comes with HHD gives the participants autonomy and a more positive psychological outlook towards their health.

Physical Health Benefits

Not only were there psychological benefits associated with HHD, but improved physical health came up in various discussions. Heather reaps the physical health benefits associated with dialysis:

My life has improved one hundred percent since before I was on dialysis and I didn't think that would happen but it has. I can breathe again, I can move again. There were days before we started dialysis I slept all day. I would get up and do the minimal amount of things because I couldn't breathe and I would go back to sleep...I've lost fifty pounds since I've started. And it's still working like it's still coming off. So that's something I never thought would happen again.

Dialysis treatments have allowed Heather to become healthier and lose a significant amount of weight. Although Heather's reported health improvements are associated with dialysis in general, other participants reported improvements in physical health specific to HHD. Kyle discusses the physical health benefits with slower treatments:

Well you're generally feeling a lot better. I can't feel this well on three days a week. My body just does not like four hour treatments. Like I get bad headaches, the sweats, all kinds of stuff... the shakes. Really, really bad. On eight hours I don't have any of that.

Kyle benefits from an eight hour HHD treatment, contrary to a typical four hour treatment in-centre. With HHD Kyle has the option to speed up or slow down the dialysis process. Similarly Vickie benefits from the option to perform dialysis on a day she isn't feeling great: "You feel more in charge of your health. If I'm not feeling well one day, OK. I'll just do an extra treatment, where I don't have that option if I come in here [in-centre]. So that's a good thing". Vickie can

improve how she feels day-to-day by having dialysis available in her home. She doesn't have to wait for her next appointment and can choose to conduct an extra treatment. Treatments are readily available in her home which offers improvements in physical health. Not all participants discussed, in detail, the physical health benefits however; most did associate HHD with improved physical health in general, compared to in-centre HD.

Section 4.06

Perceived Barriers

Management of Supplies

HHD requires storing and managing a stock of supplies in one's home. Many participants discussed the physical and psychological challenges they encounter with managing supplies. Drew discussed the added workload with supply management: "So for me it's almost a full time job. You have to look after rotation of your supplies. I look at those as the different challenges that you have to make sure you're not over stocked...expiry dates". Participants maintain a calendar that tells them when to place an order for more supplies which does help with organization. In terms of their experience, this is not an obstruction but more of an administrative chore. The participants are capable of managing their supplies but describe it as a nuisance. Alexa describes it as "the pain of placing orders". The other side to this emerging theme is the participant's ability to physically carry the supplies from their storage areas to their treatment rooms. They have to transport heavy supplies from one part of the house to another. Participants with mobility challenges rely on a caregiver to transport the supplies for them; otherwise they would not be able to continue HHD.

Self-Cannulation

Self-cannulation was one of the most common barriers that emerged. Many participants do not look forward to self-needle. Charles describes how he feels about his temporary central venous catheter (CVC) versus an arteriovenous graft (AVG):

Well the line is temporary but it's easier than sticking yourself. I'm using a line [CVC] and when my arm is ready I go back and stick myself. It takes a lot of nerves. You know most people don't like to see blood let alone stick a needle in their arm.

Although participants dislike accessing the blood stream, there are some that are too squeamish for self-cannulation. Kyle relies on his wife to perform the needling:

Well my wife's a nurse. I did my training here and my wife did it. I did everything but the needles, my wife does the needles. I can't needle myself they are too big. Have you seen the needles, I don't like sticking myself with those.

Kyle has an AVG that has shifted deeper in his arm and states: "hitting the tube doesn't hurt its getting through my arm". Physical pain of the needle and the inability of self-cannulation were the underlying factors of this barrier.

Travel Limitations

Another barrier that emerged from the data was the inability to travel. HHD equipment and supplies are not designed for travel and treatments can only occur at home. Participants talked about the flexibility with HHD and the option to postpone a treatment; however they can only forgo dialysis for a few days as Cindy explains:

I could miss a dialysis but then it would be three days and I have to kind of watch what I drink and that. But it would be good if there was something that I could travel more because travelling is expensive if you go on dialysis.

Cindy has to maintain a strict diet if she skips a few treatments and she cannot travel for longer than three days. She knows there are options to receive dialysis for an extended vacation, but this needs to be planned in advance and may cost her money depending on the location. Gary discussed the availability of in-centre HD abroad along with the additional costs and time commitments: “If I have to travel I have to do additional treatments and if I’m going out of town I have to make arrangements at the other end if I’m going to be gone for an extended period of time”. Patrick also touches on the issues involved with arranging remote treatments: “Not necessarily restrictive because you can find places to do dialysis but there’s an additional cost and additional factors in order to get things done that way”. Participants know they can pre-arrange dialysis elsewhere, but this means added expenses such as transportation to and from the in-centre location and payment per treatment (outside of Canada). When Nick was asked about enhancing his dialysis experience he comments on the desire for a more portable machine:

I would say having a more portable machine because when I go on vacation I have to make sure I call wherever I’m going, whatever city I go to and arrange dialysis before actually I go. Having a portable machine would be nice to be able to carry it with me. Maybe go to a hotel room and plug it in and able to dialyze on my own that would be a significant advantage.

To enhance the overall HHD experience participants like Nick want a more portable dialyzing unit so they can avoid receiving in-centre HD while traveling.

Troubleshooting Alarms

As previously discussed, some participants solely rely on their caregiver to perform the treatments and others are capable of full self-dialysis. Participants whose caregiver performed most of the dialysis process were not concerned about alarms or operational aspects of the dialyzer. Only participants that were more independent discussed the challenges of troubleshooting alarms, because of course they were responsible. Marj is one of these participants and she discusses some difficulties with HHD:

So you're basically taking three peoples jobs and doing it all by yourself and that can be challenging because you need to understand all those three positions and know them well to be able to have a perfect treatment or to have an effective treatment not perfect and effective treatment. So that's a challenge and you learn as you go. You learn as the longer you do it the more you learn and the more you get better at it. Obviously during the treatment when there's alarms those become the most challenging because you only have a certain amount of time to figure out your problem and to get it going because you start to clot and you cannot continue if your blood has started clotting. So you only have a very small amount of time like a very small window I think about less than 5 minutes to be able to get yourself going otherwise you've lost your circuit of blood. And that's something that you never want to do but it does happen.

Although Marj is capable of troubleshooting most alarms that may occur during dialysis, the consequence of failing to resolve the alarm weighs on her. There is a time window, where she must fix the problem or else she faces losing a circuit of blood, and must restart. Participants are

trained and can learn through experience. The challenge is not so much their capability but the constant responsibility of resolving their own issues.

Section 4.07

Perceived Severity

Compulsory for Survival

Throughout the interviews participants shared thoughts of the severity of HHD. Some participants like Paul commented on the method of connection to the machine: “It’s archaic...its medieval really and its crazy I mean you stick needles in a guy and then the blood falls out and oh please. There’s got to be a better way than that.” To Paul self-cannulation is the most severe component of HHD and is part of every treatment. For others like Sandra, there were less specific remarks about the severity of dialysis:

Well just being on dialysis in general is silly because you’re not normal. You can’t just travel anytime you want to. You can’t just pick up and go so you are attached to your machine in a way for survival.

Many participants acknowledged a changed lifestyle with HHD. Although treatments can be flexible, participants are still required to maintain a weekly minimum. This obligation makes some participants feel constantly bound to their machine. Participants rely on dialysis as a means of survival and many realize the severity of their situation. Gary: “Well I don’t like doing it. To me it’s a nuisance but I know I have no choice. I have to do it unless I go and have a transplant done”. Participants understand that there may be a long or infinite wait to receive a kidney transplant and dialysis is the alternative RRT for survival.

Mindset

Many participants reported feeling depressed especially during HHD inception. Drew for instance makes several comments about his depression associated with HHD: “At first it’s exciting to go on the machine and then it gets a little depressing...the machine like I said has made me depressed over certain time periods”. Drew reported feeling depressed in the early stages of HHD but also periodically over the years. Drew has been using HHD since 2011 and has adopted a certain mindset that helps him deal with depression:

If you let the machine run your life then you know you’re stuck. It’s something you’re going to anchor with and you’re going to get depressed over if it’s running your life. But if you can run your own life and do your social bit and get that in at certain time periods then it comes to be easier on your lifestyle, easier pressure on you.

Drew’s depression stemmed from a changed lifestyle adopting dialysis. The pressure to constantly perform treatments and manage CKD is a psychological challenge. Marj shares this feeling: “When your life gets taken away from you with this disease, which it does, you really look for anything that helps you get back to your normal life because you are no longer living a normal life”. Larry reports: “It’s always on your mind and it’s always part of your lifestyle”. Participants reported feeling depressed with HHD because their lifestyle had changed dramatically (when compared to a life without dialysis) which becomes a difficult reality to accept. But once they realized what their life would be (if at all) without dialysis, it helped them change their perspective. Heather discussed the physical health benefits she experienced with dialysis (see *section 4.05*) and later discusses the outcome of those improvements:

I'm more active again, I'm out socializing again and if you're looking at me on the street you wouldn't know that there's something wrong with me. Ten months ago you would have known. It's been a lifesaver. And it's improved my outlook on life. Basically I was dying, just slowly. But it gives you that sense of; I can do this.

Heather struggled changing her lifestyle for dialysis, but over time and as her health improved, she accepted dialysis and her perspective lens changed. Several participants initially struggled with HHD however, their mindsets changed as they started to develop an appreciation for HHD.

Section 4.08

Self-Efficacy

Confidence with Experience

With independent HHD comes more responsibility and incidentally, a patient's confidence is tested. Participant's self-efficacy emerged as a common theme from the interviews. Marj discusses the learning curve of HHD and her ability to cope at home:

The nurses I guess said it's an eight week trial program they put you through in-centre. I mean you never really a hundred percent feel confident at home until you start doing it at home because regardless of what you're taught in-centre your never really on your own until you're at home and then that's when things can happen. Because when your in-centre even though things are happening there's always someone there to rectify it or to control it. And with some people that might be an easy learning curve for them but for me I'm a type of person that regardless of what's being said to me and what's being taught to me I need to actually go through it in order to learn it.

Marj continued to explain that she actually has to experience an alarm to learn how to handle it quickly to avoid aborting the dialysis treatment:

So even though the transition was nice to be home it took a while before you learned all the issues that could happen and how you could fix them on your own it takes a while because you actually have to go through them and learn from that right. So that was a bit difficult and you know you do lose circuits of blood and stuff like that. So it can be discouraging but you know.

It seems a participant's experience with troubleshooting alarms was a direct reflection of their level of self-efficacy with HHD. Participants whom exhibited high self-efficacy with HHD prefer to resolve many of the HHD issues independently without seeking support from their nurse. James was one of the more confident participants and discussed the learning curve of HHD:

Some people's internal strength is not that strong and when they are hit with the news they have to do dialysis they just can't manage having all of that built into their home and doing it themselves and feeling separated from the hospital and the nurses. I love to be separated from them as much as I can. I don't even call them at all. Why? Because I feel like I should be able to conquer this myself. They are always there for me but I feel like I shouldn't need them. Give me the information and let me absorb it...let me learn it and I can do my own stuff.

James feels very comfortable resolving many of the alarm issues because he has experienced most of them already. He feels he can resolve the issues independently and strives to uphold his autonomy.

Caregiver Support

Self-efficacy was also related to the level of caregiver support. Participants who primarily relied on a caregiver did not discuss their level of self-efficacy because they lacked accountability to the success of their treatments. However they did admit that HHD would be difficult without their caregiver. Gord: “My wife. She could tell you more about that than I can really because she does it all...if I had to do it myself it would be tough”. Al: “The wife does it all. I mean it’s harder on her than it is on me”. More male participants relied solely on their wife as their caregiver than females did from their husbands.

Participants with minimal caregiver support often found themselves back with in-centre HD. Vickie, who conducts dialysis independently, feels that caregiver support would enhance her HHD experience:

I think that having somebody there to do it with you. Like if I’m feeling very sick or dizzy, because I get vertigo sometimes, I still have to try and program and hook everything up and set up my machine. It would be easier if you had somebody to do that with you. Like right now when I feel overwhelmed I come into the centre to do a treatment. But it would be nice to have somebody to just sort of say, I’ll clean your machine today, I’ll set it up, I’ll do whatever. So I think it’s easier to have somebody going home to have someone to help them.

Vickie feels overwhelmed with the challenges she encounters and the constant duties associated with HHD. Vickie wished she had someone to count on at home to help her through difficult times.

Participants who conduct HHD autonomously combined with very supportive caregivers maintain a high level of confidence. Even when the caregiver does not assist with actual treatments, the emotional and emergency support they provide can be instrumental as Nick discusses:

I think this is one of the biggest things. You do need someone there to be with you to give you that emotional support. My wife is a very loving person and always there for me and helping any way she can. So I mean a person at home without any type of caregiver I would not recommend HHD. They can still do it but just having a person there to be with them all the time and giving them support when it is needed I think is a big advantage. For me I'm thankful that my wife is there for me.

Caregivers help participants ease the burden of being alone with HHD. Even if the participant is not reliant on their caregiver there is comfort in knowing they are there for support.

Vascular Access

Self-efficacy was also directly linked with the type of dialysis access. Many participants are not comfortable with the self-cannulation process, and some would delegate this task to their caregiver. However, with a CVC access line confidence levels were higher. Kyle: "Have you seen the needles, I don't like sticking myself with those. I don't know, can't do it. Now I have a line and I do everything on my own, totally independent". With a CVC line Kyle can perform the entire dialysis treatment independently which increases his confidence. As previously discussed, self-cannulation was an emerging barrier for the participants and therefore, negatively impacts their self-efficacy.

Section 4.09

Summary of Results

In summary, this chapter covered the recruitment results, socio-demographic information, summarized participant responses to each interview question and analyzed emerging themes. All twenty patients approached by the PI agreed to participate in the interviews which occurred during five clinic days. Thirteen male and seven female participants answered the socio-demographic and interview questions entirely. The large majority of participants reported choosing HHD because of a nurse or physician influence combined with a desire to dialyze at home and return to a relatively normal lifestyle. Participants spoke very positively of HHD when comparing it to in-centre HD. HHD empowers the participants to take control of their disease management and allows them to develop their own personal treatment plan. Reported negative aspects of HHD were self-cannulation, troubleshooting alarms, psychological challenges and the time commitment for machine hook-up and disconnect. Above all, managing and storing heavy supplies was the most common barrier. Most participants reported having adequate caregiver support and in total twelve labelled their spouse as the primary caregiver. Participants that frequently returned in-centre for treatments reported plumbing issues, anxiety and the absence of their primary caregiver as the cause. The overall consensus for enhancing the HHD experience is the desire for a smaller more portable machine that would allow the participants to perform treatments away from their home and ultimately eliminate travel restrictions. This combined with smaller and/or fewer supplies were the most prominent suggestions for enhancing the HHD experience. A more in-depth analysis of the interviews identified emerging themes linked with the HBM constructs. Table 4 summarizes these themes:

Table 4		
Summary of Emerging Themes		
HBM Constructs	Emerging Themes	Captured Reports
Perceived Benefits	Personalized and Flexible Treatment Schedule	“There’s no schedule. It’s my schedule. I can do it as much as I want or as little as I want if my needs change you know around my family”
	Autonomy and Psychological Benefits	“There’s such a feeling of power there like you feel really good because your taking good care of yourself and you learn how to”
	Physical Health Benefits	“Psychologically it really makes me feel like I’m independent” “Well you’re generally feeling a lot better. I can’t feel this well on three days a week”
Perceived Barriers	Management of Supplies	“Challenges I find are ordering the materials and keeping on track with all that. And then the storage and carrying it back and forth and there’s some heavy bottles involved”
	Self-Cannulation	“You know most people don’t like to see blood let alone stick a needle in their arm”
	Travel Restrictions	“Not necessarily restrictive because you can find places to do dialysis but there’s an additional cost and additional factors in order to get things done that way”
	Troubleshooting Alarms	“Obviously during the treatment when there’s alarms those become the most challenging because you only have a certain amount of time to figure out your problem”

Perceived Severity	<p>Mindset</p> <p>Compulsory for Survival</p>	<p>“You can get depression being on the machine because you’re now stuck with that lifestyle. But then you got to look at being on the machine as a second wind of life because without the machine you wouldn’t be around.”</p> <p>“You can’t just pick up and go so you are attached to your machine in a way for survival.”</p>
Self-Efficacy	<p>Confidence with Experience</p> <p>Caregiver Support</p> <p>Vascular Access</p>	<p>“...it took a while before you learned all the issues that could happen and how you could fix them on your own... you actually have to go through them and learn from that.”</p> <p>“...just having a person there to be with them all the time and giving them support when it is needed I think is a big advantage.”</p> <p>“I have a line [CVC] and I do everything on my own, totally independent”</p>

Table 4 Summary of Emerging Themes

Chapter 5: Discussion

Section 5.01

Introduction

This chapter includes an interpretation of the results and an analysis of the emerging themes in accordance with the Health Belief Model (HBM) constructs. First, the participant's socio-demographic results will be discussed followed by a discussion of the interview results. The purpose of this study was to investigate the home hemodialysis (HHD) experience and to identify common benefits and barriers that emerged from the interviews. Therefore, results from perceived benefits and perceived barriers will be discussed and compared to existing research. Since perceived severity and self-efficacy also emerged, they too will be discussed and compared with current research.

Section 5.02

Socio-Demographics of Participants

The participant information collected prior to the interviews was intended to describe the population under study. Since the sample size was determined by achieving data saturation, having 20 patients participate was not prefigured. All 20 patients that were introduced to the PI agreed to participate in the study, which may reveal their desire to improve the HHD experience. There were more males (13) than females (9) that participated in the study. There was no selection bias as the PI did not hand-pick patients for an even ratio of males to females. Age was also a non-exclusive criterion. Participant's age ranged from 31-85 years with an average age of 56 years. Many of the elderly patients relied on their caregiver to conduct dialysis, were as the

younger more capable patients performed their own treatments. All 20 participants reported living in a house which suggests that adequate space is required for having a dialyzer and storing supplies. Perhaps a dialysis patient living in an apartment or condo may not have enough space in their smaller living arrangements to adopt HHD. Although only 4 participants had a University level education the participant's level of education did not seem to impact their experience. 15 participants were married and 1 had a common law partner. This suggests that spousal support contributes to the success of HHD. Participants that were single (2), divorced (1) or widowed (1) reported the lack of caregiver support as one of their primary challenges. In terms of the financial variances reported, participant's personal or household incomes did not surface in the interviews. There was no indication that a lower income had a negative impact on their HHD experience.

Section 5.03

Perceived Benefits

The first HBM construct discussed in the results was the participant's perceived benefits to HHD. Three themes surfaced from the interviews under this construct. The first and most common was the personalized and flexible treatment schedule that HHD offers. The participants echoed a sense of freedom with HHD especially when compared to in-centre hemodialysis (HD). Participants were very appreciative for the flexible dialysis schedule and the ability to personalize treatments around their lifestyle. These findings are consistent with Morton et al. (2010) who found the freedom and ability to carry on with daily activities uninterrupted by treatment schedules or hospital appointments to be the most common positive characteristic for independent dialysis. Morton et al. (2010) qualitative results were derived from semi-structured

interviews and thematically analyzed, however participants were not exclusively HHD patients and therefore results cannot be generalized to the HHD population.

This feeling of freedom was linked to the second sub-theme: autonomy and psychological benefits. Autonomy and psychological benefits were grouped as one sub-theme because they had a parallel relationship: when autonomy was embraced by participants they generally had a more positive attitude towards HHD. Sadala, Miranda, Lorençon and De Campos Pereira (2010) found that when peritoneal dialysis (PD) patients assume the responsibility of self-care they learn to value the autonomy in their own care. Since this thesis focuses on HHD patients, there is consistency to the pattern of autonomy for all independent dialysis. Woods et al. (1996) supports this fact by suggesting independence is best encouraged by allowing HHD patients to take responsibility for their own well-being. HHD gives participants independence and puts them in control which gives them autonomy and improves their experience psychologically.

Improved physical health was the last emerging theme within perceived benefits. With HHD offering a more intense and frequent therapy, participants reaped the benefits of improved physical health when compared to in-centre HD. Participants could choose to perform dialysis if they were not feeling well and did not have to wait for their scheduled in-centre treatment. For some participants it is unclear if their comments on improved health outcomes were exclusively associated with HHD or dialysis in general. It should also be noted that these reported benefits are from participant perceptions and do not reflect tangible laboratory data like in the McFarlane et al. (2003) study, associating nocturnal home hemodialysis (NHHD) with improved biochemistry (balanced blood chemistry), blood pressure, cardiac function, and sleep patterns.

Section 5.04

Perceived Barriers

There were four themes that emerged from the analysis of perceived barriers. The first was management of dialysis supplies. All participants reported having a designated room for their supplies (e.g., garage, spare bedroom, or basement). The challenge here was physically moving the heavy supplies from one room (storage room) to another (treatment room). In some cases these two rooms would be on different floors or at other ends of the house. Some participants relied on their caregiver to transport their supplies because of mobility issues. The other challenge with supplies was the space required to store them. Participant's would lose an entire room for storing supplies, and even had overflow into other rooms. Zhang et al. (2010) found that of the patients who did not choose HHD, 5% of patients had inadequate space at home. This is the only evidence to indicate spatial inadequacy as a HHD barrier. Zhang et al. (2010) do not specify if the patients lacked room for the dialyzer, supplies or both. Although the dialyzer is large, the participants in this study reported their supplies to be more of an issue.

The second theme to emerge was self-cannulation. Participants had a general dislike with the physical pain associated with the needling process. Only participants with arteriovenous fistula (AVF) and arteriovenous graft (AVG) access experience pain with self-cannulation. Participants that identified having an AVG reported having pain only puncturing the skin until they reached the graft. It is unclear if the level of pain varied with AVG versus AVF access. Verhallen et al. (2007) and van Loon et al. (2009) acknowledge the button-hole method as the superior AVG needling technique however none of the participants in this study discussed their cannulation technique. Central venous catheter (CVC) access does not involve needling which

explains why most participants reported this type of vascular access as their preferred method. For some participants self-cannulation takes a lot of nerves while others were even too squeamish and relied on their caregiver to perform this task. Although self-cannulation was the second most common barrier to emerge in this study, previous research by Cafazzo et al. (2009) found that fear of self-cannulation was perhaps the most common perceived barrier. According to Cafazzo et al. (2009) this fear included more than just the perception of pain, but also the potential occurrence of mishaps and complications. Self-cannulation is therefore a consistent and reoccurring barrier for HHD patients.

As for the travel restriction barrier, participants know they have the option to receive HD while away from home but ultimately, in-centre HD replaces HHD. The burden to make the arrangements combined with out-of pocket expenses seemingly deters participants from vacationing. For this reason many participants do not travel for more than three days (longest reported interval between treatments). This study coincides with reports from Morton et al. (2012) that although travel on dialysis therapy is possible, it requires substantial coordination. A six month prospective study by Corbett, Prout, Haynes, Edwards and Frankel (2014) investigate biochemical, microbiological and hematological parameters for patients receiving maintenance HD and found that HD away from a patient's usual HD unit is associated with increased risk of bacterial infections, anemia, and inflammatory response and subsequently increase morbidity. Corbett et al. (2014) also state that arranging HD at an alternative center is a significant logistical undertaking, with the burden of responsibility falling predominantly on the patients to ensure that they have access to this treatment while they travel. The current travel barriers for HHD patients, suggest that vacationing decreases a patient's HHD experience and developments should be focused on the portability of HHD and/or improving maintenance HD programs.

Troubleshooting alarms was the final barrier to emerge. This sub-theme was generalized by the participants and specific types of alarms were not discussed. Participants discussed the burden of the added workload with HHD and taking over the responsibilities of multiple in-centre healthcare professionals. Referring back to Cefazzo et al. (2009) findings, pre-HHD patients were afraid to lose the hospital support, especially for unexpected situations. Many participants felt they did not lose the hospital support because their nurses could be contacted on their pager. However, speaking with their nurse over the phone is not the same as readily available on-site care. Participants are not always successful in rectifying alarms by themselves. Although pre-dialysis training prepares them for alarms, participants felt they had to experience each specific alarm before they could truly acquire the ability to deal with it themselves. Participants confirmed that their ability to troubleshoot improved over time with experiential learning. Even with the knowledge and skill to troubleshoot an alarm, the weight of that responsibility was a heavy burden for some participants.

Section 5.05

Perceived Severity

Perceived severity is a HBM construct that was not expected to be utilized for organizing results as the purpose of this thesis was to identify the benefits and barriers of HHD. However, several comments were made throughout the interviews related to perceived severity of HHD. Therefore, perceived severity was added and two themes emerged from its contents.

Many participants recognize the severity of their situation and perceive dialysis as a means of survival. Many are grateful for having access to this life sustaining therapy in their homes. The downside is feeling bound to their machines. Their renal health has deteriorated to

the point they cannot survive without a dialysis. Having the dialyzer in their home is a constant reminder of their disease and the seriousness of their situation. There are no current studies that focus primarily on HHD patient perceived severity however, Janz and Becker (1984) found that diabetes patients, who are more realistic about the consequences of the disease, are motivated to take action to control their diabetes. Therefore patients who perceived their diabetes as more severe were more involved in their care, and as a result experienced fewer diabetes-related complications (Janz & Becker, 1984). Although many dialysis patients have diabetes, it is unclear if this pattern is consistent with HHD patients and requires further investigation.

The second theme to emerge from perceived severity was the mindset of participants. Morton et al. (2010) suggest that patients might choose between therapies based on their perception regarding which therapy most embodies particular characteristics that minimize impact on their lifestyle. All participants in this study chose HHD as their preferred renal replacement therapy (RRT) and perceive it to be the most appropriate modality to suit their lifestyle. However many participants reported depression, especially when first adopting HHD. They were depressed because of the impact dialysis had on their lifestyle (controls their life). This depression seemed to fade as participants reshaped their point of reference from a life without dialysis, to an extended life because of dialysis. Participants began to appreciate HHD which had a positive impact on their mindset. Chilcot, Norton, Wellsted, Davenport, Firth and Farrington (2013) had similar findings with 160 dialysis patients and found that higher levels of depression were associated with a poorer understanding of the illness (coherence) and the perception that kidney failure has severe consequences and a more cyclical timeline. They conclude that distinct patterns of depression symptoms are associated with illness perceptions. Chilcot et al. (2013) focus on depressive symptom trajectories over the first year of dialysis.

These results suggest there are consistencies with developing depressive symptoms in the early years of adopting dialysis when participants perceived severity was higher.

Section 5.06

Self-Efficacy

Self-efficacy was the fourth and final HBM construct utilized to organize the data from the interviews. Like perceived severity, this construct was not initially included in the methodology however its addition was helpful for analyzing the data. Reports from self-efficacy yielded three emerging themes: a) confidence with experience; b) vascular access and; c) caregiver support.

Reports indicate that a participant's confidence builds over time as they are exposed to a variety of alarms. As stated in *section 4.08*; it seems a participant's experience with troubleshooting alarms was a direct reflection of their level of self-efficacy with HHD. McLaughlin et al. (2003) proposed that successful HHD adoption is derived from changing knowledge, attitudes, and then skills. These authors found the most prevalent knowledge barrier was lack of a satisfactory explanation of the various techniques and the most prevalent attitude barriers were that patients should not dialyze without direct supervision and the fear of failure to perform self-care dialysis adequately. Participants with the highest self-efficacy utilized their knowledge from training, and continuously developed their skills with proactive learning and a positive attitude. The eight week pre-HHD education period does not allow patients the opportunity to troubleshoot all the alarms while in-centre and is merely baseline knowledge, where tangible experience at home acts as the real learning curve. For example, some participants who faced alarms at home for the first time were unsuccessful troubleshooting and

consequently had to abort the treatment and restart dialysis (losing a circuit of blood). In dealing with the same alarms in the future, participants had success in troubleshooting and gained confidence in their abilities. Therefore participants that have been using HHD for a long time feel more confident with the technical aspects of dialysis. Some of the more experienced participants reported dialyzing on Sundays (when nurses aren't available) because they are comfortable troubleshooting alarms and have developed a high degree of self-efficacy.

Another theme contributing to self-efficacy was the type of vascular access. The results revealed that AVF and AVG access can negatively affect ones self-efficacy while CVC access has been associated with improving ones self-efficacy by eliminating self-cannulation. According to MacRae, Ahmed, Atkar and Hemmelgarn (2012) AVF may be underutilized:

Vascular access remains the Achilles heel of HD patients. Complications of vascular access, including infection and thrombosis, are a significant source of patient morbidity and mortality, with considerable impact on quality of life. Although AVF have the lowest complication rate, apprehension and fear of painful needling may dissuade patients from choosing an AVF as an access. (p. 1632)

Participants only briefly discussed past vascular issues, such as poor vasculature for AVF and AVG displacement. AVF and AVG are similar and therefore participants generalized these access types with self-cannulation. For participants that previously relied on their caregiver to perform cannulation and have since switched to CVC access, they have gained the confidence to become completely autonomous. Cafazzo et al. (2009) found that patients who are overwhelmed by the multiple tasks of learning dialysis, lack confidence in self-cannulation. Cafazzo et al. (2009) state that the optimal strategy to teach and learn self-cannulation has not been studied

systematically and the risk-benefit ratio of the various types of vascular accesses in HHD requires further clarification. According to the ORN (2013b) 80.8% of HD patients at Lakeridge Heath have CVC access (ratio of in-centre HD and HHD not specified). If self-efficacy improves with CVC access there should be more research to expand on this causal relationship.

Participant's level of caregiver support also influenced self-efficacy. The majority of participants that were dependent on their caregiver were males. Results suggest that if these participants lacked caregiver support they would be unable to cope independently and end up transitioning to in-centre HD. This can be connected to research by Zhang et al. (2010) who found a disproportionate number of single males preferring in-centre HD as a result of their reluctance to bear the added workload at home. Participants who lacked a caregiver or who relied on their caregiver for HHD had low self-efficacy, where more independent participants with periodic caregiver support reported high self-efficacy. The level of caregiver support varied for each participant however it seemed the balance of responsibilities was a direct reflection of their self-efficacy. Although we identified a trend in patient self-efficacy, it would be beneficial for future studies to examine the self-efficacy of the caregiver. Mowatt et al. (2004) found that HHD was more stressful for caregivers than patients. The dynamic of the patient-caregiver relationship has a significant impact on the HHD experience. Future research should explore the self-efficacy of the patient and caregiver as separate entities.

Section 5.07

Health Belief Model

The HBM was chosen to act as the theoretical framework for this study. It has been defined as a change behaviour model that consists of six fundamental constructs (perceived

susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy). Because it has previously been used as a change behaviour model its relevance to this study was initially questioned. However upon further inquiry the HBM provided value to this study in facilitating content organization with its constructs. Previous research by Wiebe and Christensen (1997) and Cefazzo et al. (2009) used the HBM as a tool to fit with their research methods. These authors used different approaches operationalizing each construct which helped code their data. Employing a thematic analysis on rich qualitative data can sometimes be challenging. According to Guest, MacQueen and Namey (2011) thematic analysis should be flexible and responsive to the naturally emergent nature of the process, but many factors need to be considered beforehand to ensure the analysis is both efficient and meaningful. The purpose of this study was to identify the benefits and barriers associated with the HHD experience. In using predetermined themes (perceived benefits and perceived barriers) the efficiency of the analytical process increased. The constructs of the HBM became more useful during data analysis as perceived severity and self-efficacy emerged. Although these themes were not the main focus of the study, they were valuable in reporting the complete HHD experience. Given the population under study, perceived susceptibility and cues to action did not emerge. Participants were all HHD patients and therefore are not susceptible to HHD, nor are they deciding to initiate HHD.

Section 5.08

Summary of Discussion

In this chapter we discussed the participant's socio-demographics and the four HBM constructs, comparing their corresponding themes to existing research. Perceived barriers proved to be the most powerful dimension with five emerging themes (Management of Supplies, Self-

Cannulation, Travel Restrictions and Troubleshooting Alarms). The HBM proved to add value to the study and was an excellent foundation to comprehend the HHD experience. The modified use of the HBM and its constructs furthers the utility of the model with a different analytical approach. In the next chapter we conclude with a critical analysis of the overall study and acknowledge the theoretical and practical implications.

Chapter 6: Conclusion

Section 6.01

Introduction

In conclusion we take a comprehensive look at the dimensions of this study. The strengths, limitations, risks, benefits and potential biases of the study will be identified followed by a discussion of implications for research and practical use. The study will conclude with recommendations for future research and closing remarks to revisit the purpose of the study and examine the relevance of our end results.

Section 6.02

Study Conclusion

Study Strengths

The strength of this study lies in the methodology. The study does not corroborate or falsify a hypothesis but rather embodies a naturalistic discovery into the world of a home hemodialysis (HHD) patient.

When performing as a discovery oriented research instrument, qualitative researchers tend to construct study specific sets of questions that are open-ended in nature so the investigators provide openings through which interviewees can contribute their insiders' perspectives with little or no limitations imposed by more closed-ended questions.

(Chenail, 2011, p. 255)

Previous qualitative studies examining HHD patients primarily used questionnaires as their data collection tool which narrowed the scope for participant response. The specific, open-ended question designed for this study allowed the participants to speak freely about their dialysis experience. When participants were asked a specific themed question they often veered off and conversed on another topic (relevant to their HHD experience). Although their responses may not have matched with the specific question asked, it brought their foremost thoughts to the surface. According to Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles and Grimshaw (2010): “In studies that use semi-structured interviews that are analyzed using content analysis, sample size is often justified on the basis of interviewing participants until data saturation is reached” (pg. 3). Interviewing twenty participants and reaching data saturation was a significant advantage and represented approximately 40% of HHD patients at the community based hospital. This relatively large sample size was beneficial for seeking consistency in the findings and validating the emerging themes. Another notable strength was the use of the Health Belief Model (HBM) constructs to organize the data and the flexibility of the thematic analysis. Originally only two HBM constructs were going to be used to categorize the data (perceived benefits and perceived barriers) but two more constructs were later added (perceived severity and self-efficacy). Adding these unanticipated constructs demonstrates the genuine importance to comprehend the rich qualitative data. Utilizing these constructs allowed for more themes to emerge and added depth to exploring the HHD experience. Last but certainly not least, this is the first study conducted at the community based hospital in the Durham Region. Many previous studies focused on HHD patients in Toronto, making this study unique to the HHD population in the Durham Region.

Study Limitations

A limitation for this study was the non-randomization sampling method due to the nature of the dialysis cohort. The HBM provided structure and set the stage for analyzing the data. Therefore if this framework was not used, or a different theoretical model replaced it, findings may have varied. Excluding patients that did not clearly communicate in English for pragmatic reasons eliminated the opportunity to identify possible communication barriers. It should also be noted that this thesis was written as a representation of the researcher's own observations and analysis and therefore may not signify objective truths.

Potential Biases

This study may have a response bias, which according to Lavrakas (2008) refers to conditions or factors that take place affecting the way responses are provided. The participants may not have been entirely truthful with the interviewer for fear of giving an inappropriate answer and therefore may not have revealed an accurate depiction of their experiences. A response bias could have skewed the study's results however, given the nature of the data collection process; participants were likely to share truths about their HHD experience. There was also the potential for instrument bias as the principal investigator (PI) personally collected, analyzed and interpreted the data. According to Poggenpoel and Myburgh (2003) the researcher as instrument can be the greatest threat to trustworthiness in qualitative research if time is not spent on preparation of the field, reflexivity of the researcher and the researcher staying humble. The PI in this case had extensive background knowledge in the dialysis field through both research and personal experiences. This experience combined with the PI's ability to recognize

the research process itself as a focus of inquiry greatly reduced the potential for instrumental bias.

Risks and Benefits

There were no physical risks for participating in this study. There may have been psychological risks associated with the interview process, however none were reported. During the interviews, participants may have felt anxious when asked a question or felt embarrassed to answer. Although the interview questions were not designed to cause anxiety or embarrassment, a registered nurse was available on-site for psychological support if needed. There was no direct benefit for the participant but their participation contributes to a better understanding of their HHD experience. This may lead to future improvements in dialysis programs and have an indirect influence to their HHD experience.

Section 6.03

Research Implications

Theoretical Implications

Qualitative interviews primarily seek to understand meaning, and in this case we investigate what it means to live as a HHD patient. The results from this study were organized into various themes that align with the constructs of the HBM (perceived benefits, perceived barriers, perceived severity and self-efficacy). These categorical constructs break down the HHD experience as perceived by the participants. It was stated earlier that perceived benefits and perceived barriers were expected to emerge based on the design of the interview questions. It was important for the PI to understand that findings do not emerge only at the last stages of the

research, but recognize the context of the interview itself as an interactive learning tool. This mindset allowed for flexibility and as a result, perceived severity and self-efficacy were added for data analysis. Exploring all four HBM constructs provided depth to understanding the patient experience and educates the reader on the various dynamics of HHD. These constructs represent highlights (both negative and positive) as perceived by a HHD patient and together shape their lived experience.

Practical Implications

Current developments and the Ontario Renal Plan were introduced in *section 1.08*. The ORN (2014) recognizes an opportunity to enhance autonomy, quality of life, and outcomes for patients with CKD, while reducing costs to the overall healthcare system through increased uptake of independent dialysis. This study has discussed many of these opportunities and provided a foundation for developing practical solutions. Previous research shows that in-center dialysis is the most expensive and resource intense form of RRT. Therefore, reducing costs to the healthcare system means increasing the uptake of independent dialysis while maximizing retention. According the ORN (2013a) 74.9% of independent dialysis patients in Ontario were retained in the 2012-2013 fiscal year. To improve attrition rates it is important to identify what barriers these patients face at home. By eliminating or even reducing the impact of these barriers more patients will be able to continue HHD for longer.

Highlighting the benefits of HHD is also important, especially during pre-dialysis education. Healthcare professionals can educate the patients and their families on the benefits that HHD offers including flexible treatment schedules, autonomy and improved health. Understanding the HHD experience from a patient's perspective provides valuable insight for

decision makers, health care providers and other stakeholders to improve CKD programs. Perhaps this insight can also help future patients decide if HHD is the appropriate modality for them.

Section 6.07

Future Research

This study explored twenty HHD patients and identified several aspects of their chosen modality. Benefits, barriers, severity and self-efficacy emerged as the prominent themes to represent their personal experiences. It is encouraged that future research builds on these findings with a focus in the following areas:

Education:

Investigate the elements of the dialysis education program for patients and for caregivers. Is it sufficient and efficient? Is it retained by the patient and their caregiver? Can the level of caregiver support be pre-determined? If so, do current education programs provide the knowledge and skill for patients and their caregivers to be successful in supply management, vascular access, and troubleshooting alarms? Are there opportunities for real-time access to training such as web-based learning modules?

Caregiver Support:

Consider the patient and how they wish to lead their lives in regards to personal preference and their caregiver support. Can patients choose to have multiple caregivers trained to ease the burden of care? Are the caregivers being equipped with adequate learning tools? Does a model for more in-home support allow more patients to adopt HHD?

Health Benefits:

Confirm the physical health benefits discussed in the results such as weight loss and higher energy levels. Moreover, differentiate the physical health benefits between various dialysis modalities. For example, does HHD contribute to more weight loss compared to in-centre HD? To what degree do patients experience improved health from adopting any type of dialysis versus HHD?

Water Treatment:

Investigate the frequency and reoccurrence of HHD plumbing issues and strategies for improving water treatment systems to increase their reliability. When there are plumbing issues, patients have to return in-centre for HD treatments until these issues are corrected. How can this be prevented and are there temporary solutions to avoid returning in-centre? Also, how can patients be compensated for their increased water bills and who should be responsible (i.e. provincial or federal government)?

Electronic Data Sharing:

Explore the benefits and barriers of the HHD documentation process and the opportunity to move to an electronic automated system to track treatment logs. How might technology improve information sharing between healthcare professionals, patients and caregivers? Will a treatment tracking system encourage patients to improve their health through readily available information? Will new technologies be challenging for some patients to use?

Section 6.08

Closing Remarks

The seed of this research project began years before its commencement when I volunteered at the Lakeridge Health in-centre HD clinic. The experience working with these patients intrigued my curiosity and has since been the motivation behind my work. Qualitative research is an inquiry project, but it is also a moral, allegorical and therapeutic project (Denzin & Lincoln, 2005). The development of this study was a very satisfying process and I truly believe this research can help change the world of dialysis in positive ways.

This study has surpassed its goal by identifying not only the perceived benefits and barriers, but also the perceived severity and self-efficacy associated with HHD. The HBM was an effective theoretical framework especially for organizing the emerging themes. The semi-structured interviews allowed the participants to express their views without restrictions and successfully captured the essence of their experience. Seeing all twenty patients fully participate speaks volumes to their desire for improving their HHD experience. Perhaps the information they shared may contribute to an improved HHD experience for all.

To conclude, I leave the reader with a short but powerful quote from one of the participants: “What I tell people it’s like brushing your teeth. It’s part of your routine...you just do it”. Throughout this study we explored the various experiences of HHD patients. Despite their differences there is a mutual realization that dialysis is a life sustaining therapy. CKD patients will continue using dialysis despite any challenges they encounter. We should not be satisfied with our current RRT methods and technologies, striving for continuous improvement. It is my sincere hope that this research will create new avenues for improvements and enhance the overall dialysis experience.

References

- Agar, J. W., Hawley, C. M., & Kerr, P. G. (2011). Home hemodialysis in Australia and New Zealand: How and why it has been successful. *Seminars in Dialysis*, *24*, 658-663.
- Austin, L. T., Ahmad, F., McNally, M. J., & Stewart, D. E. (2002). Breast and cervical cancer screening in Hispanic women: a literature review using the Health Belief Model. *Women's Health Issues*, *12*(3), 122-128.
- Boateng, E. A., & East, L. (2011). The impact of dialysis modality on quality of life: A systematic review. *Journal of Renal Care*, *34*(4), 190-200.
- Bowling, A., & Ebrahim, S. (2005). Handbook of health research methods: investigation, measurement and analysis. New York, NY :McGraw-Hill International.
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3* (2), 77-101.
- Brod, M., Tesler, L. E., & Christensen, T. L. (2009). Qualitative research and content validity: developing best practices based on science and experience. *Quality of Life Research*, *18*(9), 1263-1278.
- Cafazzo, J. A., Leonard, K., Easty, A. C., Rossos, P. G., & Chan, C. T. (2009). Patient-perceived barriers to the adoption of nocturnal home hemodialysis. *Clinical Journal of the American Society of Nephrology*, *4*, 784-789.
- Champion, V. L., & Skinner, C. S. (2008). The Health Belief Model. *Health Behavior and Health Education: Theory, Research, and Practice*, *4*, 45-65.
- Chenail, R. J. (2011). Interviewing the Investigator: Strategies for Addressing Instrumentation and Researcher Bias Concerns in Qualitative Research. *Qualitative Report*, *16*(1), 255-262.
- Chilcot, J., Norton, S., Wellsted, D., Davenport, A., Firth, J., & Farrington, K. (2013). Distinct depression symptom trajectories over the first year of dialysis: associations with illness perceptions. *Annals of Behavioral Medicine*, *45*(1), 78-88.
- Christensen, A.J., Benotsch, E.G., & Smith, T.W. (1997). Determinants of regimen adherence in renal dialysis. In D.S. Gochman (Ed) . *Handbook of Health Behavior Research II* (pp. 231-244). New York, NY: Springer.
- Corbett, R. W., Prout, V., Haynes, D., Edwards, C., & Frankel, A. H. (2014). Problems associated with hemodialysis and travel. *Journal of travel medicine*, *21*(4), 255-259.
- Cresswell, J. W. (2003). Research design: qualitative, quantitative, and mixed method approaches. Thousand Oaks, CA: Sage Publications.
- Cummings, K. M., Jette, A. M., & Rosenstock, I. M. (1987). Construct validation of the Health Belief Model. *Health Education & Behavior*, *6*(4), 394-405.

- Davison, S. N. (2010). End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology*, 5(2), 195-204.
- Denzin N.K., & Lincoln Y.S. (2005). *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314-321.
- Fisher, J. D., & Fisher, W. A. (2000). Theoretical approaches to individual-level change in HIV risk behavior. In Peterson, J. and DiClemente, R. (eds) *HIV Prevention Handbook*. (pp. 3-55. New York, NY: Kluwer Academic/Plenum Publishers.
- Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health*, 25(10), 1229-1245.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), 59-82.
- Guest, G., MacQueen, K. M., & Namey, E. E. (2011). *Applied thematic analysis*. Los Angeles, CA: Sage Publications.
- Henriques, V., Anes, A., & Sardo, D. (2014). Patient empowerment in hemodialysis and physical barriers through cognitive impairment. *INTED2014 Proceedings*, 3777-3781.
- Hines, S. C., Glover, J. J., Holley, J. L., Babrow, A. S., Badzek, L. A., & Moss, A. H. (1999). Dialysis patients' preferences for family-based advance care planning. *Annals of Internal Medicine*, 130(10), 825-828.
- Holloway, I. (1997). *Basic concepts for qualitative research*. London, ENG: Blackwell Science.
- Holly, J. L. & Sinnakirouchenan, R. (2011). Peritoneal dialysis versus hemodialysis: risks, benefits, and access issues. *Advances in Chronic Kidney Disease*, 18(6), doi:10.1053/j.ackd.2011.09.001, 428-432.
- Janz, N.K., & Becker M.H. (1984). The Health Belief Model: A decade later. *Health Education Behavior*, 11(1), doi: 10.1177/109019818401100101, 1-47.
- Koch, M., Kohnle, M., Trapp, R., Haastert, B., Rump, L. C., & Aker, S. (2011). Comparable outcomes of acute unplanned peritoneal dialysis and haemodialysis. *Nephrology Dialysis Transplant*, 27, doi: 10.1093/ndt/gfr262, 375-380.
- Kvale, S. (1996). The interview situation. *Interviews: An Introduction to Qualitative Research Interviewing*, 124-135. In Nigel King & Christine Horrocks *Interviews in Qualitative Research*. Thousand Oaks, CA: Sage Publications.

- Lavrakas, P. J. (2008). Response bias. *Encyclopedia of survey research methods*. Thousand Oaks, CA: SAGE Publications. doi: <http://dx.doi.org.uproxy.library.uoit.ca/10.4135/9781412963947>
- Lincoln, YS. & Guba, EG. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.
- MacRae, J. M., Ahmed, S. B., Atkar, R., & Hemmelgarn, B. R. (2012). A randomized trial comparing buttonhole with rope ladder needling in conventional hemodialysis patients. *Clinical Journal of the American Society of Nephrology*, 7(10), 1632-1638.
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ: British Medical Journal*, 320(7226), 50–52.
- McFarlane, P., Bayoumi, A., Pierratos, A., & Redelmeier, D. (2003). The quality of life and cost utility of home nocturnal and conventional in-center hemodialysis. *Kidney International*, 64, 1004-1011.
- McFarlane, P. A., Pierratos, A., & Redelmeier, D. A. (2002). Cost savings of home nocturnal versus conventional in-center hemodialysis. *Kidney International*, 62, 2216-2222.
- McFarlane, P., & Komenda, P. (2011). Economic considerations in frequent home hemodialysis. *Seminars in Dialysis*, 24(6), 678-683.
- Mclaughlin, K., Manns, B., Morris, G., Hons, R., & Taub, K. (2003). Why Patients with ESRD do not select self-care dialysis as a treatment option. *American Journal of Kidney Diseases*, 41(2), 380-385. Retrieved from <http://dx.doi.org/http://www.sciencedirect.com/science/article/pii/S0272638602691498>
- Morton, R. L., Devitt, J., Howard, K., Anderson, K., Snelling, P., & Cass, A. (2010). Patient views about treatment of stage 5 CKD: a qualitative analysis of semi-structured interviews. *American Journal of Kidney Diseases*, 55(3), 431-440.
- Morton, R. L., Snelling, P., Webster, A. C., Rose, J., Materson, R., Johnson, D. W., & Howard, K. (2012). Dialysis modality preference of patients with CKD and family caregivers: A discrete-choice study. *American Journal of Kidney Disease*, 60(1), 102-111. Retrieved from <http://dx.doi.org/>
- Mowatt, G., Vale, L., & Macleod, A. (2004). Systematic review of the effectiveness of home versus hospital or satellite unit hemodialysis for people with end-stage renal failure. *International Journal of Technology Assessment in Health Care*, 7(2), 258-268.
- NVivo qualitative data analysis software; International Pty Ltd. Version 10, 2012.
- Ontario Renal Network (2014). Ontario Renal Plan. Retrieved from http://www.renalnetwork.on.ca/ontario_renal_plan/#.U5d5ydePOSo
- Ontario Renal Network (2013a). Attrition from home dialysis: increasing home dialysis by reducing attrition. Retrieved from <http://www.renalnetwork.on.ca/cms/One.aspx?portalId=256223&pageId=269670#.VFpLfcM9bD0>

- Ontario Renal Network (2013b). Proportion of incident hemodialysis patients by vascular access type and CKD regional program, Ontario, FY12/13. Retrieved from http://www.renalnetwork.on.ca/ontario_renal_plan/vascular_access/ckd_data/incidence_and_prevalence/#.VFkRg8m9bD1
- Ontario Renal Network (2011). By the numbers: Proportion of patients by modality. Retrieved from http://www.renalnetwork.on.ca/ckd_system_atlas/indepdial/
- Orem, D. E. (1991). *Nursing concepts of practice*. New York: McGraw-Hill.
- Poggenpoel, M., & Myburgh, S. (2003). The researcher as research instrument in educational research: A possible threat to trustworthiness? *124*(2), 418-21, 320.
- Quinn, R. R., Laupacis, A., Hux, J. E., Moineddin, R., Paterson, M., & Oliver, M. J. (2009). Forecasting the need for dialysis services in Ontario, Canada to 2011. *Healthcare Policy*, *4*(4), e151.
- Rioux, J., Cheema, H., Bargman, J. M., Watson, D., & Chan, C. T. (2011). Effect of an in-hospital chronic kidney disease education program among patients with unplanned urgent-start dialysis. *Clinical Journal of American Society in Nephrology*, *6*, doi: 10.2215/CJN.07090810, 799-804.
- Rosenstock, I., Strecher, V., & Becker, M. (1988). Social learning theory and the health belief model. *Health Education & Behavior*, *15*(2), 175–183.
- Rosenstock, I., Strecher, V. (1997). The health belief model. *Cambridge handbook of psychology, health and medicine*, 113-117.
- Sadala, M. L. A., Miranda, M. G., Lorençon, M., & De Campos Pereira, E. P. (2010). Nurse-patient communication while performing home dialysis: the patients' perceptions. *Journal of renal care*, *36*(1), 34-40.
- Somma, C., Trillini, M., Kasa, M., & Gentile, G. (2013). Managing end-stage renal disease in the elderly: state-of-the-art, challenges and opportunities. *Aging Health*, *9*(5), 539-552.
- Thodis, E. D., & Oreopoulos, D. G. (2011). Home dialysis first: A new paradigm for new ESRD patients. *Journal of Nephrology*, *24*(04), 398-404.
- van Loon, M. M., Goovaerts, T., Kessels, A. G., van der Sande, F. M., & Tordoir, J. H. (2009). Buttonhole needling of haemodialysis arteriovenous fistulae results in less complications and interventions compared to the rope-ladder technique. *Nephrology Dialysis Transplantation*, gfp420, doi: 10.1093/ndt/gfp420.
- Verhallen, A. M., Kooistra, M. P., & van Jaarsveld, B. C. (2007). Cannulating in haemodialysis: rope-ladder or buttonhole technique?. *Nephrology Dialysis Transplantation*, *22*(9), 2601-2604.
- Wiebe, J.S., & Christensen A.J. (1997). Health beliefs, personality, and adherence in hemodialysis patients: an interactional perspective. *Annals of Behavioral Medicine*, *19*(1), 30-35.

- Wilson, F. L., Mood, D. W., Risk, J., & Kershaw, T. (2003). Evaluation of education materials using Orem's self-care deficit theory. *Nursing Science Quarterly*, *16*(1), 68-76.
- Woods, J. D., Port, F. K., Stannard, D., Blagg, C. R., & Held, P. J. (1996). Comparison of mortality with home hemodialysis and center hemodialysis: A national study. *Kidney International*, *49*(5), 1464-1470. Retrieved from <http://dx.doi.org/http://www.nature.com/ki/journal/v49/n5/pdf/ki1996206a.pdf>
- Zhang, A., Bargman, J. M., Lok, C. E., Porter, E., Mendez, M., Oreopoulous, D. G., & Chan, C. T. (2010). Dialysis modality choices among chronic kidney disease patients: Identifying the gaps to support patients on home-based therapies. *International Urology and Nephrology*, *42*(3), 759-764.

Appendices

Appendix A – Lakeridge Health Standardized Health Checklist

Process Interventions 1: 0✓ of 27

Current Date/Time TJB

DH	Add Interv	Change Directions	Change Level	Change Status	Document Interv's	Document Now	Edit Admin Data	≥More
----	------------	-------------------	--------------	---------------	-------------------	--------------	-----------------	-------

HH-Clinic Visit

Current BP Sit BP Stand Heart Rate

Home BP range-pre tx sit Stand
 Post tx sit Stand

Pt concerns

Home blood sugars

Details

Comment

Goal wt (kg)-min
 Goal wt (kg)-max

Pt's goal wt (Kg)
 Avg IDWG (L or Kg)

Comment

Pt concerns

+	(Enter own response)
A	Appetite decreased
C	Constipation
CO	Pt/family not coping
CP	Chest pain
D	Diarrhea
E	Energy levels decreased
ED	Edema
F	Fatigue
H	Hypertension
HA	Headaches
HO	Hypotension
IN	Signs of infection
M	Muscle cramping
N	Neuropathy
NV	Nausea/vomiting
R	Restless legs
S	Sleep concerns

SO	Short of breath
T	Thirst
TE	Techniques
TH	Therapy
WG	Weight gain
WL	Weight loss

Appendix B – TCPS 2: CORE



Appendix C – UOIT REB Approval



RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

Date: November 28th, 2013

To: Chris Purves (Graduate Student) and Manon Lemonde (Supervisor)

From: Bill Goodman, REB Chair

REB File #: 13-059

Project Title: The lived experience of patients using home hemodialysis: a qualitative study

DECISION: APPROVED

START DATE: November 28th, 2013

EXPIRY: November 28th, 2014

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the above research proposal. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and the UOIT Research Ethics Policy and Procedures.

Please note that the (REB) requires that you adhere to the protocol as last reviewed and approved by the REB.

Always quote your REB file number on all future correspondence.

Please familiarize yourself with the following forms as they may become of use to you.

- **Change Request Form:** any changes or modifications (i.e. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or unexpected Events Form:** events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol. (I.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** must be completed when the research study has completed.
- **Renewal Request Form:** any project that exceeds the original approval period must receive approval by the REB through the completion of a Renewal Request Form before the expiry date has passed.

All Forms can be found at <http://research.uoit.ca/faculty/policies-procedures-forms.php>.

REB Chair Dr. Bill Goodman, FBIT bill_goodman@uoit.ca	Ethics and Compliance Officer compliance@uoit.ca
---	---

University of Ontario, Institute of Technology
2000 Simcoe Street North, Oshawa ON, L1H 7K4
PHONE: (905) 721-8668, ext. 3693

Appendix D – Lakeridge Health REB Approval



NOTIFICATION OF RESEARCH STUDY TO COMMENCE

To the Principal Investigator:
Christina Vaillancourt
Student: Chris Purves
Lakeridge Health

cc: LH Programs: Hemodialysis

attach: Research Team Form

From: Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging,
Lakeridge Health
(for Administrative Approval)

Chair, Lakeridge Health Research Ethics Board
(for Research Ethics Board Approval)

RI-ID# 2014-004
Study Title: The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study
Funding Source: n/a

All research studies must receive both Administrative Approval and Research Ethics Board Approval prior to commencement. Administrative Approval requires approval of the department impact, resource utilization (including sufficient funds to cover all expenses related to the study), and execution of a research Contract/Agreement. The above named study has been approved for administrative and resource utilization merit by Lakeridge Health under the current funding agreement. Any changes to the agreed funding, or protocol revisions that have an impact on resources, will require re-approval.

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

2017/01/20

Barry R. Guppy, MD, MPA, FRCPC
Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging
Lakeridge Health

Date



1 Hospital Court
Oshawa, ON
L1G 2B9



NOTIFICATION OF RESEARCH STUDY TO COMMENCE

To the Principal Investigator:
Christina Vaillancourt
Student: Chris Purves
Lakeridge Health

cc: LH Programs: Hemodialysis

attach: Research Team Form

From: Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging,
Lakeridge Health
(for Administrative Approval)

Chair, Lakeridge Health Research Ethics Board
(for Research Ethics Board Approval)

RI-ID# 2014-004
Study Title: The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study
Funding Source: n/a

All research studies must receive both Administrative Approval and Research Ethics Board Approval prior to commencement. Administrative Approval requires approval of the department impact, resource utilization (including sufficient funds to cover all expenses related to the study), and execution of a research Contract/Agreement. The above named study has been approved for administrative and resource utilization merit by Lakeridge Health under the current funding agreement. Any changes to the agreed funding, or protocol revisions that have an impact on resources, will require re-approval.

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

2014/01/20

Barry R. Guppy, MD, MPA, FRCPC
Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging
Lakeridge Health

Date



1 Hospital Court
Oshawa, ON
L1G 2B9



NOTIFICATION OF RESEARCH STUDY TO COMMENCE

To the Principal Investigator:
Christina Vaillancourt
Student: Chris Purves
Lakeridge Health

cc: LH Programs: Hemodialysis

attach: Research Team Form

From: Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging,
Lakeridge Health
(for Administrative Approval)

Chair, Lakeridge Health Research Ethics Board
(for Research Ethics Board Approval)

RI-ID# 2014-004
Study Title: The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study
Funding Source: n/a

All research studies must receive both Administrative Approval and Research Ethics Board Approval prior to commencement. Administrative Approval requires approval of the department impact, resource utilization (including sufficient funds to cover all expenses related to the study), and execution of a research Contract/Agreement. The above named study has been approved for administrative and resource utilization merit by Lakeridge Health under the current funding agreement. Any changes to the agreed funding, or protocol revisions that have an impact on resources, will require re-approval.

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

2014/01/20

Barry R. Guppy, MD, MPA, FRCPC
Vice President, Medical & Academic Affairs, Research and Diagnostic Imaging
Lakeridge Health

Date



1 Hospital Court
Oshawa, ON
L1G 2B9



In addition to Administrative Approval, the above named study has been approved for ethical and scientific merit by the Research Ethics Board (REB). This research study may now commence, contingent upon the following:

(i) As a reminder, the REB and LH operate in compliance with applicable laws and regulations including, but not limited to, the International Conference on Harmonization for Good Clinical Practice (ICH/GCP) Guidelines as set forth in Part C Division 5 under the Canadian Food and Drugs Act and the Tri-Council Policy Statement (TCPS2) on *Ethical Conduct for Research Involving Humans*, 2010. Lakeridge Health is registered with the U.S. Department of Health & Human Service under IRB registration number IRB00003507. As the Principal Investigator, you are responsible for the ethical conduct of all research team members during the course of the study, and for cooperating with monitoring activities determined by the REB. As such, you and your Research Team (see attached) agree to undertake the study in conformity with the approved protocol, and to immediately report to the REB:

- any revisions, additions, deletions or other amendments via the *Amendment/Revised Consent Form*;
- any local, and specifically relevant external serious adverse events via the *Internal Serious Adverse Event (SAE) Report Form*; and
- any deviation or new information with respect to the protocol via the *Protocol Deviation Form*

(ii) In the event of confidentiality concerns or privacy breach, such as inappropriate and/or unauthorized use of information, you are to immediately report these to both the REB and to the LH Privacy Officer (in accordance with Ontario health privacy legislation – *Personal Health Information Protection Act, 2004*) via the *Privacy Breach Report Form*.

(iii) As the Principal Investigator, you are further expected to submit:

- an annual progress report and annual re-approval via the *Annual Report/Re-Approval Form* if the study is expected to continue beyond the Expiry Date; and
- a *Study Closure Form* along with a copy of the final report when the study has been completed.

Contact Information:

CONTACT	NAME	PHONE
Principal Investigator	Christina Vaillancourt	905.576.8711
LH Research Department	Research Liaison	905.576.8711 x2745
Research Ethics Board	Chair	905.576.8711



1 Hospital Court
Oshawa, ON
L1G 2B9



REB Meeting Date: Monday January 6, 2014

REB Review Type: A Full Board Meeting
 The Chair with Notification to All Board Members

REB Approval Date: January 6, 2014

REB Approval Expiry Date: January 6, 2015

The Research Ethics Board has received the following documentation for study entitled:

"The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study"

Documents approved until the expiry date noted above:

- Protocol dated September 20, 2013
- Recruitment Letter/Verbal Script version 1 dated 1/8/2014
- Main Informed Consent Form version 1 dated 1/8/2014
- Consent Form for Audio Recordings version 1 dated 1/8/2014

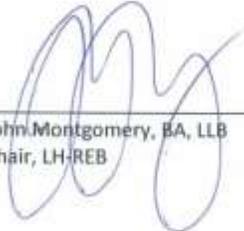
Documents Acknowledged:

- Letter from Director of Medical Radiation Sciences Program dated Dec.2/13



1 Hospital Court
Oshawa, ON
L1G 2B9



Signed:  OR 
John Montgomery, BA, LLB OR Douglas McIntosh, MD, MA, BSc
Chair, LH-REB Vice-Chair, LH-REB

Please quote your file number (RID#2014-004) on all future correspondence.

Notification of Research Study to Commence Release Date: January 23, 2014

Appendix E – Consent Form



CONSENT FORM

Title of Study: The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study

Principal Investigator: Christina Vaillancourt
905-576-8711
cvallancourt@lakeridgehealth.on.ca

Supervisor: Manon Lemonde, RN, PhD
Associate Professor, Graduate Program Director
Faculty of Health Sciences
University of Ontario Institute of Technology
905-721-8668 (2706)
Manon.Lemonde@uoit.ca

Student: Chris Purves, BHSc
MHSc Candidate
University of Ontario Institute of Technology
647-406-5273
Chris.Purves@uoit.ca

Introduction

We invite you to take part in a research study at Lakeridge Health. The study is described below. Before agreeing to participate in this study, it is important that you read and understand the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the principal investigator to explain any words you don't understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Purpose of Study

The purpose of this research is to report common barriers/challenges that home hemodialysis (HHD) patients experience. Interviewing the patients individually offers a unique perspective into their lived experience at home. Reporting the barriers they face will provide insight to overcome them and improve their dialysis experience. Limiting the amount of barriers will create an opportunity for more dialysis patients to be able to perform independent dialysis and for longer.

You are being asked if you wish to participate in this study because interviewing HHD patients individually offers a unique perspective into their lived experience at home.

There will be a total of 10-20 participants in this study.

Your involvement in the study will approximately take 30 minutes.

Study Procedures

The principal investigator will meet patients during regular clinic hours on Wednesdays and introduce the research project to each patient individually. The principal investigator will provide the patient with the recruitment letter and read through it with the patients. The study involves a private one on one interview between the principal investigator and the participant. Patients that are interested in participating may choose to have the interview immediately in a private room at Lakeridge Health Whitby. Patients who do not wish to start the interview immediately may schedule an interview on another date with the principal investigator.

Before each interview the principal investigator will provide patients with a consent form and answer any questions or concerns they might have. If the patient provides consent and signs the consent form the interview process will begin. Participants will not be

asked to share their name. Instead they will be assigned a code number and a nickname by the principal investigator to differentiate between participants. There will be one page of demographic information to be filled out by the participant followed by five themes that the principal investigator will verbally read in one at a time. The duration of the interviews will last approximately 30 minutes and will vary based on the length of participant responses. These interviews will be audio recorded to ensure the accuracy of the data collection. The audio recordings will be deleted from the recording device once the study is complete (August 2014). When the interview is finished the principal investigator will verbally thank the participant and notify them that their involvement is complete.

Eligibility

The participants must be home hemodialysis patients from the Lakeridge Health program and be capable of speaking English. Participants will not be excluded based on age, race, gender, religion, education level or any other demographic status. Home peritoneal dialysis patients will be excluded from the study.

Researchers

Chris Purves will conduct the one on one interview.

Expectations of the Participant

Participants will be asked to read through the recruitment letter with the principal investigator outlining the study aims and participation requirements. They will be asked by the principal investigator if they are interested in participating. If the participant is interested, they can choose to have the interview right away or on a future date. If the participant prefers to post pone the interview the principal investigator and the participant will schedule the interview for another date. If the participant wishes to proceed with the interview immediately they will be directed to a designated room at Lakeridge Health Whitby for privacy. The participant will be provided with the consent form and read through it. They may ask the principal investigator questions before signing the consent form. The participant will be provided with a one page demographic information sheet. Once this sheet is complete, the participant will be asked five themes about their home dialysis experience. There is no time limit for responses and participants may choose to refuse to answer any question or terminate the interview at any time. The interview will take approximately 30 minutes. This interview is all that is required of the participant.

Possible Risks

There are no physical risks associated with this study. There may be psychological risks associated with the interview process. During the interviews participants may feel anxious when asked a question or feel embarrassed to answer.

Possible Benefits

There is no direct benefit to participant but their participation will contribute to a better understanding of their lived experience of undergoing hemodialysis treatment at home by identification of the barriers/challenges.

Costs

There are no associated costs with the study procedures.

Compensation

You will receive no payment or reimbursement for any expenses related to participating in this study. Your participation may contribute to the creation of new diagnostic tests, new medicines or other events that may have commercial value. However, your participation in this study will not entitle you to a share in any future economic benefits.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed.

Your anonymity and confidentiality are of utmost importance and will be protected at all times. All information will remain confidential. Your name will not appear on the interview form and a code number and a nickname will be assigned to it. The investigator will keep all information you provide in a sealed envelope. The recorded information from the interview will be transcribed by the principal investigator and will be kept in a locked cabinet in the research office at the University of Ontario Institute of Technology, to which only the principal investigator has access. The recorded information from the interview will be transcribed by the principal investigator on a password protected computer. The recording will be destroyed following the completion of the study in August of 2014.

Data collected from the interview will be recorded and transcribed by the principal investigator on a password protected computer. Audio data will be terminated once the study is complete (August, 2014).The University of Ontario Institute of Technology and

the Lakeridge Health Research Ethics Boards may review records related to the study for quality assurance purposes, as it oversees the conduct of this study.

Right as a Participant

Your participation to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. If you wish to withdraw from the study you must verbally inform the principal investigator. Written notification is not required. If you wish to have your data withdrawn you must contact the principal investigator at their contact information located on page 1 of this document. Your decision not to participate or withdraw from the study will not affect your care at Lakeridge Health.

Questions/Concerns

The principal investigator will be available to answer questions throughout the study. If you agree to participate in this research study, please sign the form on the next page. Your signature indicates your consent and that you have understand the information regarding this research study. By signing this form you are not waiving your legal rights.

If you have any questions about this study or would like to be informed when the study is completed, please contact Chris Purves at 647-406-5273. You will also be given a copy of the consent form to keep.

Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact UOIT Research Ethics Officer, at compliance@uoit.ca or call 905.721.8668 Ext. 3693. You may also contact Lakeridge Health Research Ethics Board Chair at 905-576-8711.

Appendix F- Consent Form For Audio Recordings (Version 1- 1/8/2014)



CONSENT FORM FOR AUDIO RECORDINGS

The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study

Investigator: Chris Purves

I hereby consent to be audio recorded during participation in this research project. These recordings will be used to report the home hemodialysis patient experience and provide insight to overcome any challenges/barriers these patients may face. I understand that I am free not to participate in this part of the study, and that if I do agree to participation, I am free to withdraw from this part of the study at any time (for example, before or even after the audio recording is made) without any consequence or comprising the quality of care at Lakeridge Health.

Printed Name of Participant

Date

Signature of Participant

The person who may be contacted about the research is Chris Purves at Chris.Purves@uoit.ca, or 647-406-5273.

Printed name of person who obtained consent

Date

Signature of person who obtained consent

In addition, I give permission for this audio recording to be used for:

- other research projects on the same topic
- teaching and demonstration at Lakeridge Health
- teaching and demonstration at professional meetings outside Lakeridge Health
- not to be used for anything else.

In giving permission for the use of the audio recording beyond the current research, I have been offered the opportunity to hear the audio recording and I understand that I am free to withdraw my permission for other uses of the recording at any time.

Printed Name of Participant

Date

Signature of Participant

The person who may be contacted about the research is Chris Purves at Chris.Purves@uoit.ca, or 647-406-5273.

Printed name of person who obtained consent

Date

Signature of person who obtained consent

Share Your Voice!

Who: Home hemodialysis patients

What: Interview with UOIT Masters Student
Chris Purves

When: Feb 12th & 26th / March 19th & 26th

Where: Lakeridge Health Whitby

Why: To understand the patient experience



"The purpose of this research is to identify common barriers/challenges that home hemodialysis patients face. Interviewing the patients individually offers a unique perspective into their lived experience at home."



Chris Purves - 647-406-5273 - Chris.Purves@uoit.ca

Appendix H – Recruitment Letter/Verbal Script



Recruitment Letter / Verbal Script

Dear potential participant,

My name is Chris Purves and I am a Masters student at the University of Ontario Institute of Technology. In the past I have volunteered in the dialysis unit at Lakeridge Health Whitby. This experience has given me the opportunity see what dialysis is all about and I have focused my research in this area.

This is an invitation to participate in an individual interview that should last approximately 30 minutes. During the interview, you will be asked to reflect on your experience with home hemodialysis. This data will be included in a research project I am conducting that investigates the lived experience of patients performing hemodialysis at home.

The interview can start right now or it can be scheduled another time. The interview will be audio recorded and will take place in a private room at Lakeridge Health Whitby. You will be asked to fill out a one page information sheet and then you will be asked five questions about your dialysis experience. You will be given a nickname that the researcher will use in the research. Your name, address, or contact information will not be collected. Other members of the research committee may be given access to the data for research purposes. Your decision to participate or any information being collected will not be shared with Lakeridge Health staff and your care will not be affected.

If you are interested in participating in this study, I will provide you with the consent form and I can answer any questions or concerns you might have. You may choose to stop the interview at any time or refuse to answer any question without any consequence. If you agree to the terms outlined in the consent form we can begin the interview. If you wish to schedule the interview on a later date, we can decide on a day and time to meet at Lakeridge Health Whitby. If you do not wish to participate please disregard this letter.

Thank you for considering participating in this project,

Chris Purves, MHS Sc Candidate | chris.purves@uoit.ca | 647-406-5273

Appendix I – Interview Questions



“The Lived Experience of Patients Using Home Hemodialysis: A Qualitative Study”

<p><i>Principal investigator use only:</i></p> <p>Participant Code: _____ Participant Nickname: _____</p>

Gender (circle): Male Female

Age: _____

City (not address): _____

Living Arrangement (e.g., house, apartment) _____

Average Annual Personal Income: \$ _____

Average Annual Household Income (if different form above): \$ _____

Marital Status (circle):

Married Widowed Separated Divorced Single

Highest Level of Education (circle):

High School College Diploma University Degree Graduate Level Degree

Other: _____

First Dialysis Treatment:

Month/Year: _____/_____

Location: _____

Type: _____

First Home Hemodialysis Treatment (if different from above):

Month/Year: _____/_____

Interview Questions:

1. Share with me how you came to start home hemodialysis therapy and your transition experience to home dialysis? Was there anything or anyone that had an influence in your decision?
2. What is it about this type of therapy that has a positive effect in your life? What do you like about it? What makes it easy?
3. What are the challenges you have found or continue to face with home therapy? What makes it hard?
4. Who or what helps you deal with the challenges? Do you rely on a caregiver? What could help you continue this home therapy?
5. In your opinion what could enhance your dialysis experience at home?

Appendix J- Clinic and Education Observation Report

Prior to the commencement of the recruitment stage, the principal investigator (PI) observed two HHD education sessions at Lakeridge Health Whitby. The purpose of these observations was to better understand the practices of the home dialysis program. The observations allowed the PI a chance to learn about the HHD assessment process and acquire a sense of the clinic environment. Descriptions of the two clinic days were logged as a journal entry by the PI and were divided into two reports. The independent dialysis education observation report describes a pre-dialysis education session with a healthcare professional, dialysis patient and their caregiver.

Clinic Day 1

On the first observation day there was a patient receiving dialysis treatment in one of the six chairs in the clinic. The patient usually performs dialysis at home with her daughter, the primary caregiver. The daughter was out of town and therefore the patient required the in-centre support for treatment. The patient freely shared some of her views. She discussed the heavy responsibility bestowed on the caregiver and suggested there should be a few different caregivers to share this burden. The patient also suggested that access to technical video support would be very helpful to be used as a knowledge refresher at home.

One of the nurses and I discussed how the clinic operates and what is required from the patients. There are approximately fifty HHD patients in the home dialysis program, with four full time nurses and one part time nurse on hand. The patients typically visit the clinic every eight weeks for a full individual assessment with various healthcare professionals. HHD patients are also required to submit their blood work on a monthly basis. The blood tests can either be

dropped off in person or results can be sent directly from the laboratory. In some cases the lab technician, who services the dialysis machine monthly, can bring their blood tests back to the clinic for them. The patients have multiple avenues to submit their blood work to the clinic. The nurse and I then briefly discussed the following fiscal matters:

- If the patient travels to the U.S. it costs \$500 per dialysis treatment, and only \$310 is covered by the Ontario Health Insurance Plan (OHIP)
- It costs \$30,000 for a home dialysis machine which is fully covered by OHIP
- On average, patients quarterly water bills are increased by \$30-\$50
- A grant program currently exists in Ottawa Region to assess HHD patients and covers up to \$50 for added water expenses, but no program exists in Durham Region.

Some patients were involved with a tender that was sent to the Ontario Government and the Regional Municipality of Durham Region. The HHD patients argued that their increased water and hydro bills should be reimbursed. The increased utility cost remains an issue for HHD patients.

Clinic Day 2

On the second clinic day I was able to observe a patient assessment. When the patient arrived, the nurse was the first contact. The nurse took her blood pressure (sitting and standing) and completed the Standardized Health Checklist (Appendix A). The nurse also explained that there were new dialyzers and a shipment will be coming soon to the patient's home. She explains that these are safer than the old ones. Some patients have to come in for a trial to learn how to use the new dialyzers but this patient will not have to because of her experience level. The patient said she does not have any problems with the dialyzer itself but is frustrated locating an

access point on her arm (AVF). Her arm was scabbed around the AVF, which made it difficult for self-needling.

The patient brought in her blood work and was overwhelmed. There were about ten to fifteen samples. The laboratory report showed low phosphate and high calcium levels. This issue was addressed by the dietician who determined that the patient was missing treatments periodically, which explained the fluctuating phosphate and calcium levels. Rather than lecture the patient about keeping up with her treatments, they discussed personalized strategies for improvement. The dietician discussed nutritional alternatives and recommended specific food types that would help maintain healthy phosphate and calcium levels. Medications were also discussed and explored further with the pharmacist.

The pharmacist explained each medication thoroughly one by one. The patient then complained about constant cramps she felt and asked for a solution. The pharmacist suggested “Gabapentin” medication to ease the neuropathic pain. This recommendation was added to the chart and the patient was ready to consult with the physician.

The physician arrived and seemed to know the patient well. They discussed the patient’s personal life before the assessment began. Setting a target weight and maintaining that weight was a top priority in the discussion. The physician addressed the issues discussed earlier in the consult. It was evident that the healthcare team worked well together and were able to collaborate effectively. The physician wrote prescriptions for Aranesp – to treat anemia, and Gabapentin – used for reducing cramping and nerve pain. The nurse returned and finished the assessment by updating the patient’s file and scheduling their next visit. The patient was happy to be finished and was expected to return in another eight weeks.

Independent Dialysis Education Observation Report

The PI observed an independent dialysis education session between a healthcare professional and patient. The patient's wife was also present and designated as the caregiver. After a brief introduction the session began with answering any questions or concerns for the patient. The patient was receiving conventional in-centre HD and was new to dialysis and naturally had a few questions for the healthcare professional. The following is a conversation between the patient and healthcare professional:

Patient: *"Why do I feel worse after Monday treatments in comparison to Wednesday and Friday treatments?"*

Healthcare Professional: *"You feel worse because you did not receive treatment on the weekend and have more fluid and waste build-up that is filtered from your blood".*

Patient: *"How long does it take to transition from in-centre HD to home?"*

Healthcare Professional: *"PD takes a couple weeks and HD depends on how fast you receive surgery for an access point. If you use an AV F you can go swimming and don't have to cover it up".*

Patient: *"Is dialysis permanent?"*

Healthcare Professional: *"If you recover you will likely need dialysis down the road".*

Following this question and answer period the healthcare professional began a presentation outlining PD and HHD modalities. For HHD, short daily and nocturnal treatment options were thoroughly explained. The patient asked questions about the space required in his home, filtering systems, cosmetic appearance and noises from the dialyzer. The healthcare professional then

explained that installation, plumbing, and supply costs are fully covered by OHIP however water and hydro bills will increase and there is no compensation (but can be claimed for a tax credit). Although HD treatments can only be done at home, there are options to travel and prearrange in-centre HD treatments with partial compensation (e.g., One HD treatment in Florida costs \$500 and the patient is reimbursed \$310 from OHIP).

When discussing PD the healthcare professional explained that if a patient has a gastrointestinal ulcer or has had previous abdominal surgeries than PD may not be the best option. This patient did not have any of these problems and the healthcare professional provided more information about PD. PD preserves the kidney function and filtering occurs naturally in the body. There are no hydro requirements (for daily PD) and the recommended treatment schedule is three times a day for thirty minutes. Nocturnal PD requires hydro and is a slower dialyzing process, however eliminates the frequent daily treatments. The healthcare professional also mentioned that PD allows patients to travel more easily compared to HD because there is no dialyzer machine. You can pack PD supplies in your vehicle and perform treatments anywhere. The healthcare professional emphasized that there is a high risk of infection with the PD access point and discussed techniques to execute a safe and sterile connection.

The patient and his wife were leaning towards choosing PD because they wanted the option to travel without arranging in-centre HD at their destination. They decided they needed more time to absorb the information and consider both options.