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An exploration of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health.

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Graduate Program in Nursing
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ABSTRACT

The number of Canadians being treated for kidney failure has more than tripled in the last 20 years, making hemodialysis (HD) a more common and expensive treatment option. Individuals having in-center HD require access to transportation to and from an HD center on average three days a week for a total of six trips. Therefore, access to transportation is a vital component for sustaining the health and well-being of this population. The purpose of this interpretive descriptive qualitative study was to explore how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health, using the World Health Organization's definition of health. A purposive sample of eight individuals were recruited and each participated in an individual audio-recorded semi-structured interview. Using inductive analysis, three interrelated themes were identified: *reliability*, *choice*, and *personal safety*. The findings highlight that individuals using transportation services for HD experience the challenge of reliable services, this included: dependability of transportation services for HD treatment and connection to health, and variations in consistency and coordination of transportation. Financial impacts and asking for support from family and friends factored participants' choice in using alternative modes of transportation when services were unreliable. Transportation services also impact the personal safety of persons on HD, as participants shared the need for resources for safer travel and behaviours reflecting need for driver education. The findings can serve to inform changes in practice, research, and policies that influence the health of this population.

Key Words: End-stage renal disease, hemodialysis, transportation for hemodialysis, transportation and health.

SUMMARY OF LAY AUDIENCE

The number of Canadians being treated for kidney failure has more than tripled in the last 20 years, making hemodialysis (HD) a more common and expensive treatment option. Individuals having in-center HD require access to transportation to and from an HD center on average for six trips a week. Therefore, access to transportation is an important component for sustaining the health and well-being of this population. The purpose of this study was to explore how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health, using the World Health Organization's definition of health. Findings identified three interrelated themes: *reliability*, *choice*, and *personal safety*. The findings highlight that individuals using transportation services for HD experience the challenge of reliable services, this included: dependability of transportation services for HD treatment and connection to health, and variations in consistency and coordination of transportation. Financial impacts and asking for support from family and friends factored into participants' choice for using alternative modes of transportation when services were unreliable. Transportation services also impacted the personal safety of persons using HD, as participants shared the need for resources for safer travel and behaviours reflecting need for driver education. Overall, there needs to be improvement in access to transportation for HD treatment as it impacts the health of individuals requiring such treatment.

CO-AUTHORSHIP STATEMENT

Navpreet Kamboj conducted the research for her master's thesis under the supervision of Dr. Yolanda Babenko-Mould and Dr. Kim Jackson who will be co-authors on all manuscripts and presentations stemming from this thesis.

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CHAPTER ONE

INTRODUCTION

Chronic illness impacts all aspects of an individual's life and for people with end-stage renal disease (ESRD), their daily routine is greatly altered by this chronic illness as they receive renal replacement therapy (RRT) to maintain health (Gilbert, Lovibond, Mooney, & Dudley, 2018). Dialysis is the most common RRT required for patients with ESRD. There are two types of dialysis options: peritoneal dialysis and hemodialysis (HD) (Gilbert et al., 2018). HD treatment involves filtering waste products, balancing electrolytes and removing extra fluid from the blood to compensate for normal kidney function (Sockrider, & Shanawani, 2017). HD can be performed at home by the individuals or family member with minimal assistance from healthcare professionals or in-center locations by healthcare professionals (The Kidney Foundation of Canada, 2013). In Canada, in-center HD treatment is the most prevalent type of dialysis with 79% of individuals on dialysis using the modality (Chartier et al., 2015). For in-center HD, some individuals require a transportation service from a transportation provider to attend their HD treatment session. This type of transportation is identified as non-emergency medical transportation (NEMT) and is presented with many challenges (Park, & Kear, 2017), that have been found to influence the meaning of health for this population.

The World Health Organization (WHO, 1946) defines health as “a state of complete physical, mental, and social well-being, and not merely absence of disease or infirmity” (p.1268). Since the formation of WHO's definition of health, it has been widely taken up around the world and has had a vital role in developing national health care systems and shifting perspective beyond the traditional boundaries of health care. WHO's (1946) definition of health is used in this study to explore the research topic, as it is suggested that

access to transportation for treatment impacts health in more ways than specific treatment adherence alone, as overall health in this study includes physical, mental, and social well-being.

Background and Significance

The frequency and duration of HD treatment is largely dependent upon the patient's health status. On average, patients that require in-center HD are usually attending a treatment facility three times a week for four hours each time (Park, & Kear, 2017). Therefore, transportation is required for six trips a week. In Ontario, individuals are responsible for paying their own transportation fare however, depending on their income status and if they are on disability social services, they may be eligible for a subsidized rate provided by the government (Region of Peel, 2018). For instance, for eligible patients in the setting of this study, the cost for using TransHelp, a transportation service in the Peel Region, is equivalent to the cost of public transit fare, however, the actual cost to this service to the government is considered to be 10-times greater than the subsidized rate. Individuals using TransHelp are charged approximately \$3.50 for one trip and the government pays the remaining cost. This same process of government subsidized cost applies to other transportation providers although the fare price may vary.

This eligibility is considered on a case-by-case basis and is determined based on the residents' needs and barriers to using conventional public transit (Region of Peel, 2018). If an individual is eligible, they must complete the application and have a registered medical professional sign the document confirming their health status. Once signed, submitted, and approved, the patient receives their client identification information that is used to schedule a transportation service. If a trip is cancelled with more than 24-hour notice from the scheduled time, there are no charges (Region of Peel, 2018). If the service

is cancelled within 24 hours, the patient is charged for the booked transportation fee. Patients are recommended to be at the pick-up location ahead of time to prevent any issues however this is not always possible. If patients are not present at the scheduled time, their transportation provider may (and usually does) leave the patient.

With the increasing number of individuals requiring HD, readily available and accessible transportation service is a challenge that can impact health outcomes. Unreliable transportation is often cited as a key barrier to individuals' adherence to HD (Obialo, Hunt, Bashir, & Zager, 2012). In fact, Madeiro, Machado, Bonfim, Braqueais, and Lima (2010) examined adherence to HD treatment regimen and identified transportation as the factor impacting individuals' adherence the greatest. Consequently, individuals who depend on a transportation service provider to attend HD are at increased risk to forego their treatment session leading to serious health implications (Chan, Thadhani, & Maddux, 2014). There has been an increase in the number of individuals who are requesting to end their treatment early due to access issues related to inflexible transportation (Chenitz, Fernando, & Shea, 2014). If the HD treatment is constantly being shortened or skipped, it can lead to serious and severe health outcomes. This may include accumulation of fluid and toxins in the body causing physiological complications such as fluid overload and shortness of breath, leading to cardiovascular complications, and in some cases death (Hoppe et al., 2018). When individuals are forced to miss or cut short scheduled HD sessions as a result of transportation, an immediate increase in admission to hospital, emergency room, and critical care units has been observed (Chan et al., 2014). This places additional strains and risks on the individual's health and increases the cost to the healthcare system.

In addition to these complications, mental and social well-being of individuals is also influenced. Psychosocial factors, such as depression and anxiety, are associated with

mortality in dialysis patients and more common for individuals with chronic kidney disease (Bargiel-Matusiewicz & Stelmachowska, 2019). Dialysis patients demonstrate mood reduction leading to the willingness to stop this life sustaining treatment (Bargiel-Matusiewicz & Stelmachowska, 2019). These symptoms may be further exacerbated by transportation issues. The Kidney Foundation's submission to the Ontario Human Rights Commission (2002) mentioned that in Toronto, there is a serious problem with the taxi services for HD, to the point where some individuals refuse to use certain taxi providers, as the stress of the delays they experience has an extremely negative impact on their health. Skipping or missing full treatment is ultimately associated with a 25% increase in mortality over a 2-year period (Clark, Farrington, & Chilco, 2013). Fortunately, improving transportation services for individuals receiving in-center HD could decrease hospitalization for each patient by 0.8 days per year (Chan et al., 2014).

The number of Canadians being treated for kidney failure has more than tripled in the last two decades and there is no cure for kidney disease (The Kidney Foundation of Canada, 2013). Individuals receiving HD treatment must attend their treatment sessions in order to maintain their health. While there is abundant literature on ESRD and HD, there is a gap exploring how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health. Therefore, this study aims to address this gap by exploring the experience of individuals using NEMT services for HD treatment and its impact on their understanding of health. Findings from this study will result in recommendations for improving health, in relation to transportation for the individuals on HD and will be disseminated to stimulate change in the areas of practice, research, and policy development and revision.

Statement of Purpose

The purpose of this study is to illuminate how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health.

Research Question

How do persons requiring in-center hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health?

Declaration of Self

There are numerous factors that assisted to inform the development and focus of this research study, HD is an area of interest for me that was awakened while working as a registered nurse in cardiology. One day, I was caring for a patient that required HD treatment to maintain health, and ultimately, to be alive. Seeing her undergo this treatment and listening to how much her life had altered since being diagnosed with ESRD and starting HD treatment inspired me to pursue a career as a HD nurse. I have been working as a HD nurse for over two years and during this time, I noticed the impact of such a strict regimen and the demand that HD treatment has peoples' lives. This challenge is further exacerbated by the transportation issues that individuals face at every treatment. Seeing individuals shorten or even miss a treatment that allows them to maintain their health due to transportation problems was concerning to me as a nurse and as a human being. This exposure stimulated me to explore how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health. As mentioned by Creswell (2003) there is undeniably a strong personal stimulus to pursue topics that are of personal interest related to marginalized individuals and a desire in creating a better society for all. This statement openly expresses my decision to pursue a study focusing on HD patients and the issue of access to transportation. This study was

based on the following assumptions which were also informed by an interpretive description design (Thorne, 2016): (a) being in a clinician and researcher role that is relevant to this topic, my experiences and perspectives ultimately influenced the interview questions I asked, as well as the interpretation of the data and presentation of the study finding, (b) the results of this study were true to the context in which those experiences occurred, (c) the experiences and outlooks of the participants guided my understanding of the results of the study, (d) in alignment with naturalist and constructivist inquiry, I acknowledge that there are multiple realities and the influence of social aspects of human experiences that contributed to the study findings, and finally (e) the interactions with the surrounding systems shaped the experience of participants. These assumptions serve as a platform to provide meaningful research that informs the improvement of access of transportation for HD treatment.

Overview of Thesis

This thesis is composed of three chapters. Chapter one provided the general overview of the topic of HD, transportation, and health, with an overview of the significance of the study, the study purpose, and the research questions. Chapter two, the manuscript, is the main component of this thesis. In chapter two, the background to the study, literature review, methodology, and findings are presented. Chapter three involves a discussion of the study implications as they relate to practice, research, and policy. It also provides the general conclusions of this thesis.

References

Bargiel-Matusiewicz, K., Łyś, A., & Stelmachowska, P. (2019). The positive influence of psychological intervention on the level of anxiety and depression in dialysis patients: A pilot study. *The International Journal of Artificial Organs*, 42(4), 167-174. doi:10.1177/0391398818823765

- Chan, K. E., Thadhani, R. I., & Maddux, F. W. (2014). Adherence barriers to chronic dialysis in the united states. *Journal of the American Society of Nephrology*, 25(11), 2642-2648. doi:10.1681/ASN.2013111160
- Chartier, M., Dart, A. Tangri, N., Komenda, P., Wald, R., Bogdanovic, B., ... Rajotte, L. (2015). *Care of Manitobans living with Chronic Kidney Disease*. Retrieved from http://mchp-appserv.cpe.umanitoba.ca/reference/ckd_final.pdf
- Chenitz, K. B., Fernando, M., & Shea, J. A. (2014). In-center hemodialysis attendance: Patient perceptions of risks, barriers, and recommendations: Barriers to hemodialysis attendance. *Hemodialysis International*, 18(2), 364-373.
- Clark, S., Farrington, K., & Chilcot, J. (2014). Nonadherence in dialysis patients: Prevalence, measurement, outcome, and psychological determinants. *Seminars in Dialysis*, 27(1), 42-49. doi:10.1111/sdi.12159
- Cresswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA: Sage Publications.
- Gilbert, J., Lovibond, K., Mooney, A., & Dudley, J. (2018). Renal replacement therapy: Summary of NICE guidance. *BMJ (Clinical Research Ed.)*, 363, k4303. doi:10.1136/bmj.k4303
- Hoppe, L. K., Muhlack, D. C., Koenig, W., Carr, P. R., Brenner, H., & Schöttker, B. (2018). Association of abnormal serum potassium levels with arrhythmias and cardiovascular mortality: A systematic review and meta-analysis of observational studies. *Cardiovascular Drugs and Therapy*, 32(2), 197-212. doi:10.1007/s10557-018-6783-0
- Madeiro, A.C., Machado, P.D.L.C., Bonfim, I.M., Braqueais, A.R., & Lima, F.E.T. (2010). Adherence of chronic renal insufficiency patients to hemodialysis. *Acta*

Paulista de Enfermagem, 23(4), 546-551. doi:10.1590/S0103-

21002010000400016

Obialo, C. I., Hunt, W. C., Bashir, K., & Zager, P. G. (2012). Relationship of missed and shortened hemodialysis treatments to hospitalization and mortality: Observations from a US dialysis network. *Clinical Kidney Journal*, 5(4), 315-319.

doi:10.1093/ckj/sfs071

Ontario Human Rights Commission. (2002). *Human rights and public transit services in Ontario*. Retrieved from

http://www.ohrc.on.ca/sites/default/files/attachments/Consultation_report%3A_Human_rights_and_public_transit_services_in_Ontario.pdf

Park, S., & Kear, T. M. (2017). Current state-of-practice: Transportation for patients with end stage renal disease. *Nephrology Nursing Journal*, 44(4), 309 Retrieved from

<http://go.galegroup.com.proxy1.lib.uwo.ca/ps/i.do?p=AONE&u=lond95336&id=GALE|A503466856&v=2.1&it=r&sid=summon>

Region of Peel. (2018). *My Trips*. Retrieved from <https://www.peelregion.ca/transhelp/my-trips>

Sockrider, M., & Shanawani, H. (2017). What is hemodialysis? *American Journal of Respiratory and Critical Care Medicine*, 195(2), Retrieved from <https://search-proquest-com.proxy1.lib.uwo.ca/docview/1860804878?pq-origsite=summon&accountid=15115>

The Kidney Foundation of Canada. (2013). *Facing the Facts*. Retrieved from

<https://www.kidney.ca/document.doc?id=4083>

Thorne, S. E. (2016). *Interpretive description: Qualitative research for applied practice* (Second ed.). New York, NY: Routledge.

World Health Organization. (1946). *Public Health Reports (1896-1970)*, 61(35), 1268-1277.

CHAPTER TWO

MANUSCRIPT

Introduction

The number of Canadians being treated for kidney failure has more than tripled in the last 20 years, making hemodialysis (HD) a more common and expensive treatment option (The Kidney Foundation of Canada, 2013). In fact, 1 in 10 Canadians has kidney disease and 47% of new renal failure patients are under the age of 65 (The Kidney Foundation of Canada, 2018). There are five stages of kidney failure, from very mild damage in stage one to complete kidney failure in stage five (Webster, Nagler, Morton, &

Masson, 2017). For people living with stage five kidney failure, also known as end-stage renal disease (ESRD), 58.4% are on dialysis and 41.6% have a functioning transplant (The Kidney Foundation of Canada, 2018).

Dialysis is conventionally classified into peritoneal dialysis (PD) and HD (Gilbert et al., 2018). In PD, a person's peritoneal membrane located in the abdomen is used to filter the blood (Gilbert et al., 2018). Generally, individuals can perform independent PD at home, creating advantages while travelling as treatment supplies can be packed in a vehicle or suitcase.

HD modality uses a dialysis machine to filter blood outside of the body. It is the most widely used renal replacement therapy (Gilbert et al., 2018). "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). HD can be performed in-center or independently by patients themselves at home. In Canada, in-center HD treatment is the most prevalent type of dialysis with 79% of individuals on dialysis in 2012 using the modality and costing an average cost of \$95,000 to \$107,000 per patient per year (Chartier et al., 2015). For in-center HD, a transportation service is needed by many to attend treatment. Transportation services by transportation providers is identified as non-emergency medical transportation (NEMT) and presents with issues that can influence the health outcomes of individuals using this service for HD (Park & Kear, 2017).

Background and Significance

Transportation for access to healthcare-related services is a vital component for sustaining health and well-being among middle-aged and older adults. Smith et al. (2017) note that due to a lack of transportation, approximately 3.6 million community-dwelling

American adults are unable to receive healthcare. This is especially true for individuals who are older, female, and with multiple chronic conditions and mobility limitations (Smith et al., 2017). Individuals opting for in-center HD share similarities such as older age, comorbidities (the co-occurrence of two or more chronic conditions), mobility limitations, and absence of caregiver support, as it offers high level acuity on-site care from healthcare providers (Agar et al., 2011). Due to high acuity, individuals having in-center HD require access to transportation to and from an HD centre on average three days a week for a total of six trips per week (Cafazzo, Leonard, Easty, Rossos, & Chan, 2009).

Transportation modes for HD treatment can include the individual driving themselves to the center, a family member or friend driving the patient, taking public transit, or using NEMT. In Southern Ontario, individuals requiring NEMT for HD must be eligible for this service (Region of Peel, 2018). Eligibility is determined on a case-by-case basis and is determined based on the individual experiencing barriers to using conventional public transit (Region of Peel, 2018). If a patient is deemed eligible, they must complete the application and have a registered medical professional, usually the nephrologist signs a document confirming their health status. Once approved, the patient has access to their client identification information that is used to schedule a transportation service. Using the identification information, they can call their transportation provider to schedule trips to and from the center. The fee for this service is government subsidized and the eligible person pays a rate that is equivalent to the rate of public transit. In Southern Ontario, the price to use this service is \$3.50 per trip, with a full refund if the scheduled ride is cancelled with more than a 24-hour notice from the scheduled pick-up time (Region of Peel, 2018). If the service is cancelled in less than 24 hours from the pick-up time, the fee is non-

refundable (Region of Peel, 2018). The transportation providers recommend individuals be present at the pick-up location ahead of time to prevent any issues (Region of Peel, 2018).

Studies have shown positive results (e.g., fewer missed appointments, fewer emergency room visits) related to including transportation services into the HD treatment programs (Blumberg 2016; Simon 2014). These studies emphasize the importance of reliable transportation services in the patients' overall sustainable health. While eligible individuals on HD may have access to transportation services, the quality of these services might not meet their health needs, therefore further influencing their overall health. Unreliable transportation has been identified as a key barrier of adherence to an HD treatment regimen (Obialo, Hunt, Bashir, & Zager, 2012). Individuals on HD using NEMT often miss their scheduled HD treatments, leading to inadequate HD, and increased mortality (Obialo et al., 2012). A survey implemented with HD patients by Ride Connection (2014), a transportation service provider in United States of America shows that 28% of the participants reported shortening their treatment because they were worried about missing their ride home and 33% reported having their treatment shortened because they were late for their session. Iacono (2004) suggest that difficulty scheduling trips, late service, and failure to be picked up are the main identified transportation problems. Transportation issues have an impact on the health of individuals because, if three or more HD treatments are shortened, it is associated with an approximate 20% increase in mortality rate (Clark, Farrington, & Chilco, 2013). Other complications include accumulation of fluid and toxins in the body leading to symptoms of respiratory distress and cardiovascular complication (Hoppe et al., 2018). From an economic perspective, having access to appropriate transportation services has resulted in significant cost savings to the healthcare system (Blumberg, 2016; Cronin, Hagerich, Horton, & Hotaling, 2008;

Myers, 2014; White, 2011). While previous studies discuss transportation challenges and physiological impact, there is a gap exploring the experience of individuals using transportation for HD treatment and its impact on their meaning of health using the World Health Organization's (WHO, 1946) definition of health where health has been defined as "a state of complete physical, mental, and social well-being, and not merely absence of disease or infirmity" (p.1268). Therefore, this study aims to address this gap by exploring the ways in which individuals experience access to transportation for in-center HD treatment and its impact on physical, mental, and social well-being.

The results of this study can raise awareness about the experience of individuals receiving HD treatment in relation to access to transportation and how it influences their meaning of health. By raising awareness, it may create interest among key stakeholders (HD center staff, management, transportation service providers, and policy developers) to discuss study findings. Increased collaboration and communication between all the stakeholders can provide a platform to engage in conversations to assess the needs of individuals using transportation services and develop a plan to tackle the challenges.

Literature Review

The purpose of the literature review is to summarize and evaluate current research on this study topic area, how it informs the thesis, and how the thesis best aligns with the research in the field (Grant & Booth, 2009). A review of the literature was conducted by retrieving peer-reviewed articles from online databases including: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, the Cochrane Library, and Google Scholar. Literature had to meet the following criteria to be included in the review: 1) published in a peer-reviewed journal or reported in government or institutional archives between 2011 and 2019, 2) written in English, 3) focused on adults (18 years of age or

older) requiring hemodialysis (HD), 4) addressed access to transportation issues, or 5) addressed health of individuals requiring HD. Literature published prior to 2011 was excluded unless it was considered a ‘classic’ source of literature useful in defining terms, concepts, or presenting meaningful background information to the topic area. Keywords used to guide the search included HD, access to transportation, ESRD and HD, HD and transportation, HD and health, and the combination of HD, transportation, and health.

The literature review is organized into three themes resulting from the reviewed literature. In the first section, the meaning of health for individuals using HD treatment is described. In the second theme, the importance of access to transportation and its associated challenges for HD treatment are discussed. In the third theme, access to transportation and its impact on health is discussed.

Meaning of Health for Individuals Using HD Treatment

HD has major impacts on many aspects of an individual’s life, as well as on the family (Calvey & Mee, 2011). Calvey and Mee (2011) conducted a qualitative study using Heideggerian phenomenology to explore the lived experience of individuals dependent on HD. A semi-structured interview guide was used to interview seven people who were on HD treatment. Data was analysed using Colaizzi’s (1978) seven-stage process. One main theme of *Sense of Self* emerged, within which emerged sub-themes: the future self, the living self, the mortal/fragile self and the growing/learning self. The future self was described by one participant as:

watching my children growing up and not being able to go out with them and show them what to do.... I never did that with my children.... something I would have liked to have given them.... not being able to do that, sort of irks at me now. (p.

203)

In describing the sub-theme of the living self, a participant noted, “my skin changed.... you feel dirty... no matter if you have a shower... I still never feel clean” (p. 204). The sub-theme of the mortal/fragile self, was quoted by a participant as “I really thought I was finished.....I saw the blood drain from my body into this machine...I saw my life's blood flow out, it was a shock, an absolute shock” as it alludes to facing their own mortality and the fragility of life (p. 205). The growing/learning-self emerged from listening to the participants discuss their experiences of starting HD treatment. The authors concluded that an individual requiring HD, must become familiar with a self whose physical appearance, mentality, functioning ability, and social ability has changed. They realized the impact of their illness and HD treatment on their family and friends. While this study was focused on the lived experience of people using HD and its relation to health, all participants were potential transplant recipients. Therefore, their perspective of health may differ from individuals who are ineligible for transplant, and therefore require HD and transportation services (if needed) to sustain health and prolong their life expectancy.

Bennett, Bonner, Andrew, Nandkumar, and Au (2013) used a descriptive qualitative design to explore the use of images as a visual communication technique for nurses and patients in the HD context. In their study, the authors used 52 cards containing specific photos, illustrations, and words to guide conversations between patients (n = 9) and two nurse interviewers about using HD. The 60-minute individual semi-structured interviews were thematically analysed, and the overall theme was *revealing the hidden struggles of living on dialysis*. From this main theme, three sub-themes were captured: (1) the increased importance of relationships; (2) the struggle with money; and (3) quality over quantity of life (Bennett et al., 2013).

Revealing the hidden struggles of living on dialysis reflected how the cards helped in uncovering these aspects of their lives. The first sub-theme, the increased importance of relationships, expressed how HD affected the participants' relationships with significant people in their lives and how vital these relationships were to the participants. A participant in this study exemplified this sub-theme by stating "I see my grandchildren in this card and that gives me the reason for dialysing. People say if I keep coming in at 4 over [4 kg] I'm going to have a heart attack" (Bennett et al., 2013, p.16). While another participant said "it makes me sad because I may not be alive and see my son grow up. The graveyard card made me think of my mortality and I'm not the healthiest person and probably won't live as long as everybody else" (p. 16). The second-sub theme, the struggle with money referred to HD affecting their income capacity and discussed overall financial struggles. Participants shared their frustration and desire for more money but not being able to engage in additional employment opportunities due to dialysis and their current health circumstances. The quality over quantity of life sub-theme related to participants' reflections on how they wanted to live their lives to the fullest. The quality of life was superior than length of life. Participants discussed restrictions of fluid, food, and limited potential for travel and holidays which exemplified the struggle for quality of life. One participant describes the quality over quantity sub-theme by stating, "we can't go anywhere at the moment because every second day I am here, and we've been going out for 5 years this July and we've never been on a proper holiday, I just really want to see more of Australia" (Bennett et al., 2013, p.18). This revealed the hidden struggles of participants using HD, however all participants in this study were males, and the findings might not have disclosed the hidden struggles of females using HD. Also, this study was conducted

in Australia and may not accurately reflect the experience of individuals in Canada, specifically Ontario.

A descriptive phenomenological approach was used by Chiaranai (2016) to elicit the firsthand experiences of Thai participants who were diagnosed with ESRD and currently on HD. A purposive sampling strategy was used to recruit 26 Thai participants to partake in individual interviews. Data was collected using a semi-structured interview guide and was analyzed using thematic analysis. The following themes emerged from the data: (a) *facing life's limitations*, (b) *living with uncertainty*, and (c) *dependence on medical technology*. The theme of *facing life's limitations* described participants' limitations of HD treatment on life relating to the physical, social, and economic aspects that often-caused emotional distress. In particular, participants reported symptoms of "decreased energy," "lack of power," "drains energy," "tiredness," "cannot concentrate," and "fatigue" (Chiaranai, 2016, p.103). Participants shared not being able to attend memorable events and milestones due to their health and HD. A participant sadly expressed,

I have never attended the school orientation of my 12-year old daughter on Mothers' Day because I have been either too tired or it happened to be on the day that I had to come for my dialysis. I know she is disappointed. I wish I were a good mother. (p.104)

Living with uncertainty was described as "the state of being unpredictable, uncertain, hesitant, and doubtful" in relation to having to use HD (Chiaranai, 2016, p. 104). As one participant stated, "every time I come here, I pray to Buddha to please let me live for another day. I only want to see my daughter graduate in the next couple of years. I do not know when I will die" (p.104). *Dependence on medical technology*, related to HD as advanced technology that prolonged participants' lives, and also referred to the dependence of participants on staff at the HD unit. As another participant stated, "by doing this, I have

no freedom.... Ever since I became attached to this machine and have to come here every other day, I cannot travel. I cannot miss my treatment schedule’’ (Chiaranai, 2016, p.105). While HD treatment isolated individuals from others, it was vital that they had access to the technology for this treatment. The research findings provided great insight into participants’ experiences that extended beyond the physical impact on health and highlighted participants’ feelings of uncertainty and technology dependence. However, Chiaranai (2016) did note that there can be vital differences in the findings from those studies conducted in other countries.

Importance of Access to Transportation and Its Associated Challenges for HD

Treatment

Smith et al. (2017) conducted a study to assess and contrast the NEMT needs of middle-aged and older adults in rural versus urban areas, and associated costs for Medicaid. Data were analyzed from 39,194 NEMT users of LogistiCare-brokered services in the State of Delaware residing in rural (68.3%) and urban (30.9%) areas. Using multivariable logistic analyses, the researchers compared trip characteristics by rurality designation. The researchers found that individuals residing in both rural (37.2%) and urban (41.2%) areas used services more frequently for dialysis than for any other medical concern. In fact, from all the NEMT needs, over 50% of trips were made for dialysis. Therefore, supporting the importance and necessity of transportation services for individuals on dialysis. While this study addresses the use of NEMT in a rural-urban comparison, the researchers did not define urban and rural areas, therefore the definition of rural and urban may not fully encompass the geographical location for the proposed study. While this study helps to understand the importance of access to transportation for people on HD, the proposed study

aims for an in-depth understanding about issues of access to transportation and how that access may influence overall health for individuals in this study who require HD treatment.

As CKD is a chronic illness with ESRD being the last stage, HD treatment is required to sustain life (Park & Kear, 2017). Park and Kear (2017) explored current and projected statistics and trends for CKD, and transportation challenges faced by patients and nephrology healthcare providers. The researchers noted that patients with CKD used transportation types that included taxi services, wheelchair vans, and stretcher services. Ambulance companies are usually limited to transporting people who are 'bed-bound' and because of this, most people requiring HD treatment used the taxi service and wheelchair van options to attend their HD treatment. However, these modes of transportation presented with challenges around reliability and efficiency. For instance, transportation companies typically employ general drivers that are not healthcare professionals. Therefore, the employed drivers were not knowledgeable or sensitive to the needs of people requiring HD treatment.

There are also mobility challenges as individuals with physical disability and older adults have tremendous difficulties getting in and out of some of the vehicles. This issue is further worsened by the lack of help from drivers as in many cases, they are told not to touch or assist patients in any way while the patients are boarding and disembarking from the vehicles due to liability concerns and company policy (Park & Kear, 2017). Unfortunately, this policy creates safety concerns for individuals requiring transportation. Park and Kear (2017) address the challenges for individuals on HD requiring transportation services. However, this study is based on transportation programs in America, that have a different healthcare system than Canada. Therefore, the challenges of access to transportation for HD may differ for individuals in the Canadian healthcare system.

Access to Transportation and Its Impact on Health

Despite the importance of HD as noted in studies discussed previously in this review, individuals on HD often do not attend their scheduled treatment session. Chan, Thadhani, and Maddux (2014) investigated factors associated with missed HD treatments and any significant harms to these individuals and the increase in overall health care utilization. An observational analysis of 44 million HD treatments from 536 individuals in the United States were included in the study. The average missed treatment rate was 1.8% or 7.1 missed treatment days per patient-year, over the five-year study period (Chan et al., 2014). Also, 34.5% of missed treatments occurred before the weekend (on Friday or Saturday). From the missed treatment, only 9.8% were successfully rescheduled as a “make-up” treatment for the next day. Chan et al. (2014) assessed the risk of hospitalization, emergency room visit, or intensive-coronary care unit (ICU-CCU) admission in the 2 days after a missed HD session compared to the risk for individuals who attended their HD session. Using a covariate adjusted logistic regression, Chan et al. (2014) found a significant increase for the risk of hospitalization (odds ratio [OR], 3.98; 95% confidence interval [95% CI], 3.93 to 4.04), emergency room visit (OR, 2.00; 95% CI, 1.87 to 2.14), or ICU-CCU admission (OR, 3.89; 95% CI, 3.81 to 3.96) after a missed HD session. Overall, 0.9 missed HD treatment days per year were due to suboptimal transportation to dialysis, inclement weather, holidays, psychiatric illness, pain, and gastrointestinal upset. This was associated with excess hospitalization (5.6 more events per patient-year), emergency room visits (1.1 more visits), and ICU-CCU admissions (0.8 more admissions).

Individuals who traveled to HD via a transportation van (OR, 1.21; 95% CI, 1.16 to 1.25) and who drove more than 17 minutes to the center (OR, 1.10; 95% CI, 1.07 to 1.15) were more likely to miss their HD treatment. The researchers suggest that improving

transportation to HD center could decrease hospitalizations by 0.8 days per patient-year. Chan et al. (2014) conclude that improved adherence to HD treatments can assist in achieving better patient outcomes by addressing systemic and patient barriers that impede access to HD care. In this observational study, the covariates may not have adequately adjusted for potentially unmeasured illness when individuals miss their treatment, and this may impact their meaning of health. An interpretive description design would allow for an exploration of how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health.

Chenitz, Fernando, and Shea (2014) explored in-center HD patients' perceptions of risks and barriers about attendance in the Philadelphia area. Semi-structured interviews with 15 'adherent' and 15 'nonadherent' HD patients were conducted to determine patients' attitudes about HD, health beliefs and risk perception about missed treatments, and to understand barriers and facilitators to HD attendance. From the analysis, the primary findings were: *common views and feelings about hemodialysis and the health care team; patient understanding of the dangers of missing hemodialysis treatments; barriers and facilitators to hemodialysis attendance; and interventions to improve hemodialysis attendance*. Both groups felt that HD was lifesaving and a necessity. Large number of participants in both groups understood and communicated that missing treatment is dangerous by mentioning the risks of skipping HD sessions.

Chenitz et al. (2014) found the most common barriers to attending HD treatments were transportation issues, specifically inadequate or unreliable transportation (mentioned in both groups), and a lack of motivation to attend HD or that HD was not a priority (mentioned by the non-adherent group only). The patients in this study traveled by car, public transit, ambulance, or a shared van. Patients who drove themselves or used public

transit reported these modes of transportation as reliable and efficient (Chenitz et al., 2014). Non-emergency ambulance transportation was also noted as a reliable source. Patients using van services reported inconsistent pick-up and arrival time along with prolonged wait times and vans not showing up, or, their ride leaving them at the center if they are even a few minutes late, as obstacles to their adherence to the HD regime. Due to the transportation issues, there were also an increased number of patients requesting to end their treatment early. A participant in this study stated, “if you’re not ready when they (transportation service) get there, they will leave you and you’ll have to sit and wait and wait and wait” (Chenitz et al., 2014, p. 370). Facilitators to HD attendance included the health care team educating HD patients about the risk of skipping HD and the individual’s relationships with other HD patients. Patient recommendations to improve HD attendance includes education about the risk of poor attendance and accessible transportation. Chenitz et al. (2014) note the participants in this were attending HD at a single institution and single geographic region in America as limitations of the study because the themes may not be transferable to other HD settings in America or internationally. As noted above, transportation services may differ widely depending on the region that may impact the experience of access to transportation for HD and its meaning of health.

Morton et al. (2012) aimed to determine the most important characteristics of dialysis and the trade-offs individuals were willing to make in choosing dialysis instead of conservative care. The researchers conducted a discrete choice experiment involving adults with stage three to five of chronic kidney disease. This study included a sample size of 105 from eight renal clinics in Australia. The findings highlighted that individuals are more likely to choose dialysis over conservative care if dialysis involved an increased average life expectancy (odds ratio [OR] 1.84, 95% confidence interval [CI] 1.57-2.15), if

they were able to dialyse during the day or evening rather than only during the day (OR 8.95, 95% CI 4.46-17.97), and if subsidized transport was available (OR 1.55, 95% CI 1.24-1.95) (Morton et al., 2012). For participants in this study, an incentive to choose dialysis and sustain life was the availability of subsidized transport. This characteristic was not dependent on the distance between a person's home and the clinic. Individuals were less likely to choose dialysis over conservative care if there was an increase in the number of hospital visits (OR 0.70, 95% CI 0.56-0.88) and if there were more restrictions on their ability to travel (OR = 0.47, 95%CI 0.36-0.61). In fact, individuals were willing to forgo seven months of life expectancy to decrease the number of required hospital visits and 15 months of life expectancy to increase their likelihood of traveling. Morton et al. (2012) concluded that individuals were willing to reduce their life expectancy to gain freedom from the restriction imposed by dialysis. The study does not differentiate the influence of different dialysis (HD and PD) modalities on patient choice, as in-center HD receive individuals to have access to transportation for an average of six trips a week whereas, PD can be done by home with occasional visits to the center. Therefore, the importance of access to transportation may be underestimated as a deciding factor in this study.

Gaps in the Literature

This literature review included peer-reviewed articles published since 2011 to capture the most relevant and recent literature about the topic of transportation for HD treatment and health. As discussed in the literature review section, there is documented research on the lived experience of individuals requiring HD treatment, and on the role of transportation for HD treatment. HD impacts (mainly negatively) individuals' perspectives of their health, and this issue is further worsened by challenges of access to transportation for HD treatment. There is a gap exploring how persons requiring in-center HD treatment

explain the ways in which access to transportation for such treatment influences their overall health using the WHO's definition of health. This is important as Morton et al. (2012) note that limited access to subsidized transportation influences individuals to choose conservative care rather than prolong life by receiving HD treatment. Morton et al.'s (2012) study combines PD and in-center HD patients under the dialysis category. Even though the transportation needs for in-center HD treatment are greater for individuals on PD, as in-center HD is only performed at the center requiring on average six trips per week, while PD is mainly performed at home and does not require frequent access to transportation. This study aims to address these gaps and provide implications and recommendations to address this problem.

There is also a lack of literature about this phenomenon in the Canadian context. This is important to consider, as transportation policies and practices vary by province and even region. Therefore, this study is needed to explore how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health (physical, mental, and social well-being).

Statement of Purpose

The purpose of this study is to illuminate how persons requiring in-center HD treatment explain the ways in which access to transportation for such treatment influences their overall health.

Research Question

How do persons requiring in-center hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health?

Methods

Design

This study used a qualitative interpretive description design to explore how persons requiring HD treatment explained the ways in which access to transportation for such treatment influenced their overall health. Interpretive description is philosophically aligned with interpretive naturalistic orientation as delineated by Lincoln and Guba (1985) (Thorne, Kirkham, & O'Flynn-Magee, 2004). Interpretive description recognizes the constructed and contextual nature of human experience, while also allows for shared realities (Thorne, Kirkham, & MacDonald-Emes, 1997). While other qualitative approaches are also methodologically rigorous, they are viewed to be somewhat rigid in terms of their application in the clinical setting as the ultimate outcome often leans to theory development as compared to practical application (Thorne et al., 1997).

Interpretive description was created as a response to nursing researchers' desire to explore, understand, and produce "legitimate knowledge" with real world applications (Thorne et al., 1997, p. 172). Interpretive description provides a methodological foundation to explore clinical-specific (or real-world) problems and questions with the purpose to reflect on previous understanding and produce new ideas that may be translated into practice (Thorne, 2016). Working as a HD nurse, I observed this problem in my clinical practice and using interpretive description can allow me to explore this topic and share findings and recommendations that may be considered and tailored to the practice context. In fact, interpretive description is well positioned to explore multi-faceted clinical problems, as studies using this approach are both informed by and can inform practice (Thorne et al., 1997). The aim of interpretive description and naturalistic inquiry is to "seek out specific individuals that might help us to better understand" (Thorne, 2008, p. 90) and "detail the many specifics that give the context its unique flavour" (Lincoln & Guba, 1985, p. 201). Therefore, there was a need for this qualitative interpretive description study to

provide insights into this study's clinically oriented problem from which ideas and recommendations for practice might advance solutions that can translate into positive outcomes in practice.

Setting

HD can be performed independently at home or in-center by healthcare staff. For this study, the setting was a large community HD center in an urban region of Southwestern Ontario. This HD center has 24 dialysis chairs with the capacity to provide care for 144 individuals.

Sampling, Participant Demographics, and Recruitment Process

Upon receiving ethics approval from the Western Office of Human Ethics (Appendix A) and the Trillium Health Partners Ethics Board (Appendix B), purposive sampling was utilized in order to obtain rich data and gain an understanding of the exploration of how persons requiring HD treatment explain the ways in which access to transportation for such treatment influences their overall health. The aim of interpretive description is to "seek out specific individuals that might help us to better understand" (Thorne, 2008, p. 90) and "detail the many specifics that give the context its unique flavour" (Lincoln & Guba, 1985, p. 201), therefore purposive sampling was the preferred sampling technique. Thorne (2016) suggests the type of research question and the study purpose provide guidance to the researcher about the sample size required to achieve the aim of the study. The nature of this study's research question requires a less extensive sample as these participants uphold specific characteristics valued to this study. For instance, they have end stage renal failure (as opposed to any other stage of renal failure); are receiving HD treatment (as compared to other modalities); and they use NEMT to attend treatment (not primarily family, self, or friend). Therefore, purposive sampling was selected for this study.

Morse (2000) adds that a sample is deemed abundant when participants who best represent the study topic are included.

Thorne et al. (2004) suggest that differences in participants' willingness to articulate, reflect, and share their experiences are to be expected. Therefore, a range for sample size is proposed as the quality of the interviews may vary from one to another. The final sample for this study included eight participants, who were selected using purposive sampling.

Inclusion criteria for this study were: participants 18 years of age or older; currently receiving HD treatment; use non-medical transportation services (i.e. TransHelp, Spectrum Patient Services, and taxi service) that do not primarily include transportation by a family member or friend; agree to be audio-recorded for the interview; able to consent for themselves to participate in the study; and are able to speak and comprehend English.

Participant demographics. All participants that met the inclusion criteria were invited to participate in the study and 10 individuals expressed interest. However, two individuals were ineligible as one individual was unable to provide consent, and another spoke minimal English and requested for an interpreter to participate in the study. Therefore, the final sample size consisted of eight participants, which included three males and five females with an age range of 57 to 81 years. The mean age of all participants was 66.5 years, for male participants was 65.7 years, and 67.2 years for female participants. Participants' length of time using HD treatments ranged from nine months to 14 years and 9 months. The mean length of time using HD treatment for male participants was 4 years and 1 month, and for female participants was 5 years and 7 months. All eight of the participants used the TransHelp transportation service provider (either the bus or van service). All participants required transportation service more than five times a week to

travel to and from their HD treatment sessions. The highest level of education completed was high school for two of the participants, while the other six participants reported having a college diploma. Seven of the participants were retired while one was on sick/disability leave. From the eight individual interviews, four were held over the phone and the other four were held in a private room at the HD center. Participants decided on the timing, location, and method (in person or over the phone) of interviews based on their schedules, convenience, and comfort that would allow participants to share their experiences.

Recruitment process. Prior to collecting data, the manager at the HD centre involved in this study was provided with the study letter of information (LOI) and consent form, and was requested to provide permission to allow the graduate student researcher (GSR) to: a) conduct the study at the centre, b) have the unit clerical assistants (UCA) distribute the study letter of information and consent form to potential participants, c) recruit participants at the centre by being personally present at the centre on certain dates and times to provide interested individuals a copy of the study LOI and consent form (if potential participants approached the GSR), and d) to use one of the private office rooms at the centre as an interview space. This space was requested to minimize any travel inconvenience to the participant. Given the focus of the study is about access to transportation and not HD treatment itself, the study team felt it was appropriate to interview participants at the centre before or after HD treatment. However, if the participants preferred to hold the interview in another location, such as a library or private meeting space in a community centre, then that would have been arranged by the GSR and the individual interested in participating in the study.

After receiving the above permissions from the centre manager, the UCA working at the centre and responsible for registering individuals requiring HD as they came in for

their visit, were informed about the study. The role of the UCA in the recruitment process was explained to the UCA. The UCA in the HD centre were requested to ask each person during registration if they used a transportation service to access the centre (not including transportation provided by a friend, family member, or driving themselves). If the person said yes that they did use a transportation service to access the centre, then the UCA gave the person a sealed envelope containing the study LOI and consent form. The LOI included the researcher team members' contact information. Individuals interested in participating in the study contacted the GSR to arrange for an individual interview to take place either in-person or over the phone.

With permission from the HD centre manager, the GSR was also personally present at the centre reception area two days per week (Wednesday and Thursday 1100-1330 and 1600-1730) for two weeks to provide interested participants with a study LOI and consent form. The GSR was seated at a respectful distance from individuals in the reception area at a small table with a study poster on display and had the study LOI and consent form available in sealed envelopes to hand out upon request to potential participants. The GSR did not approach individuals for recruitment but waited for individuals to approach the GSR with any study related questions.

Data Collection

Data was collected during a one-time in-depth individual interview using a semi-structured interview guide (see Appendix C). Participants were interviewed in English and participants could choose whether they wanted to be interviewed in-person or over the phone. The date, time, and location for the interview were agreed upon by both the GSR and the participants. Eight individual interviews were conducted between April and June 2019. Given that the accumulation of large amount of toxins may interfere with participants'

cognitive function, prior to the start of the interview, participants were asked four questions to assess cognition: 1. Awareness to person (what is your name?) 2. Knowledge of place (Where are you right now?) 3. Knowledge of time/date (What is the time and date right now?) 4. Knowledge of event (Do you know why you are here today?). These questions are frequently asked in the clinic setting to determine an individual's alertness and orientation. If participants were unable to answer all 4 questions, they would be given the choice to reschedule their interview after their HD treatment and would again be re-asked these questions prior to their future interview. No original interviews had to be rescheduled, as all participants were deemed by the GSR to have addressed the questions accurately.

For both in-person and telephone interviews, verbal consent was also obtained by reading the full LOI and consent form to the participant and audio-recording of the phone interview did not begin until all study related questions were addressed by the GSR. For in-person interviews, written consent was obtained prior to the start of the digitally audio-recorded interview. Participants preferring to participate in telephone interviews were offered to have another copy of the LOI and consent form mailed to them by Canada Post in a sealed envelope that contained a stamped and return addressed envelope. However, the participants refused this offer and signed the written consent form and submitted it to the GSR while they were on site recruiting.

Each interview was approximately 60 to 90 minutes in length and digitally audio-recorded with prior consent of participants. Individual interviews were numerically coded on the audio-recording to avoid any inclusion of personal participant identifiers. After the interviews, the audio-recordings were transcribed verbatim. The GSR used the same numeric code for the demographic forms to obtain participants' demographic data (see Appendix D) during individual interviews. The demographic data included age, gender,

length of time using HD, frequency of using transportation services to attend dialysis, type of transportation used, highest level of education completed, and employment status. A master list was maintained in hard copy format that included participants' name, phone number (if disclosed), and home address (if disclosed). Each participant on the master list was assigned a numerical code that aligned with the code noted on the participant's consent form, in the digital audio-recorded interview, and on the de-identified, transcribed interview. The master list was kept separate from the signed consent forms, in separate locked file cabinets in the study PI's locked office. The de-identified audio-recordings were permanently deleted after being assessed for having been accurately transcribed via listening to audio recordings and re-reading transcripts.

Data Analysis

Consistent with a constructivist theoretical approach, inductive reasoning was used to analyze the data. An inductive approach to data analysis is foundational to the data analysis process within qualitative research (Silverman, 2000). Inductive reasoning requires the researcher to start with the specific instances leading to generalized conclusions (Polit & Beck, 2104). In interpretive description design, a rigorous analytic process involved being fully engaged in the processes of inductive reasoning, "including testing and challenging preliminary interpretations, and conceptualizing an ordered and coherent final product" (Thorne et al., 2004, p. 5). Through inductive analysis, the researchers advance the data from descriptive claims toward abstracted interpretations, illuminating the research topic in a new and meaningful manner (Thorne et al., 2004).

Thorne et al. (1997) suggest for researchers using the interpretive description approach to have an agile and continuous relationship between data collection and data analysis. As such, after the initial interview had been conducted, the de-identified digital

audio-recordings and reflective writing were transcribed verbatim by a hired transcriptionist who had signed a study confidentiality agreement prior to starting the transcription process. The GSR listened to the audio recordings alongside each of the transcripts to ensure accuracy, clarity, and completeness of the data (Anney, 2014). As suggested by Thorne (2016) all transcribed data (interviews and reflective notes) were read several times to have a sense of the whole and the overarching ideas. Thorne et al. (1997) also suggest that rather than having preliminary coding, researchers should immerse in the data by asking questions of the data, such as: “why is this here? Why not something else? And what does it mean?” (p. 13). By repeatedly asking these questions, “the imaginal exercise shifts from seeing nothing of importance, to finding a heuristic “ahah!” to a disciplined consideration of a range of possibilities before interpretive conclusions ought to be drawn” (Thorne et al., 1997, p. 13). Undergoing this process, provided an opportunity to immerse in the data by using constant comparative analysis to compare and contrast between and within participants’ interviews, making it possible to recognize patterns and identify themes within the data set to have an in-depth understanding of the study topic.

As Thorne et al. (1997) note that there can be an infinite amount of interpretative possibilities in a data set, it is key that researchers refer to the relevance of the interpretation in relation to the research question. Therefore, for this study the research question was written in large print on a piece of paper by the GSR and constantly referred to throughout the data analysis process. QSR International’s NVivo 12 qualitative data management-analysis software assisted with the coding process. As data analysis progressed, several patterns emerged, which were then grouped into themes. The themes illuminated the phenomenon exploring how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health in a new

and meaningful manner. Thorne et al. (2004) suggests that for some researchers, creative coding (using symbols, colors or conceptual codes, and visual tools such as concept mapping) can support inductive analysis. Similarly, I highlighted the transcribed interviews and created diagrams to recognize the repeated patterns, identify themes, and ultimately create thematic understanding.

Unlike other qualitative methods such as descriptive phenomenology that requires researchers to isolate their biases or presumptions (bracketing), interpretive description encourages researchers to immerse themselves with the data and reflect on their own ideas, biases, and understandings of the topic and be able to justify how this relates or differs with the data from the interviews (Thorne, 2016). As the researcher works through the data, reflective writing allows for an opportunity to immerse in the data (Sandelowski, 1993). The GSR engaged in reflective writing after each interview and during analysis of the transcripts. This process enabled the GSR to incorporate reflections from the interviews that were relevant to the study topic and was not captured in the audio-recordings such as facial expressions, emotional reactions, voice inflections that reflected emotions during the in-person and over the phone interviews. As Thorne (2016) notes, reflective writing is an opportunity to document the experience of the interviewer within the research engagement as that becomes a core element informing the inductive analytic process (Thorne, 2016). It becomes a crucial part of what the researchers can rely on to understand the implications of their role in data collection and analysis. Throughout the analysis process, reflective writing was used to question and understand the GSR's thought processes to support the findings to the research question and the data from the interviews. The reflective writing was also a component of the audit trail for the study.

Maintaining an audit trail by recording one's thoughts and ideas as the researcher works through the data analysis process is considered highly important in interpretive description (Thorne, 2016). This process ensures the study findings are supported with adequate rationale as to how the data and analysis process informed and produced the findings. For this study, to create an audit trail of the GSR's thought processes and emerging findings, electronic copies of the de-identified and coded transcribed interviews were stored as password protected word documents, and an associated NVivo study file was also maintained and password protected.

Evaluative Criteria for Rigor

Koch's (2006) criteria of credibility, transferability, dependability, and reflexivity was used to evaluate rigor for this study. Koch's (2006) approach is based on Lincoln and Guba's (1985) criteria for rigor in qualitative research, namely "credibility, transferability, and dependability" (p.18-19). Credibility can be achieved when the researcher clearly describes and interprets their experience about the research process and as a researcher to potential users of the research (Koch, 2006). Although the interpretive description design is collaborative between the researcher and the participant, ultimately it is the researcher driving the interpretation of the data (Thorne et al., 2004). "Thus, an explicit awareness of the investigator as interpreter becomes an essential element in generating findings that have the potential for credibility or interpretive authority beyond the artistic license of the individual author" (Thorne et al., 2004, p.6). According to Koch (2006) credibility can be enhanced by using a journal to note the content and process of interactions. To achieve this in this study, the GSR engaged in reflective writing throughout the research process, including the recruitment process, interviewing, and while analyzing each transcript (Koch, 2006). The reflective writing included the GSR's concerns and challenges.

Being true to the participants' perspective is another way to demonstrate credibility (Koch, 2006; Thorne, 2016). This can be achieved through prolonged engagement with the participants (Shenton, 2004). For this study, individual 60 to 90-minute semi-structured interviews enabled participants to share their experience about the study topic. The interviews were audio recorded and transcribed verbatim and reviewed by the GSR for accuracy to enhance credibility. During participant interviews, whenever possible, the GSR rephrased participants' responses to ensure she had the same and accurate understanding of participants' perspectives. As suggested by Whately (2012), credibility was further improved by constant consultations between the GSR and the supervisor and committee member throughout the research study.

According to Koch (2006) transferability corresponds to the *fittingness* of the study findings to other similar contexts. To establish transferability, the original context must be described adequately to the readers. In this study, transferability was achieved by conducting an in-depth analysis of the transcribed interviews through immersion in the data. The interview guide facilitated a rich discussion about the research topic leading to thick descriptions discussed by the participants. The use of probing questions in the interview to clarify participants' responses assisted the GSR to obtain detailed data about the phenomenon under study, therefore giving sufficient information that could be transferred to other similar contexts. An iterative process of interpretation between the research team was carried out. By enacting this process, it is proposed that participants' experiences were accurately portrayed in the themes that formed the interpretive descriptions. Consequently, the study findings may be transferable to other similar contexts. To support readers' judgment about transferability of this study, detailed descriptions of the study context including the setting, participants' demographics, and methods was noted in this thesis.

For research to be dependable as defined by Koch (2006) is for its process to be audited. This means, all the steps involved in the decision-making process in relation to the study are documented (Koch, 2006). Sandelowski (1986) states that a study and its findings are “auditable when another researcher can clearly follow the decision trail used by the investigator in the study. In addition, another researcher could arrive at the same or comparable but not contradictory conclusions given the researcher’s data, perspective and situation” (p. 34). For other researchers to create audit trail linkages and confirm dependability, a decision trail also referred to as an audit trail should be provided. The audit trail identifies the decisions made by the research team from the beginning of the study to the end of the study (Koch, 2006). This includes the theoretical, methodological, and analytic decisions made by the research team throughout the study (Koch, 2006). Therefore, an audit trail for this study documented decisions like the reasons for the study interest, the preparatory phase where decisions about the study plan and reasons for the selected methods were selected by the GSR. The decision-making process during interviews, throughout the data analysis phase, with an emphasis on the evolving themes, and during the writing of this dissertation were included in the audit trail.

Reflexivity allows researchers to become self-aware of their assumptions, beliefs, values, and prior experiences and its impact on the interpretation of the data (Clancy, 2013; Koch & Harrington, 1998). “Reflexivity implies the ability to reflect inward toward oneself as an inquirer (Sandelowski & Barroso, 2002, p. 222). This involves the willingness to acknowledge and consider the many ways the researcher influences research findings and the what comes to be knowledge. For this study, the GSR remained reflective towards her own assumptions, beliefs, and prior experiences as a HD nurse to become fully aware of

herself to enhance reflexivity. The reflective writing provided an opportunity to express herself and give a full account of the relationship between herself and the participants.

Ethical Considerations

This study was approved by the Western University Health Sciences Research Ethics Board and Trillium Health Partners Research Ethics Board (See appendix A and B for Ethics Approval Letters). Prior to voluntarily participating in the study, participants were explained the purpose of the study, had any/all their questions answered, and signed a consent form. To preserve anonymity, numerical coding was used for all participants. All information collected in this study was kept confidential and only accessed by the GSR and members of the research team.

Findings

Three interrelated themes were identified which illustrated the experience of access to transportation for HD treatment and its influences on participants' overall health: a) *Reliability*, b) *Choice*, and c) *Personal Safety*.

Theme One: Reliability

Reliability was characterized by the requiring access to transportation to attend HD treatment and maintain their health and the unpredictable variabilities in transportation service. This theme includes the sub-themes of dependability of access to transportation services for HD treatment and connection to health, and variations in consistency and coordination of access to transportation.

Sub-Theme: Dependability of access to transportation services for HD treatment and connection to health. Participants in this study reported that access to dependable transportation is necessary for them to attend their HD treatments. Participants expressed that dependable access to transportation influenced their physical and mental

health. A participant shared that lack of dependable transportation would affect her health by stating:

Yes, that would affect me. It is a big impact on us, and we all get nervous over it because if we don't go for our treatment you know how we feel, and we don't want to miss our treatment. It is good you ask me that question because that's how I feel. I have to miss treatment. (Participant 2)

In this quote the participant shared the importance of access to transportation to attend HD treatment. This participant expressed they understand that without access to transportation their health worsens, however access to transportation is at the root of their ability to attend treatment. Without transportation their health would be negatively impacted leading to overall poor outcomes. This participant shared:

Well you know when you don't have your dialysis, it's bad and really impacts your health because you build up a lot of toxins. You must go three days a week. It would make my health worse if I didn't go to dialysis because of transportation and also makes me nervous. (Participant 2)

Other participants shared their frustration about being heavily reliant on transportation providers, as their health does not support their ability to drive themselves to the HD center. When asked about ways to improve the service and meet their health needs, a participant shared “I don't think anyone can make a difference... I think if I can drive my own that would be better” (Participant 6). However, their health did not allow for them to be able to drive to the center therefore they were dependent on access to transportation for their health.

Participants expressed that they felt that they would be resigned to having to miss HD treatment if they did not have dependable access to transportation. As a participant

noted, *“I call the dialysis people and tell them I don't have ride, I'm not coming in today. I have to miss”* (Participant 2). In this example, the participant shared this would be their action when transportation is not accessible and although participants understood the consequences of missing treatment, they felt that access to transportation enabled them to attend treatment and when this access was removed or not dependable, they were unable to adhere to the prescribed treatment. This starts the cascade of events that cause poor health.

Sub-Theme: Variations in consistency and coordination of access to transportation.

Participants in this study reported concerns with consistency in the transportation dispatching process post- hemodialysis, and with their overall transportation schedule timing. The participants discussed that due to uncoordinated dispatching, they were being driven to other cities before they were dropped off home post HD treatment. A participant reported:

...they come to pick me up and they take me somewhere else before they take me home. Like I live in xxx and sometimes they take me to all these places and this area and that area before they take me home. I don't like that because if they are picking me first and then picking up 2-3 more people, those people should be after me. ...This is a problem for me. It wastes my time and it has been an hour they have been driving you around the place picking up other people. (Participant 5)

This example was a common experience to the participants as this occurred frequently. A participant related this experience to getting a tour of the city *“Ah, yah, getting a tour of the city (laughs)”* (Participant 7), and another shared *“when they pick you up, they drive you around town. They give me a tour (laughs)”* (Participant 8). While another participant

related it to a merry go round and they shared *“You go merry go round, you have 3-4 people, they will drop Mr. A, Mr. B., Mr. C. and your turn comes after 45 minutes and you sit down there for 45 minutes so you can be a little weak”* (Participant 6). Participants reported that after HD treatment, they usually do not feel well and want to go home and rest. One participant noted, *“Well the only thing is that after dialysis, you’re hungry and weak”* (Participant 1). Therefore, being driven around post HD for an extended period of time was not ideal for their health, as it worsened their physical symptoms and their mental health. In addition to being driven around post HD, participants also reported concerns with how trips were coordinated. One participant mentioned, *“Another couple was going to my city, so why do I have to go with the people that are going to a different city? I could go with the people going to my city because it was a big van”*. (Participant 3). In this example, the participant discussed that it was unclear why they had to ride in a vehicle that was going to another city rather than driving to their city. The ride home should only take twenty-minutes on average, however due to this lack of coordination it was over an hour-long commute. The participants felt that the individuals in charge of coordinating trips did not consider the participants’ home address and didn’t access a map to coordinate the trips. This poor coordination added to the experience of being driven around for extended period of time after HD and consequently influenced their health. Along with the inconsistent dispatching, participants shared their experiences related to inconsistency in their transportation schedule timings before and after HD treatment. One participant reported:

The hard part is that you have to wait, rides can come anywhere from on-time, early, to quiet late... it could be anywhere from 1-3 hours for a ride... Another thing is the longer you wait the hungrier you get and the weaker you get. (Participant 1)

Although participants had an assignment pickup window time, they shared that the actual pick-up time was rarely accurate to their scheduled time. A participant shared:

She (driver) was hurrying me and I got out of the machine and I even forgot my coat she reminded me, you didn't wear your coat and I was like your hurrying me, if you want to go, then go. I will find my way home, that day I already had a bad day and she made my day even worse. I was rushed to get out of there, and I was already was nervous with the machine. (Participant 2)

In this example, when rides are early and drivers are not willing to wait few minutes, participants felt rushed to get off the machine, and this usually resulted in shortening of treatment time. If participants decided not to shorten their treatment time, they ended up missing their transportation and had to wait for the next driver or seek other ways to get home. Not only was the early arrival of rides a concern, but also individuals shared having to wait for hours for their scheduled ride to arrive. Another participant shared:

I understand that if one person is late everyone else is late but not for 2 hours. This happens very often, five or six times a month that this happened. Other people have the same problem and you call them (transportation company) and tell them, and they don't do nothing. I know people who wait here until 3 for the vehicle which is ridiculous...Last week they booked me to come here, but not back. I was sitting here till 2 o'clock and I call and said my ride is not here. Generally, it would be here by 12 o'clock and he said 'OH' 10 minutes your ride will be here and 10 minutes turn into 2 o'clock and I'm here waiting, and I finish (HD treatment) from 10:30. (Participant 3)

This participant noted the impact on her mental health, “I would like it when I finish dialysis to not sit here for 2 hours as I want to go home. That gets me mad I want to cry. I want to

scream. But who will I scream to?” (Participant 3). To cope, a participant shared “I pray I pray, nothing you can do. I talk to the Lord. I wait for them to come.” (Participant 4) Participants shared the same frustration as they expressed that they felt their voices were unheard and when they expressed their concerns to the transportation organization, their concerns were unaddressed and ignored. This influenced their mental health and as access to transportation is necessary for HD treatment, they felt as though this was part of the experience of having ESRD and being on HD.

Another participant shared their experience of waiting 4.5 hours for transportation after HD treatment and its impact on their health:

It makes you a little bit disappointed and angry because you are not waiting 1 or 2 hours, when its 4 hours you are hungry as it is you are here the whole day. You finish at 4 o'clock and then wait up to 8:30 then after dialysis because you have no food when you come here, most of the times I never eat when hungry because I don't feel hungry in the morning, so I don't eat. Then you are here for four hours of treatment and then waiting another 4 hours here for pick up, that's a long time. There is no coffee or tea available here. So, what do you do? (Participant 6)

This participant shared this was an unusual experience that occurred. This participant did not have food with him therefore, having to wait for 4.5 hours for the transportation before going home was unideal and considering many HD patient take medication post HD if can greatly interfere with their medication regimen and worsen their physical symptoms and create stressful situations.

Other participants noted there were instances when they waited for their ride to the HD center and the ride did not show up. “*I am supposed to be picked up between 6 o'clock*

and 6:30 a.m. One morning they never picked me up and I call and say I have to go to dialysis, and I don't see my ride.” (Participant 7)

Participants in this study reported the impact of these inconsistencies on their health. *“In the morning when I come, I take my medication there and apply my medication there. So, if transportation is late it has problems with my medication, and I am rushing to take it.” (Participant 5).* The medication in this example was used to numb the area prior to inserting needles to start HD. This participant shared that if he does not apply the medication it causes great pain for him as being cannulated with 2 needles 3 times a week was stressful and painful.

Other participants noted the inconsistency made them anxious and worried about getting to the center for their treatment:

The only thing what I am worried about is the lateness because you have to be on the machine at a certain time and you go on late and then you have to wait a little longer for the nurse to put you on and if you late it is your problem. (Participant 4)

The anxiety was related to transportation not being reliable therefore they were unsure whether they will be on time to start their treatment. If there is a delay getting on the machine, then individuals had to shorten their treatment or else they may miss their ride if it comes early to on-time. Also, there is another set of patients scheduled to start treatment at a specific time therefore, it is vital that the HD start times are followed.

Theme Two: Choice

Choice was characterized by the feeling of having or not having a choice in using alternative modes of transportation if their scheduled ride was not reliable, as discussed in Theme One. This theme includes the sub-themes of financial impact and asking for support from family and friends.

Sub-Theme: Financial impact. Participants discussed their financial situation and the importance of having access to reliable transportation. Participants mentioned that if the scheduled transportation was missed and they had to use an alternative form of transportation (Uber or taxi), it created financial challenges as they were on a fixed income. Many participants were unemployed or retired with minimal income that they were using to pay for their scheduled transportation trips, therefore having to pay for alternative transportation was an additional expense that influenced their monthly budget. One participant reported:

I am a widow and I lost my husband. I depend on my pension. It is very hard on me. I don't want to spend unnecessary money. You know if I can I try to save as much as possible because you know you never know what will happen to me down the road. This is a very big challenge for us. (Participant 2)

When services are unreliable, individuals have to seek private transportation such as Uber or taxi services. A participant shared “*Now that I’m in City A it’s going to be \$30 each way, so I can’t afford to miss my ride.*” (Participant 1) Due to this fear of having to use transportation services and experiencing the financial burden, individuals opted to near wait for extended period of time for their scheduled ride or shorten/skip their treatment which had health implications.

For those individuals that did opt to call an Uber or private taxi if there were problems with their scheduled ride, they expressed the impact on their mental health and feelings of financial insecurity. “*It gets me mad because the money I could save to pay them (transportation provider) for the next month, I have to use it to pay for the taxi... From my home to here it is \$25. So, \$50 going and coming, that’s ridiculous.*” (Participant 3)

For individuals that did not have the option to seek alternative transportation services if their ride was missed, cancelled, or delayed, meant they had to wait for an extended period of time for the next available driver to pick them up. *“I waited for them to come and eventually I did go home, but that was four-hour delay.”* (Participant 6) Although some individuals had the choice of calling an Uber or taxi, they acknowledged that this was not in any way a preferred choice for them due to the financial challenges, but one they had to make this choice because without access to transportation, they were not able to attend HD treatment.

Sub-Theme: Asking for support from family and friends. Participants discussed the choice of asking a family member or friend for a ride to the center or home if their scheduled transportation was missed, cancelled, or delayed, or not appropriate for their health needs. A participant shared, *“My son had to leave work. I call and I tell him my ride is not here yet and he said mommy wait 20 minutes and I will come pick you up on my lunch. Right now, I can’t leave.”* (Participant 3) In this example, participant shared that although the family was supportive, they felt as if they were burdening their social support system and being dependent on them. The participants also shared this created stress for the family/friends as they have to manage their lives while supporting the needs of access to transportation for the participants.

Another participant discussed that while the family can help certain days on other days the participant does not have that choice. *A participant shared:*

“I asked my daughter to come and pick me up because it was Saturday. I was lucky it was Saturday, my children they work all the way downtown, and there would be no one to come pick me up. My brother in law lives in another city and he will take

a long time to come here. So, I might have to miss dialysis if I don't have a ride.”

(Participant 2)

In this instance, participant felt the choice was to resign HD treatment if there was no access to transportation and if family/friends were unable to support them and this influenced their social, physical, and mental health.

Theme Three: Personal Safety

Personal Safety includes the sub-themes of resources for safer travel and behaviours reflecting the need for driver education. Participants discussed the characteristics of this theme as the challenges that make their transportation experience unsafe.

Sub-Theme: Resources for safer travel. Participants in this study reported challenges with the type of vehicle they had to ride in to and from the HD center and lack of access to necessary equipment for enter and exit the vehicle and its impact on their health. One participant reported, *“I got a hip replacement three times, so when they come in the taxi, the taxi is lower. I don't mind but the problem is that my leg has to go up and when it goes up, I get pain... When the car or taxi is low I have so much pain.”* (Participant 8) Other participants also shared the experience of pain and influence on physical health and consequently personal safety when the appropriate vehicle was not available. If they chose not to use this vehicle then they would have to wait for another driver with no guarantee of having the appropriate resources or seek other private transportation.

Another participant also shared a story about the transportation service being uncomfortable and unsafe:

There was a lady and three people with walkers going into the small taxi and one of them had to hold the walker in the front seat because the taxi cannot hold two walkers

in the trunk... holding the walker in the front on her lap, that is not safe. (Participant 3)

In the example, the participant shared concerns about personal safety as this scenario can lead to serious damage. When these scenarios were observed and experienced, the participants accepted the situation because participants felt they could not refuse the ride because they had no other option to get home. If they did refuse, they would have to wait until they find you another ride to get home and this could take several hours.

Participants also shared how the type of vehicle influenced their personal safety and consequently health. *“They have this taxi and pick up 3 or 4 people and there is no room. Then you are sitting down for half an hour and there is no movement, this makes you very weak and gives you cramps.”* (Participant 6) Another participant discussed the vehicle type and impact on their physical health:

In the van, the seats are high especially in the front and it is difficult for me to get in because I'm short. After I've had my dialysis, this (fistula) is still very tender and if I put any pressure on it, it will bleed. So, I have to be very careful, because I can't hold on to the handle to pull myself up because that is too much stress on the arm. (Participant 7)

Participants also shared their experience of lack of access to necessary resources such as ramps for mobility on and off the vehicle, and its impact on her health. A participant shared her experience of entering a vehicle that did not have a ramp, even though she has a prosthetic leg and requires a ramp. She stated:

I have to lie on my belly to go up into the van, it's not low, because it's a high van and I said to the driver can you help me I have an amputated leg and my leg even dropped off because I had to bend and it slipped out. I want a proper vehicle where

I can go up with my walker and not have to climb up and my leg coming out that is embarrassing. (Participant 3)

In this example, as there was no ramp to enter the vehicle the participant had to lie on her stomach and not only is this concerning for her physical health but also influenced mental health as it created concerns to her self-identify and feelings of shame.

Another participant shared their concerns about resources as they mention:

One driver gave me a plastic something, you know that plastic dollar store stool you give to your kids to brush their teeth. One of them gave me one of those to step on to and I said no no no no no! I will not do that. I don't want to fall. I rather take the chance of going up and it would be hard for me than rather step on a stool that could side. (Participant 1)

In this instance, the participant shared that getting into some of the vehicles is very hard because just the way they are designed they do not have equipment on the side to hold on to and step on to and off. Also, there is quite a distance to step up to enter. Some drivers have accommodated to the lack of necessary accessible resources, these solutions create risk for falls and overall concerns to personal safety.

When asked if participants informed the transportation providers about the challenges to their personal safety, a participant responded, *“Yes, many times. Nothing really happens you know (laughs). They know I have a walker but still did not provide me with anything.”* (Participant 7) This created frustration towards their transportation companies and their own health situations.

Sub-Theme: Behaviours reflecting need for driver education. Participants shared their experiences of interacting with transportation drivers and how their personal safety and overall health was either being either supported or potentially compromised due

to drivers' behaviour. They reported varied experiences with the drivers ranging from positive to less than helpful. One participant shared:

I had good experience, most of the drivers are very kind, they bring you to the door to make sure you are okay and once in a while you get a bad driver who doesn't not want to do anything. I once got very upset with him it was very icy and I could not get to the door and he wouldn't walk with me and I was afraid to walk as I've fell quite a bit and he was the only one to help. (Participant 2)

In this instance, the participant shared the unsupportive behaviour of the drivers influences personal safety and overall health as they are nervous because if they fall and hit their head it could cause worsening health and overall functioning. Also, the participant shared that their family is worried about their mobility for falls. Another participant shared a similar experience and reported they had to *"hold onto the walker and struggle up the driveway."* (Participant 3)

Participants discussed their experiences of the lack of support from drivers and its impact on their personal safety. One participant shared, *"he (driver) said no, we're not allowed to help you in the van...and I said next time you come and can't help me into the van I won't take you."* (Participant 5) One participant expressed, *"They need to put a stop to some of these treatments that we get from these drivers especially taxi drivers."* (Participant 4) The treatment the participant received from drivers could include, *"what they do is look at you and if you look alright, they think you're alright, they may not know that your quite weak, so the assumption is that your fine."* (Participant 1) One participant noted the need for educating drivers in order to enhance health, *"some of these drivers need to be trained to be doing this type of job because they are dealing with fragile people."* (Participant 3)

In all these instances, the participants felt that the driver was the only individual present who could support them during the transportation journey and if this person did not assist it often resulted in concerns for their personal safety and specifically their physical health which then influenced their social and mental health. As the participants expressed mobility issues and did not always have the equipment needed to embark and disembark the vehicles, the drivers' unsupportive behaviours further created challenges influencing their experience of access to transportation.

Discussion

The theme of *reliability* was characterized by participants' requirement of access to transportation to attend HD treatment and maintain their health, and to the unpredictable variabilities in transportation service. This theme includes the sub-themes of dependability of transportation services for HD treatment and connection to health, and variations in consistency and coordination of transportation. Participants reported being dependent on transportation services and this affected their health because of the interplay of issues of access to transportation, dependence on transportation, and need for HD treatment. Without accessible transportation, participants felt they would have to miss treatment even though they understood the importance of HD treatment for their health. These study findings concur with the results from previous studies where researchers found that individuals were more likely to use dialysis, a life-saving and sustaining treatment, over conservative care, if subsidized transportation is available (Chan et al., 2014, Chenitz et al., 2014, Iacono, 2004; Morton et al., 2012).

All participants in this study reported a lack of consistency with transportation trips that included inconsistent dispatching and delayed pick up and drop off timing. Participants were being driven around to other cities after their HD treatment rather than being taken

straight home. Transportation dispatchers required the drivers to pick up other individuals prior to dropping the participants off and this created challenges to the participants' health. As HD is demanding on the human body (Polikandrioti et al., 2017), being driven around post HD treatment worsened their health and symptoms as they felt weaker, very tired, experienced cramping, and were emotionally upset as they were hungry and wanted to go home to eat and rest after HD treatment.

Inconsistent pick-up and drop-off times were common experiences of the participants. Participants that were being picked up late for their HD treatment to go to the center reported feeling stressed about being late to start their treatment and feeling rushed in the morning once they were at the center and this disrupted their medication schedule. There was inconsistency when the participants were picked up from the center to go home, as many reported having to wait for hours post-treatment for their ride. One participant even reported waiting 4.5 hours before the driver came to pick up the participant. Participants' meaning of health due to such circumstances was reflected in feelings of sadness, anger, frustration, anxiousness, wanting to cry, being hungry, and tired. Fatigue is considered to be a common, and often restricting symptom for HD individuals therefore timely service is necessary (Jhamb, Weisboard, Steel, & Unruh, 2008).

These study findings concur with the results of previous research about transportation challenges where researchers reported inconsistent pick-up and arrival times, prolonged wait times, transportation not showing up, or, leaving without the individual at the center if they are even a few minutes late, as obstacles to their HD treatment adherence (Chenitz et al., 2014). A study by Ride Connection (2014), a transportation service provider in the United States of America, about HD treatment patients and their transportation issues showed that 28% of the participants reported shortening their treatment because they were

worried about missing their ride home and 33% reported having their treatment shortened because they were late for their session.

Other research exploring the topic of access to transportation also concludes reliable transportation has positive impacts on the health of individuals. Transportation is a basic but crucial step for ongoing health care especially for those with chronic diseases (Syed, Gerber, & Sharp, 2013). Individuals with chronic disease require access to clinician visits, medication access, and other services to manage their health and without reliable transportation, delays in care are experienced. Such delays in care may lead to a lack of medical treatment, chronic disease exacerbations, or unmet health care needs that can worsen health outcomes (Syed et al., 2013). Having reliable transportation improves the number of visits to access health care, such as diabetic clinics leading to better monitoring, early detection, and timely preventive care (Thomas et al., 2018). Access to transportation may mean the differences between worse clinical outcomes leading to frequent emergency department visits and timely care that improves health outcomes.

Choice was the second major theme in this study. Participants shared their feeling of having or not having a choice in using alternative modes of transportation if their scheduled ride was not reliable. This theme includes the sub-themes of financial impact and asking for support from family and friends. Many individuals discussed their financial situation and how being on a fixed income did not give them a choice to call an Uber or taxi if their assigned ride was going to be delayed, or the service did not have all the necessary resources (i.e., ramp) needed for them to travel. Having to pay \$50/day for transportation when they were already registered for this subsidized transportation was not a choice they could make. Therefore, they were forced to wait a long time for another driver to come and pick them up.

Other participants had a choice of asking for support from family and friends if there were issues with transportation (i.e., missed, delayed, and not having the necessary resources). However, for some participants this choice was only possible on days their family and friends were home (usually weekends), therefore on other days they would also be forced to wait for their transportation to eventually come and take them home. In a survey on primary mode of transportation, only 10% of participants reported relying on friends or family members as their primary mode of transportation because they felt guilty about burdening their social supports and did not want to be dependent on others (Ride Connection, 2014). These findings are similar to the current study as, the choice of asking a family member or friend to drive the participant home was often not taken as many did not want to burden their support system and create issues in the family dynamics. Together these feelings and experiences influenced their social health.

These study findings concur with the results of previous research that discussed how financial impacts and support systems were factors in an individual making a decision about using alternative transportation if their scheduled transportation service was unreliable (Mercado-Martinez, da Silva, & Correa-Mauricio, 2017; Ride Connection, 2014). Similar to the findings of this study, Ride Connection (2014) found that any cost that individuals must incur for medical transportation could be a substantial burden if not a barrier to the health of individuals requiring transportation for HD treatment.

This study revealed that *personal safety*, the third major theme, was a major concern for individuals needing to access transportation for HD treatment. *Personal safety* included the sub-theme of having resources for safer travel and behaviours reflecting the need for driver education. Resources for safer travel included the type of vehicle they had to ride in to and from the HD center and lack of access to necessary resources to embark and

disembark the vehicle and its impact on their health. Participants shared the experience of riding in the vehicle and discussed that it felt unsafe and uncomfortable. There were instances when participants were having to hold their mobility assistive devices (walkers) in the passenger seat. This is unsafe because if the airbags were deployed it could cause serious damage to the participants. There were also concerns about trying to enter the vehicles as they were often not accommodating to their physical needs. Participants shared having hip replacements and that entering a taxi that is low creates pain and discomfort for the participant. Furthermore, some of the taxis are small and there may be up to four passengers in the taxi creating discomfort as there is no room for movement. This has health implications as participants shared this caused cramping in their legs, distress, pain, and frustration. These issues are further worsened by uncoordinated dispatching where participants are being driven around town prior to getting dropped off at home.

Lack of access to necessary resources to enter and exit the vehicle was another factor influencing personal safety. Participants reported the lack of ramps and side rails on all vehicles therefore they did not feel safe to enter the vehicle. One participant also reported having to lie on her belly in order to enter the vehicle and her prosthesis fell off, therefore not only impacting physical health but also her mental health as it creates feelings of sadness and embarrassment.

The Government of Ontario (2015) implemented The Accessibility for Ontarians with Disabilities Act that aims to make an accessible Ontario for citizens by 2025. Accessibility standards are laws that government, businesses, non-profits, and public sector organizations must follow to become more accessible for individuals with disabilities (physical and mental). Furthermore, transportation organizations such as TransHelp mention they are aiming to reach 100% accessibility by 2025 (Region of Peel, 2019). Given

that 2025 is only six years away, more efforts are required to make an accessible Ontario for individuals requiring HD treatment and who must access transportation services in Ontario in order to obtain that treatment.

Personal safety also revealed a sub-theme of behaviours reflecting need for driver education. Participants reported a lack of consistency in the behaviours of drivers as some were polite and respectful, but others were not helpful, not understanding, and uncompassionate. The participants suggested a need to educate drivers about the basics of HD treatment and its health implications, and the needs of this population. Since many drivers were not helping participants get into or out of the vehicle, the participants felt this was an issue to their health as they could fall and hurt themselves. This lack of help may be due to the liability issues as some participants reported they were told by drivers they are not allowed to touch the riders and therefore cannot help them. TransHelp, operated by the Region of Peel, states “a TransHelp driver will help you to and from the first accessible door to the taxi or TransHelp vehicle. We call this “door-to-door” service” (Region of Peel, 2019). However, participants did mention that when they asked drivers to walk with them on the icy driveway to their door in the winter, some drivers refused.

These study results are similar to previous research about transportation and its challenges (Iacono, 2004; Park & Kear, 2017; Ride Connection, 2014). From the issues reported by HD patients using Medicaid funded transportation, conflicts/arguments with drivers was the second most common problem reported by 21% of respondents, and 5% of participants reported concerns about safety (Iacono, 2004). Park and Kear (2017) also discussed the need for educating drivers as transportation companies typically hire general drivers who do not have healthcare experience. The authors mention this creates a gap in knowledge and sensitivity to the needs of individuals about HD and chronic illness

concerns. Similar to the current study, Park and Kear (2017) also noted that older adults and physically disabled individuals using transportation for HD have tremendous difficulties with getting into some of the vehicles. To make matters worse, drivers are told (by their company's policy) not to touch or assist the riders while they are boarding and disembarking from the vehicles due to liability (Park & Kear, 2017). Participants in the survey by Ride Connection (2014) also reported they felt the drivers lacked knowledge about HD and their needs. Some participants felt that the drivers and transportation systems are not compassionate with the riders.

Implications and Recommendations for Practice, Research, and Policy

As HD is a necessary treatment to live for individuals with ESRD, non-emergency medical transportation (NEMT) services are essential for people to have their treatment and manage their health. The findings of this study have a number of implications for clinical practice, research, and policy. The results highlight the importance of access to reliable transportation and areas that would enhance the health of individuals on HD. Without access to reliable services, individuals are more prone to shortening or missing their treatment, which leads to poor health implications. At the practice level, nurses providing care for individuals using NEMT should be aware of the challenges of transportation and assess whether treatment is being influenced by these challenges. As transportation can create poor health implications, nurses must assess individuals on HD for symptoms of deteriorating health that may be caused by inadequate treatment. From here on, there can be improved interdisciplinary collaboration and communication between the healthcare team, transportation provider representatives, families and individuals on HD to assess the transportation schedule and make appropriate changes to prevent poor treatment and health outcomes. Findings from this study identified the variations in

consistency and coordination of transportation. Therefore, if possible, healthcare staff can inform drivers in advance if the individual will be late for their ride to decrease anxiety related to missing their scheduled ride and promote treatment adherence.

Participants in this study reported having to wait by the entrance for their driver and this can be challenging in the wintertime as the cold air enters the waiting area. Participants shared this to be uncomfortable. It is therefore recommended that healthcare and transportation providers consider having a designated area inside the clinic away from the entrance as the waiting space where drivers can meet the individuals waiting for transportation. Participants also reported concerns about uncoordinated dispatching leading to lengthy travel time. It is recommended that dispatchers aim to match individuals residing in one area to travel together rather than individuals going to different cities being placed in the same vehicle.

Transportation providers should consider routinely conducting audits and surveys to improve and enhance the safety and accessibility of transportation vehicles. As participants reported concerns about their personal safety, surveys and audits can create an opportunity to assess the current practices and make a plan to improve services. Participants also reported the need to educate drivers to better accommodate for the health needs of individuals on HD and using transportation services. It is, therefore, recommended that transportation organizations revise their current orientation for new drivers to include the health needs of individuals on HD and conflict resolution. Also, ongoing education for all drivers should be provided in order to improve the unsupportive behaviours of drivers.

Participants identified challenges that factored into their experience of transportation for HD treatment and its influence on health. The findings revealed the theme of *choice*, with a sub-theme being financial impact. Further research could explore

the extent of financial impact on the health of participants on HD. The findings also identified the theme of *personal safety*, with a sub-theme being behaviours reflecting the need for driver education. Lack of literature on current orientation and education provided by transportation organization to drivers could lead to limited findings and evidence for educational opportunities. The findings from this research can enable the development of interventions to improve safety, clinical outcomes, and meaning of health for persons on HD.

As the setting of this study was limited to one HD center in a suburban area, replication with other HD centers in different geographical locations is needed to understand the impact of access to transportation for HD treatment on health for individuals residing in different locations.

Transportation challenges are believed to be at the start of the domino effect of routinely missing or shortening treatment leading to poor/no HD treatment sessions, and consequently negative health outcomes. Therefore, it is recommended that policy makers develop upstream approaches that address the root causes of this problem, lack of access to reliable transportation. Upstream approaches can include presenting these findings to the Ministry of Health and Ministry of Transportation to create awareness about this issue in order to advance political action. Also, political change can be advocated by completing a cost-benefit analysis to determine the financial impact on the health care system from the lack of access of transportation. As participants used government subsidized transportation, community members, healthcare professionals, and key stakeholders need to advocate to have current transportation policies reviewed to include more frequent and reliable transportation services. Findings from this study identified a lack of clarity in policy implementation regarding drivers assisting riders to board and disembark the vehicles. As

participants on HD reported feeling weak and tired after treatment, it is beneficial if drivers can support these individuals. It is therefore recommended that if transportation providers do not already have current policies regarding supporting riders, they should consider creating and implementing these policies, so all drivers are aware of the expectations.

Many individuals reported lack of access to resources such as ramps and other equipment required to embark and exit the vehicle. There is a need for transportation providers to have necessary resources to promote accessibility. The continuous lack of these resources can create severe negative health outcomes for the individual. It is therefore recommended that transportation providers consider creating a policy on the resources that must be present in all vehicles (such as ramps, railings, ability to kneel the bus for easy boarding, and other equipment needed), and continuously monitor and maintain all equipment to prevent any harm to individuals' personal safety.

Strengths and Limitations

To my knowledge this is the first interpretive description study exploring access to transportation for HD treatment and its influences on the overall health of this population using the WHO's definition of health. This study's findings contributed to the currently limited research evidence in this area, particularly in the Ontario healthcare system. Therefore, the findings from the study provide a foundation for the potential of positive change in the healthcare system for individuals requiring HD treatment. This study has some limitations that deserve mention. All of the participants were receiving HD treatment in one HD center; therefore, findings from this study may not be compared to other individuals, populations, or locations.

Conclusion

This interpretive description qualitative study explored how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health. Data analysis revealed three interrelated themes: a) *Reliability*, b) *Choice*, and c) *Personal Safety*. Transportation services that lacked reliability also influenced the choices the participants felt they had, and transportation services impact the personal safety of persons on HD. The findings call for a transformation in practice, research, and policy in order to more fully support individuals using in-center HD that require transportation services for this life sustaining treatment. These study findings have contributed to advancing the limited amount of research on the issue of transportation access issues for individuals using HD and its meaning to individuals' health.

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.
- Anney, V. N. (2014). Ensuring the Quality of the Findings of Qualitative Research: Looking at Trustworthiness Criteria. *Journal of Emerging Trends in Educational*

Research and Policy Studies 5(2), 272-281. Retrieved from
<https://pdfs.semanticscholar.org/1419/f7b54e6b7f1215717a5056e0709f8946745b.pdf>

Bennett, P. N., Bonner, A., Andrew, J., Nandkumar, J., & Au, C. (2013). Using images to communicate the hidden struggles of life on dialysis. *Journal of Communication in Healthcare*, 6(1), 12-21. doi:10.1179/1753807613Y.0000000031

Blumberg, M.T. (2016, June). *Atlanta Regional Commission: Health care and transportation intersection*. Workshop on Exploring Data and Metrics of Value at the Intersection of Health Care and Transportation, Washington, D.C.

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(4), 784-789.
 doi:10.2215/CJN.05501008

Calvey, D., & Mee, L. (2011). The lived experience of the person dependent on haemodialysis. *Journal of Renal Care*, 37(4), 201-207. doi:10.1111/j.1755-6686.2011.00235.x

Chan, K. E., Thadhani, R. I., & Maddux, F. W. (2014). Adherence barriers to chronic dialysis in the united states. *Journal of the American Society of Nephrology*, 25(11), 2642-2648. doi:10.1681/ASN.2013111160

Chartier, M., Dart, A. Tangri, N., Komenda, P., Wald, R., Bogdanovic, B., ... Rajotte, L. (2015). *Care of Manitobans living with Chronic Kidney Disease*. Retrieved from
http://mchp-appserv.cpe.umanitoba.ca/reference/ckd_final.pdf

- Chenitz, K. B., Fernando, M., & Shea, J. A. (2014). In-center hemodialysis attendance: Patient perceptions of risks, barriers, and recommendations: Barriers to hemodialysis attendance. *Hemodialysis International*, *18*(2), 364-373.
- Chiaranai, C. (2016). The lived experience of patients receiving hemodialysis treatment for end-stage renal disease: A qualitative study. *Journal of Nursing Research*, *24*(2), 101-108. doi:10.1097/jnr.000000000000100
- Clancy, M. (2013). Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher*, *20*(6), 12-16. doi:10.7748/nr2013.07.20.6.12.e1209
- Clark, S., Farrington, K., & Chilcot, J. (2014). Nonadherence in dialysis patients: Prevalence, measurement, outcome, and psychological determinants. *Seminars in Dialysis*, *27*(1), 42-49. doi:10.1111/sdi.12159
- Colaizzi PF (1978): Psychological research as the phenomenologist views it. In: Valle RS, King M (eds) *Existential phenomenological alternatives for psychology*. Oxford University Press, New York.
- Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.
- Cronin, J. J., Hagerich, J., Horton, J., & Hotaling, J. (2008, March). *Florida transportation disadvantaged programs: Return on investment study*. Tallahassee, FL: Florida State University.
- Gilbert, J., Lovibond, K., Mooney, A., & Dudley, J. (2018). Renal replacement therapy: Summary of NICE guidance. *BMJ (Clinical Research Ed.)*, *363*, k4303. doi:10.1136/bmj.k4303

- Government of Ontario. (2015). *About accessibility laws*. Retrieved from <https://www.ontario.ca/page/about-accessibility-laws#section-0>
- Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, 26(2), 91-108. <http://doi.org/10.1111/j.1471-1842.2009.00848.x>
- 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.
- Hoppe, L. K., Muhlack, D. C., Koenig, W., Carr, P. R., Brenner, H., & Schöttker, B. (2018). Association of abnormal serum potassium levels with arrhythmias and cardiovascular mortality: A systematic review and meta-analysis of observational studies. *Cardiovascular Drugs and Therapy*, 32(2), 197-212. doi:10.1007/s10557-018-6783-0
- Iacono, S. A. (2004). Transportation Issues and Their Impact Upon In-Center Hemodialysis. *Journal of Nephrology Social Work*. Retrieved from https://www.kidney.org/sites/default/files/v23_a6.pdf
- Jhamb, M., Weisbord, S. D., Steel, J. L., & Unruh, M. (2008). Fatigue in patients receiving maintenance dialysis: A review of definitions, measures, and contributing factors. *American Journal of Kidney Diseases*, 52(2), 353-365. doi:10.1053/j.ajkd.2008.05.005
- Koch, T. (2006). Establishing rigour in qualitative research: The decision trail. *Journal of Advanced Nursing*, 53(1), 91-100. doi:10.1111/j.1365-2648.2006.03681.x
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour : The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890. doi: 10.1046/j.1365-

2648.1998.00725.x

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Madeiro, A.C., Machado, P.D.L.C., Bonfim, I.M., Braqueais, A.R., & Lima, F.E.T. (2010). Adherence of chronic renal insufficiency patients to hemodialysis. *Acta Paulista de Enfermagem*, 23(4), 546-551. doi:10.1590/S0103-21002010000400016

Mercado-Martinez, F. J., da Silva, Denise Guerreiro V, & Correa-Mauricio, M. E. (2017). A comparative study of renal care in Brazil and Mexico: Hemodialysis treatment from the perspective of ESRD sufferers. *Nursing Inquiry*, 24(2), e12163-n/a. doi:10.1111/nin.12163

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5. doi:10.1177/104973200129118183

Morton, R. L., Snelling, P., Webster, A. C., Rose, J., Masterson, R., Johnson, D. W., & Howard, K. (2012). Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. *CMAJ : Canadian Medical Association Journal = Journal De l'Association Medicale Canadienne*, 184(5), E277-E283. doi:10.1503/cmaj.111355

Myers, A. (2014). *Non-emergency medical transportation: A vital lifeline for a healthy community*. Washington, D.C.: National Conference of State Legislators. Retrieved from <http://www.ncsl.org/research/transportation/non-emergency-medical-transportation-a-vital-lifeline-for-a-healthy-community.aspx>

NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018.

- Obialo, C. I., Hunt, W. C., Bashir, K., & Zager, P. G. (2012). Relationship of missed and shortened hemodialysis treatments to hospitalization and mortality: Observations from a US dialysis network. *Clinical Kidney Journal*, 5(4), 315-319.
doi:10.1093/ckj/sfs071
- Park, S., & Kear, T.M. (2017). Current state-of-practice: Transportation for patients with end stage renal disease. *Nephrology Nursing Journal*, 44(4), 309-315.
- Polikandrioti, M., Koutelekos, I., Gerogianni, G., Stefanidou, S., Kyriakopoulos, V., Floraki, E., & Babatsikou, F. (2017). Factors Associated with Hemodialysis Machine Dependency. *Medical archives (Sarajevo, Bosnia and Herzegovina)*, 71(2), 122–127. doi:10.5455/medarh.2017.71.122-127
- Polit, D. & Tatano-Beck, C. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th edition). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Region of Peel. (2018). *My Trips*. Retrieved from
<https://www.peelregion.ca/transhelp/my-trips>
- Region of Peel. (2019). *About TransHelp*. Retrieved from
<https://www.peelregion.ca/transhelp/about>
- Ride Connection. (2014). *Improving Transportation for Patients Receiving Dialysis Treatments: A Report on Findings*. Retrieved from
https://nationalcenterformobilitymanagement.org/wp-content/uploads/2013/11/RideConnection_DialysisTransportation_ACLStudy_Final-Report.pdf
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *ANS. Advances in Nursing Science*, 8(3), 27-37. doi:10.1097/00012272-198604000-00005

- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in nursing science*, 16(2), 1-8
- Sandelowski, M., & Barroso, J. (2002). Finding the findings in qualitative studies. *Journal of Nursing Scholarship*, 34, (3), 213-220.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63-75. doi:10.3233/EFI-2004-22201
- Silverman, D. 2000. *Doing qualitative research: A practical guide*. Thousand Oaks, CA: Sage Publications
- Simon, M. (2014). *Medicaid non-emergency medical transportation (nemt) saves lives and money*. Retrieved from <http://web1.ctaa.org/webmodules/webarticles/articlefiles/MedCT14commentary2.pdf>
- Smith, M. L., Prohaska, T. R., MacLeod, K. E., Ory, M. G., Eisenstein, A. R., Ragland, D. R., . . . Satariano, W. A. (2017). Non-emergency medical transportation needs of middle-aged and older adults: A rural-urban comparison in Delaware, USA. *International Journal of Environmental Research and Public Health*, 14(2), 174. doi:10.3390/ijerph14020174
- Syed, S. T., Gerber, B. S., & Sharp, L. K. (2013). Traveling towards disease: Transportation barriers to health care access. *Journal of Community Health*, 38(5), 976-993. doi:10.1007/s10900-013-9681-1
- The Kidney Foundation of Canada. (2013). *Facing the Facts*. Retrieved from <https://www.kidney.ca/document.doc?id=4083>
- The Kidney Foundation of Canada. (2016). *Facing the Facts*. Retrieved from <https://www.kidney.ca/document.doc?id=4083>

- The Kidney Foundation of Canada. (2018). *Facing the Facts*. Retrieved from <https://www.kidney.ca/file/Facing-the-Facts-2018.pdf>
- Thomas, L. V., Wedel, K. R., & Christopher, J. E. (2018). Access to transportation and health care visits for medicaid enrollees with diabetes: Medicaid transportation and diabetes visits. *The Journal of Rural Health, 34*(2), 162-172.
doi:10.1111/jrh.12239
- Thorne, S. E. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.
- Thorne, S. E. (2016). *Interpretive description: Qualitative research for applied practice* (Second ed.). New York, NY: Routledge.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*(2), 169-177. doi:10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.3.CO;2-B
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1-11.
doi:10.1177/160940690400300101
- Webster, A. C, Nagler, E. V., Morton, R. L., & Masson, P., (2017). Chronic kidney disease. *The Lancet, 389*(10075), 1238-1252. doi:10.1016/S0140-6736(16)32064-5
- White, D.L. (2011, May). *Advantages of public transportation to the Medicaid transportation model*. APTA 2011 Bus & Paratransit Conference, Memphis, TN.
- Whitely, A. (2012). Supervisory conversations on rigour and interpretive research. *Qualitative Reserach Journal, 12*(2), 251-271. doi: 10.1108/14439881211248383
- World Health Organization. (1946). *Public Health Reports (1896-1970), 61*(35), 1268-1277.

CHAPTER THREE

IMPLICATIONS, RECOMMENDATIONS, AND CONCLUSION

Summary of Key Findings

This interpretive description qualitative study aimed to explore how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health. Individuals who participated in this study shared their experiences of using transportation for HD treatment. Three interrelated themes were identified which illustrated the experience of access to transportation for HD treatment and its influences on participants' overall health: *reliability*, *choice*, and *personal safety*. Participants discussed the challenges related to *reliability* of transportation including dependability of transportation services for HD treatment and connection to health, and variations in consistency and coordination of transportation. From these challenges, *choice* become another main theme in this study. *Choice* was characterized by the feeling of having or not having the option of using alternative modes of transportation if their scheduled ride was unreliable. Financial impact and asking for support from family and friends were the sub-themes. *Personal safety* was the last major theme in this study and was characterized by the need for resources for safer travel and behaviours reflecting need for driver education. To tackle these challenges, it requires changes at the clinical, research, and policy level to decrease the negative impact of transportation challenges on health.

Implications and Recommendations

Implications and Recommendations for Practice

Findings from this study shed light on the need for changes in practice at HD center and at transportation provider organizations. Individuals on HD treatment require access to NEMT to prolong life and sustain health. From this study it was revealed that

transportation services are unreliable leading to negative health implications. For instance, individuals are more prone to shortening or missing their treatment if there are transportation barriers. Therefore, it is recommended for nurses to ask individuals that are frequently coming late for treatment, shortening their treatment, or missing treatment, if the reason is related to transportation. If so, social workers should be informed as they are assisting with transportation needs for HD. Also, the physician should be informed as the shortening of sessions impedes a high-quality HD treatment. Through this interdisciplinary collaboration and communication, a care plan can be initiated to tackle the barriers and adjust transportation pick-up time to better meet the needs of the individual. This may prevent the riders from shortening their HD treatment or missing their transportation and having to wait for extended period of time.

Findings from this study identified variations in consistency and coordination of transportation. This leads to lengthy waiting periods for pick-up from the center and extended travel time. For instance, individuals reported having to wait more than four hours after HD treatment for their transportation. This influences their health as they reported feeling weak and tired. In fact, post-dialysis fatigue is common, and often incapacitating symptom for this population (Jhamb, Weisboard, Steel, & Unruh, 2008). It is therefore, recommended that transportation providers inform the individual or the HD center if they will not be able to meet the scheduled transportation time. The transportation providers can also inform the individual the approximate timing for when they will be picked up. Many participants shared their discomfort of having to wait at the entrance in the wintertime as the cold air enters. Therefore, for individuals waiting for their transportation, a warm and safe designated area inside the clinic can be provided where drivers can meet the individuals waiting for their ride. If there are HD related complications that interfere with

a transportation commitment, it is recommended that the staff call the transportation providers and inform them about the situation and suggest a timing that works better for the individual requiring the service. This would lead to individuals not being left at the HD center and waiting for extended time for another driver to come pick them up and can decrease anxiety related to missed transportation.

The results of this study highlight the issue of uncoordinated dispatching leading to lengthy travel time. Therefore, the findings of this study can be used to inform transportation providers of the negative health impacts such as cramping, pain, and frustration of uncoordinated dispatching. To address this issue, providers should aim to match individuals residing in one area to travel together rather than individuals going to different cities being placed in the same vehicle. As HD appointments are on the same day and time each week, coordinators should review all the individuals requiring transportation in the center and assign group transportation based on cities to prevent lengthy travel time.

The results of this study highlight the need to supply the necessary resources, and equipment to improve the personal safety of riders. Therefore, the results of this study could be used to inform transportation providers, Ministry of Health, Ministry of Transportation about the consequences of lack of access to resources to embark and disembark vehicles. For example, the continuous lack of ramps in vehicles creates safety concerns and places individuals at risk of falls. To address this issue, transportation providers should assess all vehicles and place necessary resources required to access the vehicle. Also, annual anonymous services and routine audits can be conducted to assess the quality of the transportation including factors such as safety and accessibility of resources. This can create an opportunity to assess the current practices and make a plan to improve services.

In this study, the sub-theme of *personal safety* related to the need for driver education. Findings revealed a visible need to educate drivers to better accommodate the health needs of individuals on HD requiring transportation services. These findings can inform transportation providers about the consequences of lack of education specific to individuals using HD about personal safety. As drivers are usually the only individuals there to assist, they should support the riders, so trips are safe. It is, therefore, recommended that orientation for new drivers includes education about HD and chronic illness, safety concerns, and conflict resolution. The education should be ongoing and extended to current drivers in order to meet competency standards and promote health by preventing risks to personal safety.

Implications and Recommendations for Research

This study was to my knowledge the first study in Ontario, Canada to explore the experience of individuals requiring transportation for in-centre HD treatment and its influence on their overall health using the World Health Organization's definition of health. While there has been research on transportation challenges (Iacono, 2004; Park & Kear, 2017; Ride Connection, 2014), the impact on the meaning of health is missing. Consequently, this study contributed and added value to the limited literature on health (physical, mental, and social wellbeing) for individuals using NEMT transportation for in-center HD treatment.

In this study, participants identified factors of HD treatment that influenced their health. This includes the theme of *choice*, with a sub-theme being financial impact. To further understand the role of finances on the health of individuals on HD future study could be conducted to expand the current knowledge on this topic. This study revealed the theme *personal safety* with the sub-theme behaviours reflecting the need for driver

education. Future research should utilize various designs to explore the impact of driver education on personal safety of individuals on HD. A quantitative approach could include doing a pre and post-test study that investigates the current knowledge of drivers prior to participation in an education session, followed by a post-test to determine any changes in the knowledge and delivery of care of drivers transporting persons on HD. A qualitative approach can provide insight on their experiences and challenges of their role. Findings from further research can enable the development of interventions to optimize adherence, clinical outcomes, and meaning of health for individuals on HD.

In this study, the setting was limited to one HD center in a suburban area, but HD treatment is provided all across the province. Replication with other HD centers in different geographical locations is needed as the impact of transportation may differ from an individual residing in a rural area compared to an individual in an urban area. This study used a qualitative lens, with the purpose of gaining a deep understanding of access to transportation for HD treatment and its impact on health. Thus, further research could utilize various approaches to explore the influence of access to transportation on health.

Implications and Recommendations for Policy

Transportation is a significant determinant that influence the individuals' abilities to attend and complete their prescribed HD treatment. The findings of this study revealed the importance of access to reliable transportation for better health outcomes and the challenges influence all aspects of an individual's health. Therefore, transportation is considered to be at the start of the domino effect for poor health outcomes as missed or shortened treatment often leads to fluid and toxin accumulation leading to hospitalization and in severe cases, death (Hoppe et al., 2018). The findings from this study shed light on the need for change in policy for individuals having HD treatment to achieve better

transportation experiences and consequently health outcomes. In this study, participants discussed having to wait for extended periods of time for their transportation. To improve the quality of the service, there needs to be a revision to current policies on how missed and delayed trips are scheduled in order to provide more frequent and reliable service.

The findings of this study suggest the need for standardized policy on mandatory driver education about transportation and HD and the needs of this population. This policy should be clearly communicated to prevent any inconsistent practices. Transportation providers in collaboration with Ministry of Health, Ministry of Transportation, and other community partners could initiate and offer regular education programs designated to bridge gaps in knowledge and practices among drivers. An upstream approach can include presenting the findings of this study to the Ministry of Health and Ministry of Transportation to inform policymakers of the challenges experienced by individuals on HD in accessing transportation to help enhance NEMT programs and improve health outcomes. Furthermore, doing a cost analysis to examine the financial impact of lack of access to transportation on the healthcare system may draw the attention of Ministry officials to attune to this problem and brainstorm solutions. Nurses, patients, and families should collaborate to advocate for kidney health and transportation needs for HD treatment, in order to raise awareness to develop social policies and improve transportation programs that could improve health and health equity for this population.

The study findings revealed a lack of access to necessary resources and other equipment required to board and exit the vehicle. This impacts health by creating a risk to the personal safety of riders as they are not able to travel safely. The findings also share the impact on finances for some individuals as they have to use other transportation services if they do not feel safe entering the vehicle without the required resources such as

a ramp. It is therefore recommended that necessary resources and equipment is available and accessible in all vehicles. Furthermore, it is recommended that transportation providers consider creating a policy on the resources that must be present in all vehicles, and continuously monitor and maintain all equipment to prevent any harm to personal safety. Through these suggestions there is an opportunity to create a safe commute for individuals on HD and support their health needs.

Conclusion

This interpretive description qualitative study explored how persons requiring in-centre HD treatment explain the ways in which access to transportation for this treatment influences their overall health using the WHO's definition of health. The experiences of participants revealed three interrelated themes: *reliability*, *choice*, and *personal safety*. Reliable transportation was necessary for individuals to attend their treatment and go home after their session. When services are unreliable, it requires individuals to make a choice as to whether they will access alternative modes of transportation which creates financial challenges or seek help from their family or friends. The theme of personal safety was also identified from the study findings as many participants shared the challenges of not having necessary resources for safer travel and behaviours reflecting the need for driver education. All these factors influenced their physical, mental, and social health, and shaped their meaning of health. The findings call for an alteration in practice, research, and policy in order to more fully support individuals requiring transportation for HD, a life sustaining treatment.

References

- Hoppe, L. K., Muhlack, D. C., Koenig, W., Carr, P. R., Brenner, H., & Schöttker, B. (2018). Association of abnormal serum potassium levels with arrhythmias and cardiovascular mortality: A systematic review and meta-analysis of observational studies. *Cardiovascular Drugs and Therapy*, 32(2), 197-212. doi:10.1007/s10557-018-6783-0

- Iacono, S. A. (2004). Transportation Issues and Their Impact Upon In-Center Hemodialysis. *Journal of Nephrology Social Work*. Retrieved from https://www.kidney.org/sites/default/files/v23_a6.pdf
- Jhamb, M., Weisbord, S. D., Steel, J. L., & Unruh, M. (2008). Fatigue in patients receiving maintenance dialysis: A review of definitions, measures, and contributing factors. *American Journal of Kidney Diseases*, 52(2), 353-365. doi:10.1053/j.ajkd.2008.05.005
- Park, S., & Kear, T. M. (2017). Current state-of-practice: Transportation for patients with end stage renal disease. *Nephrology Nursing Journal*, 44(4), 309-315.
- Ramkumar, N., Beddhu, S., Eggers, P., Pappas, L. M., & Cheung, A. K. (2005). Patient preferences for in-center intense hemodialysis. *Hemodialysis International*, 9(3), 281-295. doi:10.1111/j.1492-7535.2005.01143.x
- Ride Connection. (2014). *Improving Transportation for Patients Receiving Dialysis Treatments: A Report on Findings*. Retrieved from https://nationalcenterformobilitymanagement.org/wp-content/uploads/2013/11/RideConnection_DialysisTransportation_ACLStudy_Final-Report.pdf

Appendix A

Ethical Approval from Western University Health Science Research Ethics Board



Date: 9 April 2019

To: Dr. Yolanda Babenko-Mould

Project ID: 112770

Study Title: An exploration of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health.

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 23April2019

Date Approval Issued: 09/Apr/2019 11:03

REB Approval Expiry Date: 09/Apr/2020

Dear Dr. Yolanda Babenko-Mould

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Demographic Instrument - April 6, 2019	Paper Survey	06/Apr/2019	2
Letter of Information and Consent - April 6, 2019	Written Consent/Assent	06/Apr/2019	2
Semi-structured Interview Guide- MAR 29:19	Interview Guide	29/Mar/2019	
Study Poster-April 6, 2019	Recruitment Materials	06/Apr/2019	2

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Nicola Geoghegan-Morphet, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B

Ethical Approval from Trillium Health Partners Research Ethics Board



Research Ethics Board
Trillium Health Partners
Mississauga Hospital site
6th Floor Clinical and Administrative Building
Mississauga, Ontario L5B 1B8
905-848-7580 ext. 1682

www.trilliumhealthpartners.ca

February 12, 2019

Dr. Yolanda Babenko-Mould
1151 Richmond Street
London, ON.
N6A 3K7

Dear Dr. Babenko- Mould,

RE: An exploration of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health (ID#906)

Delegated Ethics Approval

Expiry Date: January 23, 2020

This letter is to inform you that the above-named research study has been granted delegated approval by the Trillium Health Partners Research Ethics Board (REB) effective January 23, 2019 for a period of one year. After receipt of your responses to our conditional approval letter dated January 25, 2019, the following documents have been approved until the expiry date noted above:

- Protocol, version dated February 4, 2019
- Letter of Information and Consent, version dated February 12, 2019
- Study Brochure, version dated January 8, 2019
- Demographic Instrument, version dated February 4, 2019
- Semi-structured Interview Guide, dated January 8, 2019

The following items were also included in this review:

- Dr. Yolanda Babenko-Mould's CV, date received February 12, 2019
- Response to Conditional Approval letter, date received February 12, 2019

Please note that ongoing projects must be renewed prior to the expiry date and a closure form needs to be submitted once all study conduct (including data analysis) has been completed.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to participants) and/or any unanticipated developments within the research should be brought to the attention of Trillium Health Partners REB. In the event of a privacy breach, you are responsible for reporting the breach to the REB and the Trillium Health Partners Privacy Officer (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004 (PHIPA)). Additionally, the REB requires reports of inappropriate/unauthorized use of information. As the Principal Investigator, you are responsible for the ethical conduct of this study.

Credit Valley Hospital
2200 Eglinton Avenue West
Mississauga ON L5M 2N1
T: (905) 813-2200

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100 Queensway West
Mississauga ON L5B 1B8
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Queensway Health Centre
150 Sherway Drive
Toronto ON M9C 1A5
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Research Ethics Board
Trillium Health Partners
Mississauga Hospital site
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April 23, 2019

Dr. Yolanda Babenko-Mould
1151 Richmond Street
London, ON.
N6A 3K7

Dear Dr. Babenko- Mould,

RE: An exploration of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health (ID#906)

Amendment Approval - Delegated

This letter is to inform you that the following amendment(s) and documents have undergone delegated review, and have been granted approval effective April 17, 2019 by the Trillium Health Partners Research Ethics Board (REB). The following documents were included in this review and approval:

- Letter of Information and Consent, version dated April 5, 2019

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to participants) and/or any unanticipated developments within the research should be brought to the attention of the Trillium Health Partners REB. In the event of a privacy breach, you are responsible for reporting the breach to the REB and the Trillium Health Partners Privacy Officer (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004 (PHIPA)). Additionally, the REB requires reports of inappropriate/unauthorized use of information. As the Principal Investigator, you are responsible for the ethical conduct of this study.

Trillium Health Partners REB operates in compliance with the Tri-Council Policy Statement, ICH GCP Guidelines, PHIPA, and Part C, Division 5 of the Health Canada Food and Drug Regulations.

Sincerely,

Anjana Sengar BSc Phm, PharmD, ACPR

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Appendix C

Semi-Structured Interview Guide

Project Title - Exploring how persons requiring in-centre hemodialysis (HD) treatment explain the ways in which access to transportation for such treatment influences their overall health.

Interview Guide

Pre-interview:

Hello, my name is Navpreet Kamboj and I am an MScN student completing a thesis exploring how persons requiring in-centre hemodialysis (HD) treatment explain the ways in which access to transportation for such treatment influences their overall health

Before we begin, I wish to confirm a few details:

- I am not employed at the Renal Care Centre.
- The interview will last up to approximately 90 minutes and will be digitally audio-recorded.
- When the interview is transcribed, any personal identifiers such as your name will be removed from the transcripts.
- You can stop the interview at any time, and you can refuse to answer any or all remaining questions.
- I would like to confirm that the inclusion criteria has been met - you are 18 years of age or older; currently receiving HD treatment; use non-medical transportation services (i.e. TransHelp, Spectrum Patient Services, and taxi service) that do not include transportation by a family member or friend; agree to be audio-recorded for the interview; able to consent for themselves to participate in the study; and are able to speak and comprehend English. *(Wait for the participant to confirm)*
- Do you have any questions about the study or the interview before I proceed?

The questions I will be asking are intended to explore how persons requiring in-centre HD treatment explain the ways in which access to transportation for such treatment influences their overall health

1. For my first question, please describe your current hemodialysis and transportation schedule?
 Probe: How often are you using a transportation service to access dialysis treatment?
 Probe: What time is your transportation scheduled for and approximately what time do you finish treatment?
2. What is your experience of access to transportation for hemodialysis treatment?
 Probe: Typical day of coming to dialysis and leaving the center.
3. How would you define health?
 Probe: Relating the response to your health.

4. What does access to transportation mean for your health?
 - a. Probe: Ideal transportation situation to meet your health needs.
 - b. Please share an example of how having a 24/7 accessible source of transportation would mean for your health.
5. Describe the challenges you are/have experienced with transportation to and from dialysis? What makes it challenging?
6. How do the challenges of transportation impact your health?

(Points relate to the WHO definition of health)

Probe: Social- Transportation impacting your life with your family/friends. Challenges of transportation impacting your social life.

Probe: Physical - In relation to your treatment time (shortening, missing treatment). Any symptoms you experience i.e. prolonged fistula bleeding.

Probe: Mental- What emotions do you feel when you are in that moment experiencing those challenges?

7. How do you cope, recover, adjust or adapt from the challenges of transportation for hemodialysis treatment?

Probe: What resources or supports are there for you? (i.e. Family, another transportation mode)
8. Tell me about the things that your transportation provider, dialysis staff, or your family, etc. can do to help you with improving access to transportation and meeting your health needs?

Probe: Any other individual in your life (i.e. neighbours)

Probe: Policy and/or procedures that you believe would improve your health and access to transportation services for hemodialysis treatment.
9. For my last question, is there anything else that you would like to share about your experience of hemodialysis patients' access to transportation and what it means you're your health?

Post interview:

This concludes the interview. Thank you for taking time to participate in the study. Your insights are appreciated.

Appendix D

Demographic Questionnaire

Code:

When completing the following questionnaire, you may refuse to complete any questions you do not wish to answer.

1. Age: _____ years
2. Gender:
 - Female
 - Male
 - Other
 - Prefer not to answer
3. How long have you been on Hemodialysis? _____ years _____ months
4. How many times a week do you use a transportation service to attend dialysis?
 - 2 or less
 - 3-5
 - Greater than 5 times
5. Type of transportation used
 - TransHelp
 - Seniors Ride Connect
 - Spectrum Patient Services
 - Other _____
6. Highest level of education completed:
 - Less than high school
 - High school
 - College Diploma
 - Bachelor's Degree
 - Master's Degree
 - Doctorate
7. Employment Status
 - Employed Part Time
 - Employed Full Time
 - Retired
 - Self Employed
 - Unemployed
 - Sick/Disability Leave

Appendix E

Letter of Information

Project Title: Exploring how persons requiring in-centre hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health.

Principal Investigator:

Dr. Yolanda Babenko-Mould, RN, PhD
Associate Professor and Thesis Supervisor of Navpreet Kamboj
Arthur Labatt Family School of Nursing
Faculty of Health Sciences
Western University
London, Ontario, Canada

Graduate Student Researcher:

Navpreet Kamboj, RN, BScN, MScN Student
Arthur Labatt Family School of Nursing,
Faculty of Health Sciences
Western University
London, Ontario, Canada

Letter of Information

1. Invitation to Participate and Purpose of Study

For persons receiving HD at dialysis centres, a transportation service is used by many in order to be able to attend the treatment session. This type of transportation, which is identified as non-emergency medical transportation, has long presented with many challenges. Unreliable transportation is often noted as a key barrier to individuals' adherence to the HD regimen and schedule. You are being invited to participate because your experience of access to transportation for hemodialysis treatment can help explore and understand how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health. Studying this topic will allow for a better understanding of the challenges to accessing transportation and its impact on health.

2. Purpose of the Letter

The purpose of this letter is to provide you with the information needed to make an informed decision about whether or not you would like to participate in the study. It is important to know and understand what the research involves. Please take the time to read this letter carefully and should you have any questions, please feel free to ask at any time.

3. Inclusion Criteria

Inclusion criteria for this study are: participants 18 years of age or older; currently receiving HD treatment; use non-medical transportation services (i.e. TransHelp, Spectrum Patient Services, and taxi service) that do not include transportation by a family member or friend; agree to be audio-recorded for the interview; able to

consent for themselves to participate in the study; and are able to speak and comprehend English.

4. Exclusion Criteria

You are not eligible to participate in this study if you are under 18 years of age; have not used a transportation service provider for hemodialysis treatment; do not read, speak, or comprehend the English language; or do not wish to be audio-recorded for an interview.

5. Study Procedures

If you agree to participate, you will be asked to participate in one interview of a maximum of 90 minutes in length. The interview will be conducted either over the phone or in a private room at the Renal Care Centre where you receive hemodialysis treatment. Alternatively, the interviews can be held in a private room in a library or community center. There will be a maximum of 15 participants for this study. This study will run from March to December 2019.

6. Possible Risks and Harms

Given that privacy can't be guaranteed, a risk of breach of privacy exists with study participation. The research team will take extensive measures to mitigate the risk of a privacy breach, such as keeping the identifying information stored completely separate from the data and in a secured and locked area. There may be a risk to participants of experiencing uncomfortable emotions if they are sharing negative experiences. There are no other known or anticipated risks or discomforts associated with participating in this study.

You are free to not answer any questions and can stop participating at any time by letting the interviewer know that you would like to stop. If you choose to withdraw from the study during or after the interview, your data will be removed from all study records up until the data analysis process begins. Given data will be grouped, withdrawal will not be possible once the data analysis process begins.

7. Possible Benefits

There are no direct benefits to participating in the study other than the knowledge that you are contributing to our understanding of how persons requiring hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health. The results of the interviews may be used to implement programs that can be used by transportation providers to improve current transportation policies and procedures. Given this is the foundational step toward understanding the transportation phenomena, findings from this study can help administrators and policy makers to plan appropriate changes required to support the needs of individuals on hemodialysis and using transportation services.

8. Compensation

There is no compensation for involvement in this study.

9. Voluntary Participation and Rights of Participants

Participation in this study is voluntary. You have the right to refuse to participate, withdraw from the study at any time and withdraw your data prior to the start of the data analysis process, or refuse to answer any questions with no effect on your care. If you wish to withdraw data prior to data analysis, you must contact Navpreet Kamboj. During data analysis, the researchers will go back and forth to compare participants' comments, line by line, occurrence to occurrence, and concept to concept. Given that all personal identifiers such as full name will be removed and data will be grouped for analysis, withdrawal will not be possible once the data analysis process begins. Also during data analysis, the researchers will go back and forth to compare participants' comments, line by line, occurrence to occurrence, and concept to concept. This data will not include the participant's name precluding withdrawal once data analysis has started.

By consenting to participate in the study, you are not waiving any legal rights as a participant.

10. Confidentiality

All data collected will remain confidential and accessible only to the researchers of this study. If you choose to withdraw from this study prior to the data analysis stage, your data will be removed and permanently destroyed from our database. Personal identifiers (full name, address, full postal code, telephone number, email address, sex/gender, age, and voice/audio recording of the interview) will be collected during the recruitment and data collection process. Full name is being collected to contact the participants to schedule the interview. Mailing address including postal code, or email address will be collected to coordinate written consent for individuals requesting a telephone interview. Telephone number is being collected to arrange and conduct the interview. Gender and age information will be collected to understand how gender and age is represented among the participants and to ensure that a mixed sample by gender and age has been included in the study. The digital-audio recordings will help to record data so that the interview may be transcribed to support data analysis. The digital-audio recording will not contain any identifying information and will be deleted once transcription is confirmed.

All personal identifiers will be removed when the interview is transcribed. The personal information will be noted on a master list in hardcopy format, which will be kept locked in a file cabinet at Western University. Only the research team will have access to this information. Electronic copies of the transcribed audio-recorded data will be stored on a password protected document on a password protected computer. Electronic data will be uploaded to the Western University online learning management system called OWL. Only the research team will have access to this password protected OWL site. The digital audio recorder will be stored in a locked filing cabinet. Audio recordings will be permanently destroyed from the recorder after the files are uploaded to the secure OWL site for this study. As per Western University's policy, all identifiable and de-identified information will be retained for 7 years for audit and compliance purposes and will be destroyed after 7 years.

Representatives of the Western University Office of Human Research Ethics and Trillium Health Partners Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

11. Contacts for Further Information

If you require any further information regarding this research project or your participation in the study, you may contact:

Navpreet Kamboj, MScN Student
Arthur Labatt Family School of Nursing
Faculty of Health Sciences
Western University

If you have any questions about your rights as a research participant or the conduct of this study, you may contact the Western University Office of Human Research Ethics. You can also contact Trillium Health Partners Research Ethic Board.

12. Publication

If the results of the study are published or presented, your name will not be used.

13. Consent

If you have been selected for an interview, you will be asked for your consent to participate in the interview and for the audio-recording of the interview. Your consent indicates that you have read the letter of information and have had the nature of the study explained to you and what is expected of you. All questions have been answered to your satisfaction. Your consent also indicates that you agree to participate in the study and have been told that you can refuse to answer any or all questions. You have been informed that you can change your mind and withdraw your consent to participate at any time and may withdraw your data up until the start of the data analysis process by notifying Navpreet Kamboj. You understand that withdrawal from the study will not affect your current care. You have been informed that by agreeing to this consent agreement you are not giving up any of your legal rights.

This letter is yours to keep for future reference.

Appendix F

Consent Form

Project Title: Exploring how persons requiring in-centre hemodialysis treatment explain the ways in which access to transportation for such treatment influences their overall health.

Principal Investigator:

Dr. Yolanda Babenko-Mould, RN, PhD
Associate Professor and Thesis Supervisor of Navpreet Kamboj
Arthur Labatt Family School of Nursing
Faculty of Health Sciences
Western University
London, Ontario, Canada

Graduate Student Researcher:

Navpreet Kamboj, RN, BScN, MScN Student
Arthur Labatt Family School of Nursing
Faculty of Health Sciences
Western University
London, Ontario, Canada

I have read the letter of information, have had the nature of the study explained to me and what is expected of me. All questions have been answered to my satisfaction. My consent also indicates that I agree to participate in the study and have been informed that I can refuse to answer any or all questions. I have been informed that I can withdraw my consent to participate at any time, and have my data withdrawn up until the start of the data analysis process by notifying Navpreet Kamboj. I have had the opportunity to have all my questions answered. If I choose not to participate, I can hand back an unsigned copy of the consent form to the investigator. I understand that withdrawal from the study will not affect my current care. I have been informed that by consenting to being involved in this study, I am not giving up any of my legal rights.

I will receive a copy of the consent form signed by the investigator/designee.

Are you confirming your agreement to participate and be audio recorded for this study?

YES NO

Print Name of Participant

Signature

Date (DD-MM-YYYY)

I have explained the purpose of the study to the participant named above. I have answered all their questions.

Print Name of Person
Obtaining Consent

Signature

Date (DD-MM-YYYY)

CURICULUM VITAE

Navpreet Kamboj

Post-secondary Education and Degrees:

Western University
London, Ontario, Canada
2017-Current, Master of Science in Nursing

Ryerson University
Toronto, Ontario
2013-2017, Bachelor of Science in Nursing

Honours and Awards:

Western Graduate Research Scholarship 2017-2019
Nico Schreutelkamp Scholarship Award 2018
Helen Fasken Nursing Award 2018
Irene E. Nordwich Foundation Award 2018
Wellesley School of Nursing Alumnae Association
Award 2015

Professional Experiences:

Care Coordinator
Central West Local Health Integrated Network
2019-Present

Teaching Assistant
Western University
2017-2019

Registered Nurse
Trillium Health Partners
2018-2019

Registered Nurse
William Osler Health System
2017-2018

Research and Presentation Experience

Poster Presentation
St. Joseph's Healthcare Hamilton 22nd Annual
Kidney/Urinary Conference
2018

Research Assistant
Ryerson University
2016-2017