“Identifying Priority Challenges Affecting Mental Health in Adult Manitobans Receiving Facility-Based Hemodialysis: A Mixed Methods Study”

By

Russell J. Malabanan

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Department of Community Health Sciences

Max Rady College of Medicine

Rady Faculty of Health Sciences

University of Manitoba

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Abstract

Background: Chronic kidney disease (CKD) is a public health concern in Canada. As CKD is often without cure, it can lead to kidney failure, at which point kidney replacement therapy, including hemodialysis, is needed. Manitoba leads the country in both CKD and kidney failure rates per capita, with facility-based hemodialysis as the most common dialysis modality used. Challenges that come with this dialysis modality impact both physical and mental health, yet mental health care tends to be overlooked in facility-based hemodialysis care. Underdiagnosed and undertreated mental health concerns lead to poor mental health outcomes, which are associated with adverse health outcomes. There is a lack of studies exploring challenges affecting mental health in adults receiving facility-based hemodialysis in Manitoba. To improve the mental health of people receiving hemodialysis, identifying and prioritizing challenges to mental health is needed.

Objectives: This study aimed to identify priority challenges affecting mental health in adults receiving facility-based hemodialysis in Manitoba and identify potential mental health support strategies, based on the perspectives of people receiving hemodialysis, their caregivers and hemodialysis healthcare providers.

Methods: Using an observational, embedded mixed methods approach, this study conducted a cross-sectional survey at two urban facility-based hemodialysis centres in Winnipeg, Manitoba. Using two similar, but distinct community-approved and tested instruments that included both closed-ended quantitative and open-ended qualitative questions, we collected the anonymous

perspectives of people receiving hemodialysis, caregivers and hemodialysis healthcare providers. Data collected were analyzed in two groups: (1) people receiving hemodialysis and caregivers combined, and (2) healthcare providers. We used both quantitative and qualitative methods to analyze the data. Challenges and solutions to mental health were inductively and deductively identified from survey responses using summative content analysis. Thematic analysis was used to identify themes around preferences for suggested mental health support. Descriptive statistics (i.e. frequency/count and proportion) and Fisher's exact/chi-square test were used to analyze the challenges and solutions identified, stratifying and comparing responses by age, gender, role, dialysis vintage and relocation for dialysis status.

Results: We collected 124 responses from 95 adult Manitobans receiving hemodialysis and their caregivers, and 29 dialysis healthcare providers. We identified and ranked 24 challenges to mental health in people receiving hemodialysis. Overall, the top 10 priority challenges to mental health in adult Manitobans receiving hemodialysis are loss of control, difficulty coping, depression, loneliness/isolation, grief/dealing with loss, anxiety, worry/stress, dialysis-related symptoms, acceptance/adjustment to situation, and lack of confidence/trust in healthcare providers/system. We observed differences in priorities between the hemodialysis recipient and caregiver group and the healthcare provider group. Further, challenges identified by people receiving hemodialysis did not differ across age, gender, ethnicity, dialysis vintage and relocation for dialysis status.

We identified 4 potential mental health support strategies: hemodialysis recipients and caregivers prefer peer support and counselling, while healthcare providers advocated for healthcare system improvements. Both survey groups agreed on increased availability and accessibility of mental health resources. Similarly, solutions identified by both groups did not differ by their

demographic variables, including age, ethnicity, gender, role, dialysis vintage and relocation for dialysis status.

Conclusion: This is the first study to investigate priority challenges to mental health in adult facility-based hemodialysis care in Manitoba. We identified the top 10 priority challenges to mental health in adult Manitobans receiving hemodialysis and 4 potential mental health support strategies. As part of the CanSOLVE CKD *Mind the Gap* project, our findings will inform subsequent project phases, including designing and implementing a mental health support strategy to address key mental health challenges for people receiving facility-based hemodialysis in Manitoba.

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Chapter 1 Positionality

I declare my positionality here to identify influential factors, such as my identity, experience, and worldviews, that shape how this research is conducted in its entirety. First, I am a Filipino immigrant, who came to Canada in 2013, and received my citizenship in 2020. Since moving to Canada, I have lived in Winnipeg, Manitoba where I attended secondary and post-secondary school and am now pursuing graduate studies in the Community Health Sciences at the University of Manitoba. Thus, this work is primarily developed to satisfy a requirement of my program to matriculate. Being a recent immigrant has shaped my understanding of and interaction with our healthcare system, both on a provincial and federal level. As a recent immigrant/new citizen living in an urban city, I acknowledge the privileges that I have in terms of access to healthcare and healthcare coverage/benefits that not everyone might share. That said, I am cognizant of the difficulties of navigating a foreign healthcare system and seeking specialized care. I have also appreciated the importance of culturally safe care and seeing representation in the system firsthand.

I also position myself as a clinical researcher, with my work mostly focused on kidney-related research for several years prior to commencing graduate studies. Kidney disease affects some ethnicities more than others, including Filipinos. Given that Manitoba has the largest per capita Filipino community in Canada and observing a disproportionate number of Filipinos receiving facility-based hemodialysis during my work in dialysis units, I would like my work to improve the quality of care for everyone receiving hemodialysis, with delivery of individualized and culturally safe mental health care.

Chapter 2 Introduction

Chronic kidney disease (CKD) is a public health concern in Canada, with 4 million people affected by the disease[1]. Since CKD often has no cure, it can lead to kidney failure if left unmanaged or undiagnosed. With failing kidneys, the accumulation of toxins in the body can lead to death[2,3]. Manitoba has the highest rate of kidney failure per capita across the country, at 1793.9 cases per million people[4].

Dialysis is a lifesaving treatment received by people with kidney failure. Facility-based hemodialysis, the most common type of dialysis used in Canada[2,5], requires people with kidney failure to attend treatments at hemodialysis clinics, which are usually based in healthcare centres or hospitals, for four hours three times per week[5]. Side effects related to hemodialysis treatment, including fatigue, can last for hours or even days following treatment sessions and often affect one's ability to participate in daily activities[6]. Additional appointments with various health care providers are often necessary to address other medical comorbidities such as diabetes and cardiovascular disease[2,7,8]. Strict dietary and lifestyle changes must also be observed while on hemodialysis[9,10]. Altogether, receiving hemodialysis can adversely affect multiple aspects of one's physical and mental health, and overall quality of life.

However, the mental health impact of challenges associated with receiving hemodialysis treatment is often overlooked in hemodialysis care. Resulting mental health concerns are underrecognized and undertreated in people receiving hemodialysis[11]. Barriers to the identification of mental health concern include lack of appropriate mental health care training and expertise amongst hemodialysis healthcare providers, and self-perceived barriers faced by hemodialysis recipients[12,13]. Meanwhile, the undertreatment of existing mental health concerns in

this patient population is attributed to the limited strategies and supports available, which have been deemed inadequate by people receiving hemodialysis, caregivers and healthcare providers alike[13–15]. In addition, the COVID-19 pandemic has negatively impacted the mental health of people receiving hemodialysis and large parts of the general population, further straining and limiting the mental health supports and resources available to provide mental health support to people receiving hemodialysis[16]. Further, studies on the prevalence of mental health concerns among people receiving facility-based hemodialysis have largely focused on clinical diagnoses of depression and anxiety[12,14,17–19]. Yet one study identified that the ability to cope, acceptance of one's situation, feelings of isolation and hemodialysis-related complications impact mental health in people receiving hemodialysis[20].

In Canada, the prevalence of mental health concerns in adults receiving facility-based hemodialysis has been described in Ontario[21] and Alberta[14,22], though these studies largely focus on the prevalence of depression and anxiety symptoms only. Studies also show that dialysis experience and mental health outcomes can differ by age, gender, and ethnicity in people receiving hemodialysis[23–25]. Both internal and external factors related to the hemodialysis experience are thought to contribute to mental health concerns in people receiving hemodialysis. These include internal factors like psychological impact of dialysis-related symptoms, poor prognosis, quality of care received and feelings of isolation. External factors include the need to relocate to receive hemodialysis, difficulties with transportation to hemodialysis sessions, polypharmacy and drastic lifestyle changes associated with receiving hemodialysis[10,17,26–32]. Despite the high prevalence of kidney failure in the province, the importance and prevalence of specific factors/issues that impact mental health in people receiving facility-based hemodialysis in Manitoba and how these are modified by demography are unknown.

To improve the mental health of adult Manitobans receiving facility-based hemodialysis, this thesis project aims to identify priority challenges affecting their mental health and potential mental health support solutions.

Chapter 3 Literature Review

Chronic Kidney Disease

Chronic kidney disease (CKD) is a public health concern in Canada, affecting 4 million people[1]. CKD leads to progressive loss of kidney function and decreased ability to remove water from the body, regulate metabolites, and filter toxins from the blood[3,33]. Damage to the kidneys is most commonly caused by diabetes, hypertension, kidney inflammation (glomerulonephritis), and polycystic kidney disease[34,35]. Progression of CKD is measured by the kidney's efficiency in filtering metabolites from the blood and is most often reported as the estimated glomerular filtration rate (eGFR)[3,33,36,37]. eGFR can be classified into five categories, ranging from CKD Stage 1, with normal kidney filtration, to CKD Stage 5, also called end-stage kidney disease (ESKD) or kidney failure, wherein less than 15% of the kidney function remains[3]. As there is often no cure for CKD, a person with kidney failure needs kidney replacement therapy to survive, as accumulation of toxins and water causes the deterioration of one's health, and ultimately may lead to death[33,38]. According to latest statistics, over 48,000 Canadians have kidney failure[4]. Manitoba has the highest prevalence of kidney failure in Canada per capita, with 1793.9 cases per million population, compared to the national average of 1242.6 per million population[4]. Similarly, Manitoba also has the highest incidence of kidney failure per capita, with

264.7 cases per million population, compared to the national average of 180 cases per million population[4]. Altogether, these illustrate a prominent and growing health concern in the province.

Facility-Based Hemodialysis

Kidney replacement therapy is a life-saving treatment provided to individuals with kidney failure, and includes kidney transplant and several types of dialysis, including facility-based hemodialysis and home dialysis[2,39,40]. In home dialysis, people who are more medically stable provide their own dialysis treatment at home with proper training and monitoring from healthcare providers[40,41] . In contrast, care for facility-based hemodialysis treatments is provided entirely by clinical staff at a hemodialysis center[2,5]. In Canada, the majority (77%) of people with kidney failure start with facility-based hemodialysis[4]. During facility-based hemodialysis treatment, a small amount of blood is continuously removed from the body through a vascular access (such as a surgically arterialized vein on the arm or a hemodialysis catheter inserted into a vein in the neck). This blood is continuously filtered through a dialysis membrane to remove toxins and water, and then returned to the body again via the same vascular access[2,5].

People who receive facility-based hemodialysis typically come in for their dialysis treatment for 4 hours, three times a week[5]. They must regularly attend their scheduled visits, as missing dialysis sessions can often cause their health to decline abruptly and may lead to hospitalization or death due to the accumulation of fluids and toxins[2,5,42]. Further, additional lifestyle changes are also required, including limiting daily fluid intake and following dietary restrictions to decrease intake of substances that can build up in kidney failure including electrolytes such as sodium, potassium, and phosphate[9,10]. During and after dialysis, rapid changes in one's electrolyte balance, decrease in fluid volume, blood pressure, and blood glucose

levels occur. To some extent, these abrupt changes can cause people receiving hemodialysis to experience symptoms, such as nausea, dizziness, cramps during or after their treatment, and require prolonged recovery time after hemodialysis before they can return to their usual daily activities[5,6]. In addition, the presence of comorbidities, such as diabetes, hypertension and cardiovascular disease, is common among people receiving hemodialysis[7,43–45]. This may result in additional appointments with other healthcare providers outside of their dialysis schedule, further increasing their time commitment and expenses towards receiving medical care, and reducing time available for life participation[46–48]. Comorbidities, the need for multiple medications (mean of 6-20 per day) to manage symptoms, and complications of kidney failure can also lead to polypharmacy, increasing the risk for falls, hospitalization and other adverse events and decreasing quality of life, including physical and mental health[32].

In Manitoba, kidney care (including dialysis treatments) is under the direction of the Provincial Kidney Health Program[49]. This program provides a multidisciplinary approach, involving nurses, kidney doctors (nephrologists), social workers, dietitians, pharmacists and other allied healthcare providers, in providing care for individuals with kidney disease in Manitoba[49]. Currently, two-thirds of all facility-based hemodialysis treatments are delivered at four urban hemodialysis centers: Health Sciences Centre, Seven Oaks General Hospital, St. Boniface General Hospital (all in Winnipeg) and Brandon Regional Health Centre (in Brandon). The remainder of facility-based hemodialysis treatments are provided at 17 satellite hemodialysis units in rural and remote areas in Manitoba, such as in Dauphin, Russell, Pine Falls, and Garden Hill[50]. However, due to the high cost of operating these sites and limited resources and staff to work at these sites, there are limited spots for facility-based hemodialysis treatments, which are assigned to people based on their dialysis start date[51–53]. Those who are not eligible for home

dialysis or cannot be accommodated at these sites will have to travel to or relocate on a temporary or permanent basis to receive hemodialysis at an urban dialysis centre[53]. Transportation needs and relocation from one's home community to access hemodialysis care can also impose significant psychological and financial burdens and impact quality of life for Manitobans[31,54]. Thus, it is evident that hemodialysis care and its associated conditions and requirements affect multiple aspects of one's life and health.

Facility-Based Hemodialysis and Mental Health

Mental Health

Mental health can encompass many aspects of one's health, depending on the epistemological and moral framework used to develop its definition[55]. In some definitions, it refers to one's biological, psychological, and social factors that affect an individual's mental state and functioning[56]. Other definitions can include intellectual, emotional, and spiritual factors[57]. The definition of mental health adopted for this project is from the World Health Organization (WHO), which indicates that "mental health is a state of mental well-being that enables people to cope with stresses of life, realize their abilities, learn and work well, and contribute to their community. This [mental health] includes mental disorders and psychosocial disabilities as well as other mental states associated with significant distress, impairment in functioning, or risk of self-harm"[58].

The "Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition" (DSM-5) is widely adopted and used by clinicians to standardize, classify and diagnose mental disorders, and serves as a guideline as well for treating mental health disorders[59]. However, major limitations of using DSM-5 include both overdiagnosis and underdiagnosis of mental health disorders based on how

the criteria for the disorders are set and how they are interpreted in people presenting with symptoms[60], which ultimately shape and impact the care received by patients. Although standardizing and categorizing mental health concerns through the DSM-5 is important, it still excludes and fails to recognize other forms of mental health concerns, such as difficulty in coping, feeling frustrated, and guilt, which also impact people's mental health[60-61]. Thus, the definition adopted here was chosen to be inclusive of all kinds of mental health concerns, including those that are formal clinical diagnoses, such as major depressive disorder, and those that are not, like feelings of guilt, in people receiving hemodialysis.

Mental Health Concerns in People Receiving Facility-Based Hemodialysis

In addition to impacts on physical health, people's mental health is also affected when receiving hemodialysis. A qualitative study from Turkey recruited ten people receiving hemodialysis for a semi-structured interview regarding the psychological impact of their hemodialysis experience[62]. Participants reported often experiencing depression, anxiety, decreased social support, burnout, and despair[62]. Similarly, a study from Iran conducted semi-structured interviews with sixteen caregivers of people receiving hemodialysis, who reported observing similar symptoms in the people they care for[63]; mental health challenges identified in this qualitative study were depressive mood, incompatibility and reduced tolerance, mental exhaustion, and social disruption, which includes social isolation and social threats (stigma, social labels, and unstable employment)[63]. Feelings of isolation, grieving the loss of their normal life, experiencing stress that comes with constant planning, and coming to terms with mortality have also been reported in people receiving hemodialysis[64]. However, there are limited qualitative studies from Canada that explored and reported mental health concerns in people receiving hemodialysis. One study from Quebec involved 22 individuals receiving facility-based

hemodialysis participate in semi-structured interviews to explore receiving their hemodialysis treatments amidst the COVID-19 pandemic[65]. Though participants did not report a negative impact to the medical care they receive, they reported feelings of loneliness[65]. One multicenter study recruited people receiving hemodialysis, caregivers and healthcare providers from Alberta, Ontario, Nova Scotia, Newfoundland, British Columbia and Manitoba to discuss the burden of transportation for hemodialysis[31]. Although the study's focus was transportation, it reported that some people receiving hemodialysis feel guilty for heavily relying on their caregiver for their transportation needs for hemodialysis[31].

Studies show that mental health concerns are disproportionately higher in people receiving facility-based hemodialysis compared to the general population, though these studies are mostly limited to identifying depression and anxiety. For instance, the prevalence of depression and anxiety in people receiving hemodialysis was found to be 20-40% and 17%-46%, respectively, compared to their prevalence in the general population of 4.4% and 3.6%, respectively[66–69]. In a US sample of 98 people receiving hemodialysis, 27% had depressive symptoms, and 17% had major depression[70]. Data from Canada are similar. In Ontario, in a sample of 124 people on hemodialysis, 38.7% had depressive symptoms, as measured using Beck Depression Inventory (BDI-II)[71]. In Alberta, people commonly experienced depressive (29%) and anxiety (21%) symptoms as measured using the Patient Health Questionnaire-2 and 2-item Generalized Anxiety Disorder, respectively[14]. More recently, the COVID-19 pandemic further heightened the prevalence of mental health concerns in this patient population[72–75]. During the pandemic, people receiving hemodialysis experienced isolation, stress, and increased anxiety symptoms, all while having limited access to support and health care services[72,74,75]. Using Zung's self-rating anxiety and depression scales, one study found that the prevalence of

depressive symptoms (32.09%) and anxiety symptoms (34.89%) during the pandemic was higher in this patient population compared to other outpatients (7.44%) and the general population (3.7%)[72].

Among people receiving hemodialysis, studies also show that dialysis experience and mental health outcomes differ by age, gender, and ethnicity. Interestingly, age has not been a well-studied factor that could affect mental health in people receiving hemodialysis. Only one study from Albania found a significant difference in the prevalence of anxiety and depressive symptoms in older versus younger people receiving hemodialysis[23]. Anxiety and depression symptoms are 13.5 (CI 5.6-19.7) times more common in people receiving hemodialysis in the age group of 61-70 years old compared to those in the 18–30-year-old group[23]. Similarly, depressive symptoms are 2.5 (CI 1.3-5.0) times more common in the same older age group compared to the younger age group[23]. Gender disparities in how people perceive their hemodialysis experiences have also been identified by hemodialysis healthcare providers [24]. In a multicentre study that conduced semi-structured interviews with 51 nephrologists from Brazil, Canada, Hong Kong, France, India Italy, Japan, Malaysia, Poland, Sweden, Switzerland, United Kingdom and Uruguay, participants reported differences in dialysis experience between men and women[24]; themes related to women's dialysis experience included 'commitment to caregiving (subthemes: coordinating care, deprioritizing own health, centrality of family on decision-making), vigilance and self-reliance'(subthemes: tolerating symptoms, avoiding burdening of family, isolation, and coping alone), while the main theme related to men's dialysis experience was 'protecting masculinity' (subthemes: safeguarding the provider role, clinging to control and self-regard). These suggest that gender influences the psychological health and life priorities of people receiving hemodialysis. In terms of ethnicity, one secondary analysis of a cross-sectional

data from Ontario found that self-reported racialized immigrants with advanced CKD (including dialysis recipients) have higher odds of experiencing psychosocial distress (OR=2.96, 95% CI= 1.81-4.81), depressive symptoms (OR=1.87, 95% CI= 1.05-3.34), and social difficulties (OR=3.36, 95% CI= 2.03-5.57) than White individuals[25]. In contrast, a study that analyzed mental health status and mental health service utilization by ethnicity in an Ontario community demonstrated that self-reported physician-diagnosed anxiety disorders were generally lower in South Asian, Chinese and Black participants, compared to White participants[76]. Amongst those who self-reported positive for mental health concerns, fewer participants reporting Chinese ethnicity (19.8%) sought help compared to White participants (50.8%). The authors recognized that this disparity could be attributed to traditional cultural beliefs towards mental health[76]. Although this study is outside the context of hemodialysis, it speaks to the attitudes and beliefs that some ethnic groups might have towards mental health and how it could impact help-seeking behaviours. Altogether, these highlight age, gender and ethnicity as factors to consider when assessing and addressing challenges that affect the mental health of people receiving hemodialysis.

Stressors Related to Hemodialysis Care

In the literature, some causes of mental health concerns in this patient population are attributed to the overall experience of receiving hemodialysis, which includes stressors from within and outside dialysis treatment. Stressors present within dialysis treatment include the quality of care provided by clinical staff, the psychological impact of fluctuating health conditions, poor prognosis, insertion of needles to access one's blood for dialysis and the impact of dialysis on one's body image[17,26–30]. Stressors outside of one's dialysis treatment affecting mental wellness include accessing specialized care, adhering to dietary restrictions and dialysis

schedule, polypharmacy, and the impact of dialysis on one's lifestyle and the social relationships of patients with their family and loved ones[10,31,32].

For example, poor quality of care related to limited resources available (e.g. specialist on site, language interpreter, etc.) and discriminatory practices can result in feelings of frustration and anger in people receiving hemodialysis[17,26]. Poor prognosis of people on hemodialysis may lead to a feeling of hopelessness[27]. Radical and abrupt changes to one's lifestyle due to kidney failure and receiving hemodialysis require the capacity for coping[28]. People on hemodialysis have also reported experiencing anxiety around needle insertion required for hemodialysis access if one has an arteriovenous fistula[29]. Swelling of certain body parts and vascular access placement associated with receiving hemodialysis can cause body image disturbances[30].

In terms of external factors, frustration and stress related to the burden, unreliability and cost of transportation services to access hemodialysis care are also commonly reported, especially by people who live far away from a dialysis centre[31]. This is further magnified in people who require additional appointments to receive care for other medical conditions. For example, people receiving hemodialysis who wish to see an endocrinologist to help manage their diabetes may require another appointment in addition to their weekly dialysis schedule for other medical conditions or problems not related to hemodialysis. People on hemodialysis report feeling like a burden to their caregivers, which leads to feelings of guilt[31,63]; these stem from the time and effort provided by caregivers to people receiving hemodialysis, including transportation and emotional support[31,63]. Accumulation of multiple factors listed above further amplifies and contributes to the high prevalence of mental health concerns in the hemodialysis population.

Impacts of Mental Health Concerns on Patient Health Outcomes

Mental health concerns have been associated with adverse health outcomes in people receiving hemodialysis. For example, the diagnosis of depression in people receiving hemodialysis has been associated with lower quality of life, higher mortality and hospitalization risk compared to non-depressed people receiving hemodialysis. A cross-sectional study involving 117 hemodialysis recipients found that those diagnosed with depression have lower quality of life scores than those without a depression diagnosis (11.15 vs. 14.18, respectively, p=0), based on Ferrans and Powers Quality of Life index for Dialysis version III[77]. One prospective observational study of 5256 participants demonstrated that depression in people receiving hemodialysis, diagnosed using Kidney Disease and Quality of Life Short Form (KDQOL-SF), was associated with higher risks of mortality (Adjusted Relative Risk [RR]= 1.48; 95% Confidence Interval= 1.29-1.70) and hospitalization (Adjusted RR= 1.11; 95% CI=1-1.24) as compared to non-depressed people on hemodialysis, adjusted for sex, age, dialysis vintage, comorbidities, and socioeconomic factors[78].

Further, the prevalence of depressive symptoms in people receiving hemodialysis is associated with lower medication adherence and increased risk of discontinuation of hemodialysis. One cross-sectional observational study surveyed 65 people receiving hemodialysis. Based on self-reported medication adherence, investigators observed that those with low medication adherence had more depressive symptoms, as measured by Beck Depression Inventory II scores, compared to individuals with “Perfect” and “Nearly Perfect” medication adherence[79]. In a longitudinal study that followed 240 people receiving hemodialysis over 4 years and measured depression severity using Beck Depression Inventory, a 1-point increase in total BDI score was associated with a 5.2% higher risk of discontinuation of

hemodialysis when adjusted for age and comorbidities (p=0.05)[80]. In view of the adverse health outcomes associated with poor mental health, there is a need for better identification and management of mental health concerns in people receiving hemodialysis.

Mental Health Issues in People Receiving Facility-Based Hemodialysis are Under-Recognized and Undertreated

Mental health and emotional distress were identified as 'underrecognized and ignored" as a major theme in hemodialysis care, based on focus group discussions with people receiving hemodialysis and caregivers[64]. Participants in the study shared that healthcare providers do not recognize the mental health burden that they experience related to receiving hemodialysis[64]. One study surveyed the attitudes of nephrologists towards providing psychosocial care, which includes addressing mental and emotional well-being, for people receiving hemodialysis[13]. The study found that only 43% of the participants felt comfortable providing psychosocial care[13]. Further, nephrologists identified administrative paperwork burden as the main contributing factor towards the lack of time to provide psychosocial care, followed by the lack of available psychosocial care resources. Most study participants (97%) also believed that social workers are better trained than physicians to provide psychosocial care[13]. However, from the perspective of social workers, they face many challenges when providing mental health care[81]. As most hemodialysis centers are limited to referring patients to social workers as their primary, and often only, type of mental health support, social workers are overburdened with providing many types of support[81]. In addition to providing people receiving hemodialysis mental health support, their responsibilities also include helping patients navigate health and legal systems, providing financial assistance, and offering other care-related support, like end-of-life care[81,82]. This, in

turn, reduces the amount of time that social workers can provide to each patient in providing mental health support[81] .

In addition to gaps and barriers to providing mental healthcare faced by hemodialysis healthcare providers, people receiving hemodialysis also experience barriers to seeking mental health care. In a study of 160 people receiving hemodialysis in Ontario, 73.1% of participants reported at least one barrier that prevented them from seeking mental health support. The top three barriers to seeking mental health care identified in this study were: (1) they do not think their problems are severe enough (23.1%); (2) they do not think they will get depressed (22.8%); (3) they have other more important problems (18.7%). Thus, self-awareness of one's mental health state influences when people decide to seek help. Further, one study from Australia analyzed surveys and workshops wherein people receiving hemodialysis talked about their mental health[64]. They believe that healthcare providers are likely to underrecognize and ignore their mental health needs, leading them to address their own needs[64]. With regards to receiving mental health support specifically in hemodialysis units, the lack of privacy at people's dialysis stations has been identified as a barrier[14]. People receiving hemodialysis reported feeling uncomfortable sharing personal and sensitive information regarding their mental health with healthcare providers in public spaces, where other hemodialysis recipients and healthcare providers are present and can hear them[14]. With regards to being referred to a social worker, some people receiving hemodialysis have shared that differences in values, worldviews, and cultural background between them and their social worker make it difficult to understand and connect with one another, affecting how the care provided is received[83,84].

Gaps in Care - Mental Health Support

Currently, there are limited types of mental health support employed in dialysis centres across Canada[16]. The most common type of mental health support available in hemodialysis centres is referral to a hemodialysis unit social worker by dialysis healthcare providers when people receiving hemodialysis require emotional and mental health support[5,15,49,85–88]. This type of support is adopted widely in most of Canada[5,49,85–88]. Alternatively, there are non-pharmacological mental health support strategies available, including physical activity, meditation/relaxation therapy, peer support, virtual support and network education classes[16]. However, while these alternatives exist sporadically, they are limited to select hemodialysis centres across the country[16].

Given the limited types of mental health support available, people receiving hemodialysis and caregivers have reported the 'need for mental health support' as a key issue in hemodialysis care[64]. In particular, the lack of counselling, support groups and access to mental health education were identified as care gaps, with differences in health literacy, self-efficacy and self-management amongst different groups of people receiving hemodialysis identified as important factors to consider when tailoring mental health support[14,16,89]. Overall, more reliable and individualized forms of mental health support are needed for people receiving hemodialysis.

In Manitoba, there is no formal screening program for mental health concerns in people receiving hemodialysis. Social workers working within the Kidney Health Manitoba Program provide initial screening at dialysis start, but no standardized practice has been reported regarding routine follow-ups or guidelines when someone is experiencing challenges to mental health[15]. Compounded with the lack of training in providing mental health care that other

hemodialysis healthcare providers (such as physicians, nurses, and pharmacists) receive[11,13], there is an urgent need for improved mental health support strategies in hemodialysis care in Manitoba.

Priorities for mental health care, from the perspective of adult Manitobans receiving facility-based hemodialysis and the effects of age, gender and ethnicity on these priorities are unknown in Manitoba despite the province's high prevalence of end-stage kidney disease and people receiving hemodialysis. Thus, the first crucial step to improving hemodialysis care in Manitoba is to identify and prioritize challenges to mental health care and potential solutions to address these challenges.

Identifying Mental Health Priorities in People Receiving Hemodialysis in Manitoba

The *Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease* (Can-SOLVE CKD) Network[90] is a research network composed of people living with CKD[1], their caregivers[1], healthcare providers, researchers, and policy/decision makers. Funded by the Canadian Institute of Health Research Strategy for Patient-Oriented Research (SPOR)[91], the Network aims to raise awareness regarding CKD and improve kidney care received by Canadians using innovative, patient-oriented approaches, and evidence-based research and practices. The Can-SOLVE CKD 1.0 *Triple I* project aimed to improve the information, interaction and individualization of care received by Canadians receiving facility-based

[1] Collectively and most commonly referred to as *patient partners* within the Can-SOLVE CKD Network and in this document

hemodialysis[92]. The project produced a list of the top 10 challenges to address in facility-based hemodialysis care, which identified improving mental health care as one of the priorities[92].

CANSOLVE 2.0 *Mind the Gap* is a national project that aims to address gaps in mental health care for people receiving facility-based hemodialysis, by cataloging available mental health resources in each Canadian province and territory, identifying priority challenges to mental health in people receiving facility-based hemodialysis, and developing and implementing tailored mental health support strategies to address these priority challenges.

My Master's thesis addresses one of the *Mind the Gap* project objectives, which is to identify priority mental health challenges and potential solutions to address these challenges in adult receiving facility-based hemodialysis across Canada. This Master's thesis project focuses on identifying priority challenges and potential solutions *in Manitoba* using survey instruments developed by the Mind the Gap research team and administered as part of the *Mind the Gap* project.

Initially, I was a research assistant on the *Mind the Gap* team and played a key part in obtaining ethics approval, study site approvals, and collaborating and engaging with project co-leads, patient partners, and Indigenous organizations. I was also involved in the development and pilot testing of the survey instruments with the research team, patient partners, and health care providers. In addition to my thesis work as a Master's student, I continue to be involved in the *Mind the Gap* project by assisting with current project activities. These include facilitating group discussions at a recent prioritizing workshop, analyzing the survey data collected from other provinces, and plans for facilitating focus group discussions and interviews in the future.

Purpose Statement

Using an embedded mixed methods approach, this study aims to collect and draw on the perspectives and lived experiences of adult Manitobans receiving facility-based hemodialysis, their caregivers, and hemodialysis healthcare providers to identify priority challenges to mental health in adult Manitobans receiving facility-based hemodialysis and identify potential patient-centred solutions to address these challenges.

Research Questions

1) Based on the perspectives of people receiving hemodialysis, caregivers and dialysis healthcare providers, what are the priority challenges to mental health in adult Manitobans receiving facility-based hemodialysis? (*Qualitative*)
2) In people receiving hemodialysis in Manitoba, how do age, gender, ethnicity, dialysis vintage, and relocation for dialysis status impact the likelihood of experiencing challenges to mental health identified in Research Question 1? (*Mixed methods)*
3) Based on the perspectives of people receiving hemodialysis, caregivers and dialysis healthcare providers, what are potential solutions to address priority challenges to mental health? (*Qualitative*)

Chapter 4 Methods

Research Design

This is a cross-sectional, observational, embedded mixed methods study with quantitative and qualitative components (equal in priorities) mixed in both the instruments used for data collection and in data analysis. This study used self-reported, community-approved and pilot-tested instruments previously designed by the *Mind the Gap* research team. Given that mental health can be a sensitive topic, and to optimize the number and accuracy of responses, the survey was made anonymous for all respondents. The survey instruments include closed-ended quantitative and structured open-ended qualitative questions. We aimed to identify self-reported priority challenges to mental health experienced by adult Manitobans receiving hemodialysis, potential solutions to these challenges, and preferred settings/methods of receiving mental health support. The goal of this design was to expand our understanding of key mental health challenges and potential solutions to these challenges by collecting both quantitative and qualitative data in a single study phase.

Study Population and Setting

Inclusion Criteria

Eligible survey respondents included adults (age 18+ years) who currently reside in Manitoba and were able to understand verbal and written instructions and write in English, and:

i.) have lived experience with receiving facility-based maintenance hemodialysis; or

ii.) caregivers who have provided direct care or support for a person receiving facility-based maintenance hemodialysis; or

iii.) healthcare providers with experience caring for individuals with kidney failure in a facility-based hemodialysis unit.

Exclusion Criteria

Non-English speakers, cognitive impairment as identified by the individual's caregiver or hemodialysis unit staff, and individuals visiting hemodialysis unit temporarily from outside Manitoba.

For this Master's thesis project, all eligible individuals dialyzing or working at hemodialysis units situated at the Health Sciences Centre and Seven Oaks General Hospital were approached to complete the survey.

Recruitment

As part of the *Mind the Gap* project, the survey was conducted from March until November 2024 at two study sites - Health Sciences Centre and Seven Oaks General Hospital. Our team originally intended to distribute additional surveys at St. Boniface General Hospital, another major urban hemodialysis centre that provides care to 160 Manitobans receiving facility-based hemodialysis. However, we experienced significant delays with approval processes at this site. Despite attempts to expedite this process, in order to adhere to project and grant timelines, we were ultimately not able to proceed with data collection at this third site. The survey was conducted at the two sites as follows:

People Receiving Hemodialysis and Caregiver Survey

Hard copies of the survey developed were offered to people receiving hemodialysis and their caregiver, if present, during their hemodialysis treatment by myself and research team staff for 2

weeks for voluntary completion. An information letter on the front page of the survey was included to describe the purpose and anonymous nature of the survey, provide contact information of study investigators (myself and CB[2]), and indicate that in lieu of a written consent to participate, the voluntary completion and submission of the survey would serve as their implied consent. People receiving hemodialysis and their caregivers had the opportunity to complete the hard copy survey during the hemodialysis session or at home and return it in an unlabelled envelope on their next dialysis treatment day. Bedside hemodialysis nurses and research study staff helped, as requested by people receiving hemodialysis, with completing the survey. The surveys were also made available online. The QR link to the online form of the survey was available for 3 months and disseminated through a poster displayed in the waiting room at each hemodialysis unit. Links to the survey were also provided on the Kidney Foundation of Canada, CanSOLVE CKD and KidneyLink websites. The online version contained a letter of information similar to the hard copies of the survey, outlining the purpose of the study and consenting process. Internet Protocol (IP) addresses associated with the device used to complete the online survey were not collected. Completed online surveys that originated from Manitoba, per respondents' response to the "province of residence" question, were also included in this Master's project.

Hemodialysis Healthcare Provider Survey

Based on experiences with prior survey projects [92] in hemodialysis units in Winnipeg, online survey distribution was planned for healthcare providers to maximize participation. A link

[2] Clara Bohm (CB) – Co-Principal Investigator of *Mind the Gap* Project/ Thesis Co-Supervisor

to the online survey for health care providers was disseminated directly via hemodialysis staff group emails at each study site and made available for 3 months. The online survey was also made available at hemodialysis units via posters with a QR code link. Similar to the surveys for people receiving hemodialysis and their caregivers, the healthcare provider survey also contained a letter of information on the front page outlining the purpose of the study, research staff contact information, and consenting process. No identifying information, including Internet Protocol (IP) address, was collected to ensure anonymity. Dialysis staff received a reminder email to complete the survey two weeks after the survey was initially rolled out at each hemodialysis site.

Study Outcomes and Measures

Survey of Challenges to Mental Health for People Receiving Facility-Based Hemodialysis

As described above, two anonymous survey instruments, one designed for people receiving hemodialysis and their caregivers, and another designed for healthcare providers working in hemodialysis units, were used to collect perspectives on mental health in people receiving hemodialysis (*See Supplementary Material)*. The following definition of mental health was included in both questionnaires based on consultations with the research team and feedback collected during pilot testing and optimized for readability and comprehension:

> *"Mental health" refers to the state of a person's psychological and emotional well-being. It's how they feel and think inside. It's about their feelings and thoughts, whether they are experiencing positive emotions, such as happiness and contentment, or facing challenges like stress, sadness, or anxiety.*

Both survey instruments were developed and piloted in Manitoba. The patient and caregiver survey was piloted with 4 patient partners, 3 of whom are people receiving facility-based hemodialysis and 1 caregiver. The healthcare provider survey was piloted with 2 dialysis nurses from the Seven Oaks General Hospital Dialysis Unit. Using a combination of open- and closed-ended questions, these instruments investigated perspectives on challenges to mental health in hemodialysis, potential solutions to the challenges and demographic characteristics. No identifying information was collected from respondents to ensure anonymity.

These mixed methods instruments have a total of 11 (survey for people receiving hemodialysis) and 10 (survey for healthcare providers) questions each. Questions investigated current or previous experience with mental health concerns, seeking mental health support, barriers to and accessibility of mental health support, perceived top challenges to mental health and suggested potential strategies to address these challenges. An additional five questions in the healthcare provider survey and seven questions in the survey for people receiving hemodialysis and caregivers ask the respondent about demographic characteristics to help characterize survey respondents. Overall, the survey took approximately 10-15 minutes to complete, per our pilot testing and data collection.

Primary Outcome:

Our primary outcome was ***challenges to mental health in adult Manitobans receiving facility-based hemodialysis***. Answers from people receiving hemodialysis, their caregivers, and healthcare providers to the following questions on the survey were used to identify these challenges:

Patient and Caregiver Survey

Q1.) “Has kidney disease affected your mental health? If yes, please explain how so.”

Q2.) “Has receiving hemodialysis care affected your mental health? If yes, please explain how so.”

Q7.) “What do you think are the biggest mental health challenges for someone receiving hemodialysis? (List 3 challenges)”

Healthcare Provider Survey

Q1.) “Has kidney disease affected the mental health of the people receiving hemodialysis that you care for? If yes, please explain how so.”

Q2.) “Among the people that you care for, have you observed any mental health issues as a result of receiving hemodialysis? If yes, please explain how so.”

Q7.) “In your opinion, what are the biggest mental health challenges you have observed in people receiving hemodialysis? (List up to 3 challenges)”

Secondary Outcomes:

1. ***Potential solutions/strategies to address the mental health challenges in people receiving hemodialysis*** using answers from people receiving hemodialysis, their caregivers, and healthcare providers to the following questions on the survey instrument:

   Patient and Caregiver Survey

   Q11.) “What mental health resources do you think would be most useful for people receiving hemodialysis? (For example, things like peer support, online or print materials, one-on-one counselling, and others)”

   Healthcare Provider Survey

   Q10.) “How do you think we can best fill the current mental health care gaps in hemodialysis care in Canada? Please provide any other related comments:”

2. ***Preferred setting and format for receiving mental health support*** for people receiving hemodialysis using answers to the following question by people receiving hemodialysis and their caregivers.

> Q10.) "If there was a mental health care provider available, would you prefer to be seen (check all that apply to you):
>
> ☐ In-person at your dialysis station
>
> ☐ In-person in a private clinic room outside of dialysis
>
> ☐ Virtually or online
>
> ☐ By telephone
>
> ☐ Other: _____
>
> Please explain why you prefer this/these method(s):"

Sample Size

As the outcomes we intended to obtain from this study were self-reported and inductively identified, it would not be possible to calculate a statistically determined sample size. Instead, our target recruitment number was determined using rough guidelines when working with qualitative and quantitative data, and the feasibility of obtaining responses from our study sites based on previous surveys conducted at the same study sites[92]. We aimed to collect 80 responses from people receiving hemodialysis and 50 responses from healthcare providers, for a total of 130 survey responses. If met, the target numbers should provide enough power to conduct multivariate models as part of our quantitative analyses. Our planned analyses had a minimum of 4 predictors (e.g. age, gender, ethnicity, and relocation for dialysis status), and perhaps more if

interactions exist among these predictors, and thus require 40+ responses (according to the general rule of 10 outcomes per predictor[93]). We anticipated that collecting 130 surveys in Manitoba would allow us to perform logistic regression for the top 3-5 challenges identified in our analysis. For our qualitative analyses, our target numbers exceed the typical sample size of n=10-30 to reach data saturation in qualitative research [94]. With our inclusive eligibility and recruitment efforts (i.e. asking all eligible people receiving hemodialysis and caregivers in-person, accessible posters with a QR code to survey, and an extensive email list of healthcare providers), our target numbers aimed to capture diverse perspectives from different demographics and roles within hemodialysis care in Manitoba. Recruitment data from a previous survey study[92] conducted at these two study sites provided rough estimates of feasible number of participants for this study. Our target numbers correspond to 11% of the 744 adult Manitobans receiving hemodialysis (i.e. Seven Oaks General Hospital– 366 and Health Sciences Centre – 378) and 17% of approximately 300 hemodialysis healthcare providers at the two study locations. These target response rates are close to published response rates for mental health surveys in adults receiving hemodialysis in Canada (13%)[95], and within range of response rates among healthcare providers (14-35%)[96,97].

Data Collection and Management

We collected baseline mental health data and demographic data from our respondents. For baseline mental health data, we asked people receiving hemodialysis and caregivers about the impact of kidney disease/receiving hemodialysis on mental health, history of seeking and receiving mental health support, satisfaction with mental health support received, and interest in having a dedicated mental health provider in the hemodialysis unit. Similarly, we asked healthcare providers about the impact of kidney disease/ receiving hemodialysis on their

patients' mental health, referrals provided to mental health support, and interest in having a dedicated mental health provider in the hemodialysis unit. For demographic data, we collected the role, age, ethnicity, gender, dialysis vintage and relocation for dialysis status of people receiving hemodialysis and caregiver participants. For healthcare providers, we collected their role, age, ethnicity, and gender only.

Responses from all hard-copy surveys were entered by study research staff, including myself, and stored in the Research Electronic Data Capture database (REDCap), a secure web-based application with secure servers hosted by and stored at the University of Manitoba [98]. For online questionnaires completed within the REDCap database, only data from respondents who self-identified as Manitoba residents on the survey were used in this thesis project. Data will be stored for 15 years following study completion, in accordance with Health Canada regulations. Access to data is limited to myself and select *Mind the Gap* research team in Manitoba, and the University of Manitoba Human Ethics Board (for quality assurance purposes).

Data Analysis

Research Question 1: ***Based on the perspectives of people receiving hemodialysis, caregivers and dialysis healthcare providers, what are the priority challenges to mental health in adult Manitobans receiving facility-based hemodialysis? (Mixed Methods)***

To identify priority challenges to mental health, our team conducted summative content analysis of survey responses to Questions 1, 2 and 7 from both survey instruments. Responses to these questions were exported to Microsoft Excel for this analysis. One pair of coders (RM and

AS)[3] was assigned to code responses from people receiving hemodialysis and caregivers, and another pair of coders (RM and HF)[4] was assigned to code responses from healthcare providers. Coders independently coded each survey response, and consensus was reached on any disagreement by discussion or adjudicated by a third coder as necessary (CB). Initially, key challenges were identified inductively in an iterative manner from the entire survey responses to Question 7 from both instruments. Inter-rater reliability rating indicated low agreement (60-70%) during our initial coding, and subsequently increased (80%) after further discussion and re-coding. Through this process that involved all researcher team members involved with the coding process, we established a list of key challenges and criteria for each challenge to provide consistency and additional guidance when coding (*See Supplementary Material)*. Further, during coding, "depression" and "anxiety" were only coded as present if explicitly stated as is by survey respondents to ensure that we did not overinterpret responses that could be similar to these challenges (e.g. feelings of sadness, worry, etc.). The challenges and criteria used were reviewed, informed and approved by patient partners and healthcare providers on the team. Using these established challenges, we then coded further survey questions deductively, when possible, but still using an inductive approach if codes did not fit pre-established challenge themes.

Once all challenges were coded, the frequency of each challenge (i.e number of times each challenge was identified in unique surveys) was determined and ranked based on count frequency. The top 10 challenges to mental health were identified based on combined counts from both people receiving hemodialysis/caregiver and healthcare provider surveys. A chi-

[3] Ashely Seitz (AS) – *Mind the Gap* Research Coordinator
[4] Haley Farion (HF) – Master's Student (University of Manitoba)

square test, with α=0.05, was conducted to compare the difference in proportion of people receiving hemodialysis and caregivers, and healthcare providers who identified each challenge.

Given that the survey was anonymous, conventional member checking (i.e. with the actual survey respondents) could not be conducted. Instead, we discussed our coding strategy, providing a sample of our coding process as described above, and the overall ranked challenges to patient partners and healthcare providers for discussion and to identify any concerns or suggested modifications.

Research Question 2: ***How do age, gender, ethnicity, dialysis vintage, and relocation for dialysis status impact the likelihood of experiencing the identified priority challenges to mental health? (Mixed methods)***

To determine the likelihood of experiencing the identified priority challenges to mental health, we applied logistic regression to identify challenges using age, gender, ethnicity, dialysis vintage and relocation status as potential predictors. To accurately reflect the likelihood of experiencing these challenges, only the counts for challenges identified by the people receiving hemodialysis and caregiver group. Since there were only 2 caregivers who participated, the counts of the challenges they identified were combined with those of people receiving hemodialysis. For ease, these combined responses will be referred to as the '*patient*' group.

Counts for distinct challenges (outcomes) were low. To increase the count for each challenge for this analysis, demographic categories were merged as follows:

Table 1. Reclassification of Demographic Categories

Demographic Variable	Original Categories on Survey	Modified Categories Used for Analysis
Age	18-34, 35-49	Younger than 50 years old
	50-64	50-64 years old
	65-79, 80+	65+ years old
	Prefer not to answer	Prefer not to answer
Dialysis vintage	Less than 3 months, 3-6 months, 6 months-1 year	Less than 1 year
	1-3 years, 3-5 years	1-5 years
	More than 5 years	More than 5 years
	Don't know, Not applicable	Prefer not to answer
Ethnicity	White, Other (self-identify)*	Racialized White
	Indigenous (First Nations, Metis, Inuit), East Asian, South Asian, African-Canadian/Caribbean Canadian, Other (self-identify)*	Racialized non-White
	Don't know, Prefer not to answer	Prefer not to answer

*Categorized depending on how they self-identified (e.g. English -> White)

For respondents' age, the initial categories were merged into "Younger than 50 years old", "50-64 years old", and "65+ years old"; these groupings reflect the different stages in one's life, wherein employment status and life responsibilities (e.g. raising children) could differ. For dialysis vintage, the initial categories were merged into "Less than 1 year", to represent those who have just started hemodialysis and are likely still getting accustomed to the lifestyle changes associated with the treatment, "1-5 years" to represent those who are likely to be more accustomed but still navigating their disease journey, and "More than 5 years" to reflect those who likely have substantial experience with routinely receiving hemodialysis. For respondents' ethnicity, we categorized their response by the established classification system by the Canadian Institute for Health Information (CIHI) for race-based and Indigenous identity data[99]. Responses to other demographic variables were analyzed as originally presented on the survey.

Despite merging categories to increase the count for each challenge (outcome), the counts were still too low for classic logistic regression methods. After consulting with various resources and biostatisticians, Firth logistic regression was determined to be an ideal approach as it can (1) handle a small number of outcomes (≥ 2-5 outcomes compared to 5-10 outcomes for classic logistic regression), and (2) handle highly disproportionate outcomes amongst categories[100]. This approach was tested on the challenges "loss of control" and "lack of acceptance/adjustment to situation", as these challenges had the highest counts overall and thus should have had enough power for this analysis.

Due to overall small counts for logistic regression, we further assessed differences in experiencing the top 10 mental health challenges by demographic characteristics using Fisher exact test (if ≤ 5 challenge counts/ demographic group) or chi-square test (if > 5 challenge counts/demographic group), setting α=0.05 for both tests. For demographic variables with more than 2 groups (e.g. dialysis vintage with 3 groups of "less than 1 year", "1-5 years" and "more than 5 years") that yielded statistically significant differences in experiencing the challenge, pair-wise testing with Bonferroni correction amongst these groups was conducted.

In exploratory analyses, we combined the counts of certain challenges identified by people receiving hemodialysis that could be interpreted similarly and stratified these by demographic variables (i.e. age, ethnicity, gender, dialysis vintage and relocation for dialysis status). For example, the counts of the challenges "depression", "sadness", "grief/dealing with loss" and "loss of hope" were combined as these challenges generally refer to a depressed/saddened state (*Combination 1*). "Feeling overwhelmed", "loss of control", "difficulty coping", and "worry/stress" were also merged as these challenges generally refer to experiencing excess worry or stress due to receiving hemodialysis that leads to inability to cope and loss of

locus of control (*Combination 2*). "Worry/stress", "anxiety" and "fear" were also combined, as these challenges relate to one another, with fear as the source of (excess) worry/stress that may lead to anxiety (*Combination 3*). While coding the survey responses, there were several discussions and adjudication regarding responses that were interpreted as "loss of control", "difficulty coping" and "acceptance/adjustment to situation", given their overlapping criteria. Thus, these challenges were assessed to be similar enough in interpretation that they were also combined for our exploratory analysis (*Combination 4)*. Fisher exact test or chi-square test was conducted on these combinations stratified by demographic variables listed above, when appropriate, depending on the expected count for each outcome, with α=0.05.

Research Question 3: ***Based on the perspectives of people receiving hemodialysis, caregivers and dialysis healthcare providers, what potential mental health supports would they like to have available to address priority challenges to mental health? (Mixed methods)***

Similar to Research Question 1, two pairs of coders (RM/AS for *Patient and Caregiver survey,* and RM/HF for *Healthcare Provider Survey*) independently coded the responses to proposed solutions and strategies to address mental health challenges using summative content analysis for Question 11 of the *Patient and Caregiver Survey* and Question 10 of the *Healthcare provider Survey*. Key solutions were identified inductively in an iterative manner from the entire survey responses to these questions. Using these established solutions, we then deductively identified mental health support strategies in the survey responses, using a criterion to provide consistency and additional guidance when coding (*See Supplementary Material)*, but still adding solutions as new ones were encountered that did not fit the pre-established solutions. As the

responses to these questions were less ambiguous (i.e. directly referring to supports like counselling, etc.), inter-rater reliability rating indicated high agreement (70-80%) between coders during our initial coding. Consensus was reached on any disagreement by discussion or adjudicated by a third coder (CB). Following completion of the coding process, the frequency with which each solution was identified in unique survey responses was determined and solutions were ranked based on count. Member checking for these research questions was conducted in the same fashion as in Research Question 1. The coded solutions and criteria used for coding were reviewed, informed and approved by patient partners and healthcare providers on the team. Chi-square test, with α=0.05, was used to compare the proportion of survey respondents who identified each mental health support strategy.

To determine the preferred setting and format for receiving mental health support for people receiving hemodialysis, responses to Question 10 of the *Patient and Caregiver Survey* were analyzed. Quantitatively, the count and proportion of patient respondents who indicated their preferred setting and format in the list provided were determined for each option. Using thematic analysis, one coder (RM) inductively identified themes in the rationale provided by respondents for their preferred setting(s) and format(s).

Chapter 5 Ethical Consideration

Ethics Board and Study Site Approvals

The overall *Mind the Gap* project has received ethics approval from the Human Research Ethics Board (HREB) at the University of Manitoba (HS25793[H2022:396]). Individual study site approvals for the *Mind the Gap* project from Shared Health and Seven Oaks General

Hospital have also been received to conduct the study at their respective dialysis units. This thesis project has also received its own Human Research Ethics Board (HREB) approval from the University of Manitoba (HS26653 (H2024:293)).

Engaging With Indigenous Governing Bodies in Manitoba

We acknowledge that Manitoba has the largest Indigenous population per province in Canada (237,190 people, or 18.1% of the provincial population in 2021), comprised mostly of First Nations and Metis, and some Inuit who come to Manitoba to access specialized care[101]. Since 2023, with the goal of ensuring that health data are collected, analyzed, managed, and stored according to OCAP and OCAS principles, *Mind the Gap* is engaging with the First Nations Health and Social Secretariat of Manitoba, and Manitoba Metis Federation to ensure that research approaches are culturally sensitive and appropriate. These consultations are still ongoing. We also receive guidance from the *Indigenous Peoples' Engagement and Research Council* through the Can-SOLVE CKD Network to reach Indigenous patient partner audience on a national level with research findings and engagement opportunities.

Mental Health Resources

As this survey was anonymous, it would not be possible to provide assistance specifically to those who might have experienced discomfort or distress as a result of participating in this study. Thus, a link to a list of mental health resources in Manitoba was provided on the letter of information that came with the survey for participants to access if required. People receiving hemodialysis in Manitoba have access to and could be referred by their dialysis provider to a renal social worker at their hemodialysis unit if they required emotional and mental health support.

Chapter 6 Results

I. Survey Respondents

Demographic Data

We received a total of 124 survey responses. Of the 744 people receiving hemodialysis in HSC and SOGH hemodialysis units, 93 individuals (12.5%) receiving facility-based hemodialysis, and 2 caregivers participated in the survey. The total number of caregivers who received versus those who completed the survey is uncertain. Most people receiving facility-based hemodialysis who responded were between the ages of 50 and 79 (67%), had been on dialysis for 3 or more years (65%), self-identified as men (56%) and White (34%) (Table 2). Only 13% of respondents had been required to relocate for dialysis. Of approximately 300 hemodialysis unit staff, we collected 29 responses (10%) from healthcare providers. Of these, the majority of respondents (38%) were nurses, between the ages of 35 and 49 (62%), self-identified as women (86%) and White (62%) (Table 2).

Table 2. Demography of Survey Respondents

Characteristics	People receiving hemodialysis (n=93) and Caregiver (n=2)	Characteristics	Healthcare Provider (n=29)
Age		**Age**	
18-34	5	18-34	2
35-49	14	35-49	18
50-64	31	50-64	8
65-79	33	65-79	1
80+	9		
Prefer not to answer	3		
Dialysis Vintage		**Respondents**	
< 3 months	2	Nurse	11
3-6 months	3	Nephrologists	3
6 months - 1 year	6	Social Worker	4
1-3 years	19	Dietitian	3
3-5 years	25	Pharmacist	5
more than 5 years	37	Clinical Kinesiologist	1
I don't know	1	Prefer not to answer	2
not applicable	2		
Gender		**Gender**	
Man	53	Man	3
Woman	40	Woman	25
Transgender	1	Prefer not to answer	1
Prefer not to answer	1		
Ethnicity		**Ethnicity**	
Black	9	South Asian	3
East Asian	5	East Asian	3
Indigenous	24	White	18
Middle Eastern	1	Pacific Islander	4
South Asian	10	Prefer not to answer	1
Southeast Asian	9		
White	32		
Prefer not to answer	5		
Relocated for Dialysis			
Yes	12		
No	82		
blank	1		

Baseline Mental Health Data of Survey Respondents

Impact of Kidney Disease/ Receiving Hemodialysis on Mental Health

When asked if kidney disease and receiving hemodialysis have affected the mental health of people receiving hemodialysis, over 50% percent of hemodialysis recipients and caregivers answered "Yes", approximately 40% answered "No" (Table 3). Meanwhile, almost all (over 90%) of healthcare providers answered "Yes", and none answered "No". Further sub-analyses did not show any statistically significant differences by demographic characteristics in the people receiving hemodialysis or healthcare provider groups.

Referral for Mental Health Support

Only 8% of people receiving hemodialysis indicated that they had been referred to any mental health resource (Table 3). Similarly, when asked if people receiving hemodialysis were referred to any mental health specialist, only 14% had been referred, and the majority (84%) answered "No". Among those who were not referred, only 29% indicated interest in being referred to a mental health specialist. A sub-analysis shows that 50% of people who relocated for dialysis indicated interest in being referred to a mental health specialist, compared to only 21% of those who did not relocate ($p=0.02$). Amongst healthcare providers, only 55% had referred people receiving hemodialysis to mental health resources, and 38% had referred people receiving hemodialysis specifically to mental health specialists (Table 3). No other demographic variables predicted referral to mental health supports by healthcare providers.

Table 3. Quantitative Analysis on the Perspectives & Experiences of Survey Respondents Regarding the Mental Health of Adult Manitobans Receiving Facility-Based Hemodialysis

Category	Question	People Receiving Hemodialysis (n=93) and Caregivers (n=2)			Question	Healthcare Provider (n=29)		
		Yes	No	Unsure/Prefer not to answer		Yes	No	Unsure/Prefer not to answer
Kidney disease	Has kidney disease affected your mental health?	55 (58%)	36 (38%)	4 (4%)	Has kidney disease affected the mental health of the people receiving hemodialysis that you care for?	28 (97%)	-	1 (3%)
Receiving hemodialysis	Has receiving hemodialysis care affected your mental health?	51 (54%)	39 (41%)	5 (5%)	Among the people that you care for, have you observed any mental health issues as a result of receiving hemodialysis?	26 (90%)	-	3 (10%)
Referral to mental health resources (e.g. community organizations, support groups, friends and family)	Have you been referred to any mental health resources since you started receiving hemodialysis?	8 (8%)	87 (92%)	-	Have you referred a person receiving in-centre hemodialysis to any mental health resources?	16 (55%)	9 (31%)	4 (14%)
Referral to mental health specialist (e.g. psychologists, therapists, psychiatrists)	Have you been referred to a mental health specialist since you started receiving hemodialysis?	13 (14%)	80 (84%)	2 (2%)	Have you referred an individual receiving in-centre hemodialysis to see a mental health specialist?	11 (38%)	11 (38%)	7 (24%)
	If No, Would you have liked to have been referred to a mental health specialist?	23 (29%)	53 (66%)	4 (5%)				

History of Seeking and Receiving Mental Health Support

Most respondents (n=77; 81%) in the people receiving hemodialysis and caregiver group indicated that they had not sought previous mental health support (Table 4). Amongst those who have sought mental health support before, a sub-analysis showed that there is a higher proportion of individuals who relocated for dialysis who sought support than those who did not relocate (50% vs. 15%, p=0.001). Additionally, when asked if they have seen any mental health specialist since starting hemodialysis, only 15% answered "Yes" and 83% answered "No" (Table 4). Among those who did see a mental health specialist, 64% were satisfied with their visit and 36% were not.

Interest in Having an In-Unit Mental Healthcare Provider

When people receiving hemodialysis and caregivers were asked if they would be interested in seeing a mental healthcare provider, if one was available in the hemodialysis unit, 45% were interested and 43% were not (Table 4). In contrast, 83% of healthcare providers perceived that having a mental healthcare provider available in the hemodialysis unit would be beneficial for people receiving hemodialysis (Table 4). Most respondents, including people receiving hemodialysis and caregivers (64%) and healthcare providers (90%), believe that if a mental healthcare provider were available to provide care in the hemodialysis unit, they should be familiar with specific circumstances related to hemodialysis. Further sub-analyses showed no statistically significant difference in responses by demographic characteristics.

Table 4. Quantitative Analysis of the Perspectives and Experiences of Survey Respondents Regarding the Mental Health Care Received and Needed by Adult Manitobans Receiving Facility-Based Hemodialysis

Category	Question	People Receiving Hemodialysis (n=93) and Caregivers (n=2)			Question	Healthcare Provider (n=29)		
		Yes	No	Unsure/Prefer not to answer		Yes	No	Unsure/Prefer not to answer
History of receiving mental health support	Have you sought mental health support since you started receiving hemodialysis?	18 (19%)	77 (81%)	-	-	-	-	-
	Have you seen a mental health specialist since starting hemodialysis? (Seen means having gone to a specialist).	14 (15%)	79 (83%)	2 (2%)	-	-	-	-
Satisfaction with mental health support received	**If yes**, Were you satisfied with how the visit went?	9 (64%)	5 (36%)	-	-	-	-	-
Availability of mental health care provider in dialysis units	If there was a mental health care provider available in the hemodialysis unit, would you be interested in seeing them?	43 (45%)	41 (43%)	11 (12%)	Do you think having a dedicated mental health care provider available in the hemodialysis unit would be beneficial for people receiving hemodialysis?	24(83%)	1(3%)	4(14%)

Knowledgeable mental health care provider regarding circumstances specific to receiving hemodialysis	Do you think that the mental health care provider needs to be familiar with the specific circumstances for people receiving hemodialysis?	61 (64%)	16 (17%)	18 (19%)	Do you think that mental health care providers for people receiving hemodialysis need to be familiar with the specific circumstances related to hemodialysis?	26 (90%)	-	3(10%)

I. Challenges to Mental Health in Adult Manitobans Receiving Hemodialysis

Identified Priority Challenges to Mental Health

Overall, our team identified and ranked 24 key challenges to mental health in adult Manitobans receiving facility-based hemodialysis (Table 5). The top 10 challenges to mental health were loss of control, difficulty coping, depression, loneliness/isolation, grief/dealing with loss, anxiety, worry/stress, dialysis-related symptoms, acceptance/adjustment to situation, and lack of confidence/trust in healthcare providers/system. However, there were notable differences in the priority challenges to mental health identified by people receiving hemodialysis and caregivers, versus those identified by healthcare providers. Difficulty coping (45% vs. 25%), depression (76% vs. 16%) and anxiety (52% vs. 14%) were identified significantly more often by healthcare providers than people receiving hemodialysis and caregivers. Worry/stress was identified more often by people receiving hemodialysis and caregivers than by healthcare providers (25% vs. 3%). There was no statistically significant difference between respondent groups for all other challenges.

Table 5. Ranked 24 Challenges to Mental Health in Adult Manitobans Receiving Facility-based Hemodialysis as Identified by Respondent Group

Rank	Challenge to Mental Health	Count (%) of People Receiving Hemodialysis and Caregiver who Identified Each Challenge (n=95)	Count (%) of Healthcare Providers who Identified Each Challenge (n=29)	Total Count
1	**Loss of Control**	**37 (39%)**	**11 (38%)**	**48**
2	**Difficulty Coping**	**24 (25%)**	**13 (45%)**	**37**
3	**Depression**	**15 (16%)**	**22 (76%)**	**37**
4	**Loneliness/Isolation**	**26 (27%)**	**8 (28%)**	**34**
5	**Grief/Dealing with loss**	**25 (26%)**	**8 (28%)**	**33**
6	**Anxiety**	**13 (14%)**	**15 (52%)**	**28**
7	**Worrying/Stress**	**24 (25%)**	**1 (3%)**	**25**
8	**Dialysis-related symptoms**	**22 (23%)**	**2 (7%)**	**24**
9	**Acceptance/Adjustment to situation**	**18 (19%)**	**2 (7%)**	**20**
10	**Lack of confidence/trust in healthcare providers/healthcare system**	**15 (16%)**	**5 (17%)**	**20**
11	Anger/Irritation/Frustration	8 (8%)	8 (28%)	16
12	Feeling Overwhelmed	9 (9%)	6 (21%)	15
13	Keeping a positive mindset	13 (14%)	0 (0%)	13
14	Sadness	11 (12%)	2 (7%)	13
15	Loss of hope	9 (9%)	4 (14%)	13
16	Fear	9 (9%)	3 (10%)	12
17	Transportation for hemodialysis	8 (8)	3 (10%)	11
18	Financial burden	4 (4%)	7 (24%)	11
19	Declining health/physical function/mobility	6 (6%)	3 (10%)	9
20	other	7 (7%)	0 (0%)	7
21	Self-esteem/Self-image	5 (5%)	1 (3%)	6
22	Guilt/Regret	3 (3%)	1 (3%)	4
23	Medical complications and problems	2 (2%)	2 (7%)	4
24	Denial	1 (1%)	1 (3%)	2

Do Demographic Characteristics Predict Identification of Challenges to Mental Health?

In the people receiving hemodialysis group, there was no statistically significant difference in experiencing "loss of control" (n=37) and "lack of acceptance" across any demographic variables, including age, gender, dialysis vintage, ethnicity and relocation status (Appendix Tables 1 and 2).

After adjusting for multiple comparisons, we also found no statistically significant differences in experiencing the top 10 mental health challenges by comparing the proportion of individuals within demographic groups (age group, gender, ethnicity, and relocation for dialysis status) (Appendix Tables 3 and 4). Similarly, we found no statistically significant differences in experiencing combinations of mental health challenges when stratified by demographic variables (Table 6).

Table 6. Comparison of Experiencing Combined Challenges to Mental Health Stratified by Demographic Characteristics in Adult Manitobans Receiving Facility-Based Hemodialysis

Challenge	Demographic characteristics	Number 'Yes' by group	Number 'No' by group	p-value
Combination 1 (Depression, sadness, grief/dealing with loss, and hopelessness)	Gender	25 vs 18	28 vs 22	1
	Ethnicity	29 vs 14	30 vs 17	0.9
	Age	10 vs 16 vs 19	9 vs 15 vs 23	0.8
	Dialysis vintage	6 vs 23 vs 16	5 vs 21 vs 21	0.7
	Relocation status	7 vs 37	5 vs 45	0.6
Combination 2 (Feeling overwhelmed, loss of control, coping and stress)	Gender	32 vs 26	21 vs 14	0.8
	Ethnicity	41 vs 16	18 vs 15	0.1
	Age	13 vs 23 vs 23	6 vs 8 vs 19	0.2
	Dialysis vintage	6 vs 31 vs 22	5 vs 13 vs 15	0.5*
	Relocation status	6 vs 53	6 vs 29	0.4*
Combination 3 (worry/stress, anxiety, and fear)	Gender	18 vs 19	35 vs 21	0.3
	Ethnicity	24 vs 10	35 vs 21	0.6
	Age	9 vs 13 vs 15	10 vs 18 vs 27	0.7
	Dialysis vintage	5 vs 20 vs 12	6 vs 24 vs 25	0.5*
	Relocation status	4 vs 33	8 vs 49	0.8*
Combination 4 (loss of control, difficulty coping, and acceptance/adjust to situation)	Gender	28 vs 25	25 vs 15	0.5
	Ethnicity	36 vs 17	23 vs 14	0.7
	Age	13 vs 20 vs 20	6 vs 11 vs 22	0.2
	Dialysis vintage	6 vs 27 vs 20	5 vs 17 vs 17	0.8*
	Relocation status	5 vs 49	7 vs 33	0.4

Groups compared as follows:

Ethnicity: Racialized non-White vs Racialized White
Age: Less than 50 years vs 50-64 years vs 65+ years
Dialysis Vintage: Less than 1 year vs 1-5 years vs More than 5 years
Relocation Status: Yes vs No

In general, Chi-square test used for analysis except *Fisher's exact test

II. Mental Health Support Strategies in Facility-Based Hemodialysis Care

Preferred Settings and Methods of Receiving Mental Health Support of Adult Manitobans Receiving Hemodialysis

Respondents in the people receiving hemodialysis group indicated more than one preferred setting and format for receiving mental health support. They had equal preference for in-person mental health support provided either at their dialysis station or in a private clinic room outside of dialysis (38%) (Table 7). Some respondents also identified that receiving mental health support via telephone (20%) and virtually/online (11%) would be acceptable. Fourteen percent of respondents suggested alternative visit options under "Other", including traditional medicine. Sub-group analyses showed no statistically significant differences by demographic characteristics (*Appendix Table 5*).

Table 7. Preferences for Settings and Methods for Mental Health Support in People Receiving Hemodialysis and Caregivers

Type of Mental Health Support	Number (%) of Respondents who prefer this option (n=95)
In-person at your dialysis station	36 (38%)
In-person in a private clinic room outside of dialysis	36 (38%)
Virtually or online	10 (11%)
By telephone	19 (20%)
Other: e.g. Traditional medicine, private room in hemodialysis unit	13 (14%)
Unsure/ Prefer not to answer	6 (6%)

Themes Regarding the Types of Mental Health Support Preferred by People Receiving Hemodialysis and Caregivers

Three themes and two sub-themes were identified.

Theme 1: Value of In-Person Interaction

Regardless of location, people receiving hemodialysis value in-person clinical interactions, especially when sharing information regarding their mental health, as opposed to sharing these over the telephone or online. The physical presence of the provider provides comfort, as supported by the following quotes:

"I prefer seeing the person that I'm speaking to especially when it concerns mental health issues" (Woman, Age 65-79, White)

"*I prefer in-person at the dialysis station because I feel more comfort when I am face to face with the care provider" (Man, Age 50-64, East Asian)*

Theme 2: Reducing Barriers to Receiving Mental Health Care

Having mental health support available in hemodialysis units reduces the overall barriers to accessing mental health care faced by people receiving hemodialysis and is further explained by two sub-themes:

Sub-theme 2.1: Convenience

Most people receiving hemodialysis value receiving mental health care during their hemodialysis treatment, as it consolidates additional care that they need into one visit. This saves them time and effort by reducing the number of appointments outside their hemodialysis schedule and allots more time for life participation, as highlighted by one of the participants:

"Already in center; limited time on "days off"; don't need more appointments..."

- Woman, Age 65-79, Indigenous

Sub-theme 2.2:Transportation

Transportation associated with receiving hemodialysis and attending additional medical appointments can be a barrier to care for some people, given the cost and time spent due to the distance travelled, as mentioned in the following quotes:

" Because of my mobility issues, going to a clinic is difficult. I only go now where I have to go" (Man, Age 50-64, Indigenous)

"Dialysis already takes 18 hours of my week. Having to spend more time travelling to and meeting with a mental care health provider outside of dialysis would be onerous"(Man, Age 65-79, White)

Theme 3: Privacy is Important

The need for privacy was highlighted by people receiving hemodialysis as an important element across the different types of support options. The lack of privacy was perceived as a deterrent to seeking mental health care support, as highlighted below:

"Privacy is a huge concern, NO one wants to spill their guts in a common room with only a curtain from the next person 5 ft away." (Man, Age 65-79, White)

Preferred Mental Health Support Strategies

In total, we identified and ranked 14 potential solutions/strategies for addressing mental health challenges in hemodialysis (Table 8). The 4 most suggested mental health support strategies are counselling, increased availability/access to mental health resources, peer support and healthcare improvements. Counselling (including one-on-one, telephone and group counselling) was the most suggested mental health support strategy (49%) by people receiving hemodialysis and caregivers, followed by peer support (20%) and increased availability/accessibility of mental health sources (i.e. educational materials on available mental health resources, mental health specialist as part of care team) (18%). Similarly, healthcare

providers also advocate for increased availability and accessibility of mental health resources for people receiving hemodialysis (72%), supplemented with health system improvements (31%), such as standardized mental health care across Canada, and financial support for patients. Sub-analyses of these solutions, stratified by demographic variables, did not show any statistically significant differences across demographic groups (Appendix Table 6).

Table 8.Preferred Mental Health Support Strategies for Adult Manitobans Receiving Facility-based Hemodialysis, as Identified by People Receiving Hemodialysis, Caregivers and Healthcare Providers

Rank	Mental Health Support Strategy	Count (%) of Patients and caregivers who identified this solution (n=95)	Count (%) of Healthcare providers who identified this solution (n=29)	Total Count
1	**Counselling**	**47 (49%)**	**1 (3%)**	**48**
2	**Increased availability/ accessibility of Mental health resources**	**17 (18%)**	**21 (72%)**	**38**
3	**Peer support**	**19 (20%)**	**0 (0%)**	**19**
4	**System improvements**	**0 (0%)**	**9 (31%)**	**9**
5	Support from Allied health	1 (1%)	3 (10%)	4
6	Activities	3 (3%)	1 (3%)	4
7	Religious/Spiritual Services	2 (2%)	1 (3%)	3
8	Positive relationships outside of dialysis	2 (2%)	0 (0%)	2
9	Improved CKD/dialysis education (for patients)	1 (1%)	1 (3%)	2
10	Support for Caregiver/Family	0 (0%)	1 (3%)	1
11	Increased availability of flexible dialysis options (i.e. home dialysis)	0 (0%)	1 (3%)	1
12	Advocacy and Screening for Mental Health	0 (0%)	1 (3%)	1
13	Other	0 (0%)	1 (3%)	1
14	Further research for better treatment and approach	0 (0%)	0 (0%)	0

Chapter 7 Discussion

In this observational cross-sectional study, we conducted an anonymous survey to collect the perspectives of people receiving hemodialysis, caregivers, and healthcare providers on the mental health of adult Manitobans receiving facility-based hemodialysis. We identified and ranked 24 challenges to mental health and 14 potential mental health support strategies.

Identified Challenges to Mental Health in People Receiving Hemodialysis

Our findings are the first to present a prioritized and comprehensive list of challenges to mental health specific to people receiving hemodialysis in Manitoba. "Loss of control" is the top priority challenge to mental health to address in adult Manitobans receiving hemodialysis, as equally identified by people receiving hemodialysis and healthcare providers respondent groups. This challenge encompassed factors like lifestyle changes, adherence to a strict dialysis schedule, having to give up working or experience employment difficulties, and relocation from rural areas/ home communities to receive hemodialysis in urban settings, as highlighted by one respondent: "*No room in Garden Hill dialysis unit so I have to be in Winnipeg*" (Individual receiving hemodialysis, Man, Indigenous, Age 50-64). In our analysis, "loss of control" stems from the need to prioritize receiving hemodialysis to live, such that it results in circumstances beyond their control. Prioritizing the need for hemodialysis impacts people's ability to financially support themselves and their family, removes them from their home community and away from their support system, and changes what they can eat and drink[10,26,102] . Studies have shown that an external locus of control is common in people receiving hemodialysis, given that they rely on healthcare providers, their family and dialysis machines for survival, which can lead

to feelings of restricted freedom and control over their own health and body[103,104]. Previous studies have shown that locus of control can impact clinical outcomes. One study surveyed 105 people receiving hemodialysis using State-Trait Anxiety Inventory and Multidisciplinary Health Locus of Control scale[105]. Investigators reported that people with high external locus of control had increased symptoms of anxiety[105]. Conversely, investigators also found that those who felt that they have control over their health reported feeling less anxious[105]. Thus, helping people receiving hemodialysis with their locus of control could be a potential target for mental health support strategies.

"Difficulty coping" is the second priority we identified. In our analysis, it includes medication coping, dietary and fluid restrictions, and poor treatment compliance. Many respondents in our study indicated difficulty adjusting to dietary and fluid restrictions associated with kidney disease and receiving hemodialysis: "*Constantly thinking about water intake and which foods may be harmful*" (Individual receiving hemodialysis, Man, East Asian, Age 18-35). Struggles with dietary management are common amongst people receiving hemodialysis, which can lead to malnutrition[106]. In semi-structured interviews with 35 individuals receiving hemodialysis in Australia, the study identified themes around dietary management, including considering it as an "exacerbating disruption" that leads to additional treatment burden, change in appetite and palate, and contradicting healthy eating[107]. This study suggests that having a multidisciplinary team of clinicians with dietary expertise, incorporating personal dietary preferences and cultural considerations, and providing consistent information can help with adopting dietary changes[107]. In Manitoba, such multidisciplinary teams already exist in CKD clinics and in hemodialysis units, including renal dietitians[108]. However, the fact that dietary adjustment as part of "difficulty coping" was still identified as a priority challenge suggests that

there is still room for improvement in how this multidisciplinary team could work better with people on hemodialysis to address this challenge.

The third priority challenge to mental health identified was depression. It is known that depression is one of the most common mental health concerns among people receiving hemodialysis[109,110]. As mentioned in the literature review section of this thesis, higher depressive symptoms in this population have been associated with lower quality of life, higher risks of mortality and hospitalization, and lower medication and treatment adherence, compared to non-depressed hemodialysis recipients[77–80]. In Canada, the prevalence of depressive symptoms has been determined, using validated tools, in people receiving hemodialysis in Alberta and Ontario[14,71]. Our finding is the first to determine that depression is a challenge to mental health also experienced by Manitobans receiving hemodialysis. However, caution must be made as our findings are based on self-reports of respondents, and not based on validated tools to diagnose depression or measure depressive symptoms. Despite this, our findings still suggest that depression is an important challenge to address and warrants further studies. Future investigation could lead to understanding if there are any unique factors in Manitobans receiving hemodialysis that contribute towards the development of depression and could serve as potential target for interventions.

Other priority challenges identified by survey respondents include worry/stress, dialysis-related symptoms, loneliness/isolation, grief/dealing with loss, lack of acceptance/adjustment to situation, and lack of confidence in healthcare providers, which have also been previously identified in literature. Some individuals receiving hemodialysis indicated uncertainty regarding their future as a cause of worry and stress, especially with regards to the possibility of receiving a kidney transplant: "*Not knowing the future: uncertainty of kidney transplant*" (Individual

receiving hemodialysis, Woman, Indigenous, Age 65-79). Further, overall uncertainty regarding their health, especially with how kidney disease and feeling unwell post hemodialysis treatment will affect their bodies and their ability to perform daily function overlaps with the challenge "dialysis-related symptoms", as indicated in one response: "*Kidney disease affected my blood pressure, my heart, so I get poor appetite, I don't sleep well, I'm feeling weak!! I worry [about] everything now…*" (Individual receiving hemodialysis, Man, South Asian, Age 65-79). In our study, dialysis-related symptoms encompassed physical impacts of receiving hemodialysis, including fatigue post-treatment, pain, and cramps. Previous studies have found that symptom burden is associated with mental health outcomes and overall health-related-quality-of life (HRQOL) in people receiving hemodialysis[111–114]. One study from Alberta assessed the impact of symptom burden on HRQOL in 591 people receiving hemodialysis using the modified Edmonton Symptoms Assessment System and the Kidney Dialysis Quality of Life Short Form[111]. Six months post baseline measurements, they found that pain and fatigue were independent predictors of the mental component score of HRQOL[111].

In our study, "loneliness/ isolation" includes social isolation, stigma, lack of family support, feeling misunderstood and straining of relationships due to hemodialysis. We observed that feelings of loneliness can stem from lack of support from family: "*Since starting hemodialysis I find myself abandoned by family and friends. People see dialysis patients as a burden to society….*" (Individual receiving hemodialysis, Man, White, 65-79). Others face stigma and feel misunderstood by others, "*the fact that others do not understand the many changes*" (Individual receiving hemodialysis, Man, White, Age 65-79). Thus, literature suggests that addressing isolation requires a multicomponent approach, including family, hospital (hemodialysis units) and society[115]. "Grief/dealing with loss" in our study encompasses loss of independence, travel

restrictions, loss of identity and loss of regular activities, according to one respondent: "*Loss of physical activity that I enjoy*" (Individual receiving hemodialysis, Man, South Asian, Age 35-49). One qualitative study has identified that when one starts dialysis, a new dialysis-dependent self emerges that grieves one's old life[116]. "Lack of acceptance/adjustment to situation" includes difficulties with adjusting to new life, having kidney disease and poor treatment compliance. Importantly, acceptance of one's disease has been associated with better health-related quality of life as measured by the mental component score of the 36-item short form health survey (SF-36)[117]. One paper on the effect of acceptance on health outcomes of people living with CKD suggests that cognitive-behavioural therapy (CBT) and acceptance and commitment therapy could be effective treatments to promote acceptance[118].

We did not detect any statistically significant differences in identified challenges by demographic characteristics. This could be because the number of outcomes was too small and divided among many challenges, thus the analyses were too underpowered. Larger outcome counts for these challenges may provide more power for analysis in future studies. Given that we did not receive approval from Indigenous governing bodies in Manitoba, such as the First Nations Health and Social Secretariat of Manitoba and the Manitoba Metis Federation, in time for thesis completion deadlines, we did not conduct any sub-analysis specific to First Nations and Metis respondents.

Overall, the top 10 challenges to mental health identified in this study have been previously identified in literature. Our comprehensive list of challenges further confirms that, in addition to depression and anxiety, there are other challenges to mental health experienced by people receiving hemodialysis.

Not surprisingly, we observed differences between the two respondent groups in how often individual mental health challenges were identified. People receiving hemodialysis identified worry/stress more often than healthcare providers, while healthcare providers identified difficulty coping, depression, and anxiety more often than people receiving hemodialysis. This discrepancy between respondent groups could be due to several factors. Healthcare providers who may be familiar with symptoms and signs of depression and anxiety may observe these symptoms in people they are providing care for, who may not recognize that they are manifesting such symptoms themselves. However, the above finding could also be due to information bias. Depression and anxiety are commonly discussed in hemodialysis literature, and healthcare providers may assume that people they care for are experiencing these challenges even without performing a full mental health assessment. Lastly, it is possible that people receiving hemodialysis used different terms to describe how they are feeling other than "depression" and "anxiety".

Similarly, we also observed discrepancies in how the two respondent groups perceive mental health to be impacted by kidney disease/receiving hemodialysis and receiving mental health support. We observed more reports of healthcare providers observing the mental health of adult Manitobans impacted by kidney disease and receiving hemodialysis than from those receiving hemodialysis themselves. One possible explanation for this discrepancy could be individual differences in understanding the survey questions (i.e. "*Has kidney disease/receiving hemodialysis affected your mental health?").* Another is individual differences in threshold to the degree their mental health is affected and in what way, as one respondent highlighted: "*according to the doctors, yes [to having kidney disease affected my mental health], according to myself, no*." (Individual receiving hemodialysis, Man, Age 65-79). One study in Ontario

investigating perceived barriers to psychological treatment for depression in people receiving hemodialysis found that 23% of 160 participants did not participate in psychological treatment as they considered their problem not severe enough[21]. In the same study, 23% of participants also believed that they were not at risk of depression[21]. Another potential explanation for this finding is an individual's denial regarding their current mental health state[119]. Denial has been observed as a common coping mechanism amongst people receiving hemodialysis to perceive a better quality of life[120]. Given that there is stigma around mental health and mental health concerns, people may be averse to admitting how kidney disease and receiving hemodialysis have impacted their mental health. These observations could also explain the low interest in being referred to a mental health specialist observed in our study. However, it is also important to consider the possibility that people receiving hemodialysis may truly not perceive that their mental health has been affected by their kidney disease or by receiving hemodialysis, or at least to the degree to which they need mental health support, at the time that they responded to the survey. Among people receiving hemodialysis, we observed that those who had to relocate for hemodialysis sought and were referred to mental health support more often than those who did not relocate. This finding suggests that those who had to relocate for hemodialysis may be experiencing challenges that disproportionately impact their mental health. This finding is consistent with previous studies that documented the burden of relocation for hemodialysis for people living in rural and remote communities, including their mental health[26,121].

Among healthcare provider respondents, despite over 90% observing CKD and hemodialysis impacting the mental health of their patients, only 30% have provided referrals for mental health support. A common reason amongst those who have not provided referrals is due to the lack of information or awareness of where to refer people for help, as highlighted by one

healthcare provider respondent: "*Not aware of the resources to refer the patients to*" (Allied health provider, Man, Age 35-49). Similarly, there are low referral rates amongst providers to mental health specialists. A common reason behind those who have not provided a referral is the deferral of this responsibility to physicians, as highlighted by one respondent: "*This is usually done by a physician"* (Nurse, Woman, Age 35-49). Though some recognize that providing referrals is not within their scope of practice, they work as a team to provide referrals: "*We do that as a team. If I feel someone would benefit from seeing psychiatrist, I would speak with our Nephrologist who would send the consult*." (Allied health provider, Woman, Age 35-49). This highlights important knowledge and care gaps. To provide effective team-based care, all healthcare providers working with people receiving hemodialysis should have some knowledge of mental resources available and/or the standardized pathway to follow to ensure their patients get the mental health care they need. Although providing consults with mental health specialists remains within physicians' scope of practice, all members of an individual's hemodialysis circle of care (i.e. physicians, nurses and allied health providers) should work as a team to better advocate for the mental health of the people they care for. In many cases, multidisciplinary team members, not just physicians, can refer or direct an individual for mental health care. In the U.S., several quality improvement initiatives have promoted the incorporation of mental health research into dialysis care[122]. In particular, one study disseminated information on mental health research findings and resources via virtual education modules; this resulted in an increased overall knowledge among healthcare providers of available resources to help their patients with their mental health needs[122]. Adopting similar initiatives in Manitoba could equip healthcare providers with the required information for such referrals.

Suggested Mental Health Support Strategies

We found that respondents receiving hemodialysis value in-person interaction and their preferred settings/methods lower barriers to receiving mental health support. Regardless of the setting, people receiving hemodialysis prefer to receive mental health support in a private space. This finding is consistent with literature. One mixed methods study from Alberta conducted a descriptive qualitative approach on interview transcripts, field notes and responses to open-ended survey questions to understand the perspectives of people receiving hemodialysis and healthcare providers on interventions available to address mental health concerns[14]. The investigators found that there is not enough mental health support in dialysis units to address mental health concerns[14]. Preference for in-person care is consistent with studies comparing care delivery modalities. One U.S. qualitative study conducted semi-structured interviews with people with CKD, caregivers, and clinicians to explore preferences for Telehealth (i.e. virtual/over the phone) services vs. in-person visits during the COVID-19 pandemic[123]. Comparing the two care delivery modalities, people with CKD indicated that care delivered online did not provide them with the same level of connection with their doctors as they had in-person. In terms of location, our findings support the availability, and perhaps the integration, of mental health support in hemodialysis units. Survey respondents indicated that this method of care delivery is convenient for hemodialysis recipients, decreasing the number of appointments required to address their health needs. Transportation was identified as a barrier to seeking mental health support in our study, and can be partially addressed by integrating mental health support within hemodialysis units. The need for privacy during mental healthcare visits that we observed is also consistent with literature. The same mixed methods study from Alberta found that the lack of privacy hinders people from comfortably sharing details with their provider regarding their mental

health, especially knowing that their dialysis station neighbours could easily overhear their conversations[14]. One multicentre qualitative Canadian study held focus groups consisting of people receiving hemodialysis, their caregivers and healthcare providers to explore their perspectives on challenges and solutions to individualization of care in hemodialysis; this study also highlighted the lack of privacy in the hemodialysis unit as a challenge[124]. Thus, our findings here can serve as strong considerations when developing mental health support strategies for adult Manitobans receiving hemodialysis.

In this study, people receiving hemodialysis identified specific forms of support, including counselling and peer support, while healthcare providers suggested health system-level improvements. However, both groups agreed that increasing the availability and accessibility of mental health resources was an important strategy to help address mental health challenges in the hemodialysis population. As in previous studies, peer support was identified by people receiving hemodialysis as an important solution[54,109,125]. Other studies involving people receiving hemodialysis have identified that people value learning and receiving guidance from people with similar lived experiences[125]. In our study, one respondent shared: "*...Would prefer to talk to someone that has 1st hand knowledge of living with chronic illness. Probably be more sympathetic*." (Individual receiving hemodialysis, Woman, White, Age 50-64). Although this support is highly encouraged by people receiving hemodialysis, healthcare providers in previous studies have also called for caution with the implementation of peer support groups, citing concerns that inaccurate and potentially harmful information may be shared among people[54]. This could potentially explain the difference observed in frequency of identifying this support strategy between healthcare providers and people receiving hemodialysis in our study.

For healthcare providers, healthcare system improvements include a uniform standard for mental health care, including mental health screening, and financial support or coverage for the cost of mental health care if it is not provided in the hemodialysis unit. In terms of increased availability and accessibility of mental health resources, the majority of respondents identified that a dedicated mental health provider and materials to inform hemodialysis recipients and healthcare providers alike of available mental health resources can better support the mental health of people receiving hemodialysis. However, more resources are simply not enough, as one respondent indicated: *"...In the beginning, so many different resources are presented, [but] no one follows up*" (Individual receiving hemodialysis, Man, South Asian, Age 35-49). Thus, complementing increased availability and accessibility of mental health support with its consistent provision, including regular follow-ups after initial visits, is needed. For healthcare providers, lack of time with people receiving hemodialysis has been identified as a challenge to providing care, especially mental health care[54]. Having a dedicated mental health provider embedded in the hemodialysis could help with this issue.

Strengths and Limitations

The strengths of this study include patient-led survey design, which optimizes how to best ask people receiving hemodialysis regarding their dialysis experience and a sensitive topic like mental health. Additionally, collecting perspectives from multiple stakeholders, including caregivers and dialysis healthcare providers, provides diverse perspectives with regard to improving mental health care within hemodialysis care. Given that mental health can be a sensitive topic to discuss, participant anonymity may have encouraged people to provide more honest responses.

Limitations include the cross-sectional nature of the study design. Thus, changes in mental health priorities of individuals over time cannot be captured. Even though a definition of mental health is provided in the survey instrument, respondents' understanding and interpretation can still differ, especially considering how cultural background can also influence attitudes towards mental health. Our findings cannot be extrapolated to non-English speakers and people receiving hemodialysis outside of MB. Lastly, despite participant anonymity, social stigma may still deter people from participating. Thus, our findings may not capture or be representative of all the challenges to mental health that people receiving hemodialysis are experiencing.

Novel Findings and Contributions

Overall, our findings are the first to describe the current mental health landscape of adult Manitobans receiving facility-based hemodialysis. We identified the top 10 priority challenges to mental health and potential mental health support strategies to address these challenges. Our findings are also the first to quantify the impact of kidney disease and receiving hemodialysis on mental health in Manitobans receiving hemodialysis, identify gaps and barriers to seeking mental health support, and highlight opportunities where initiatives can be focused to promote mental health in hemodialysis care. Our findings provide information to help with the development and implementation of specific potential mental health support solutions. Thus, this study will help guide current and future efforts towards improving mental health in people receiving hemodialysis in Manitoba.

Clinical and Research Implications

Although the prevalence and burden of depression and anxiety have previously been highlighted in people receiving hemodialysis, our findings bring to light other challenges to mental health that people receiving hemodialysis experience. Knowledge of these challenges can help healthcare providers in their care interactions with people receiving hemodialysis and potentially improve patient health outcomes. Although previously identified in literature, the connection between some challenges in our findings and mental health warrants further research. We also identified potential targets for improvements required to better address mental health in hemodialysis care. Specifically, promoting referral rates to mental health resources and specialists, and providing more materials that promote available mental health resources. Thus, there is a need for consistent mental health "check-ins" in clinical care. Lastly, our study findings may help to destigmatize mental health in kidney care by continuing the conversation about mental health challenges. Ultimately, we hope that the findings help bring mental health care the attention it deserves within hemodialysis care in service of the overall well-being of adult Manitobans receiving hemodialysis.

Knowledge Translation

The results of this study will be used in the next phase of the *Mind the Gap* study to help design potential solutions to address priority challenges to mental health in people receiving facility-based hemodialysis in Manitoba. In addition to publishing the study findings in a high-yield kidney-related journal and presenting them at conferences, findings will also be shared via newsletters disseminated in the national CANSOLVE-CKD Network, Kidney Link, and via infographics on social media platforms. Findings will be presented to decision makers and

clinicians in the Manitoba Kidney Health Program and the Kidney Foundation of Canada, Manitoba Branch to help inform best clinical practices and help implement mental health support strategies at hemodialysis units in the province.

Future Directions

In order to provide a more holistic understanding of the mental health challenges and needs of adult Manitobans receiving hemodialysis, future research in this area should expand on our work to assess the effect of additional demographic factors, including employment status and socioeconomic status. As determined here, people on dialysis face employment difficulties (under *lifestyle changes*), affecting their income, and the cost burden associated with additional transportation for treatments and appointments, and medications also impacts their mental health. Thus, their socioeconomic status could potentially influence how challenges and solutions to mental health are prioritized. Investigating how the intersectionality of demographic characteristics also impacts mental health priorities is equally important. In addition, an in-depth exploration of how cultural differences among people receiving hemodialysis impact challenges to mental health and preferences for how care is provided is imperative in order to develop optimal solutions. Finally, "lack of trust in healthcare providers/ health system" is a challenge that needs to be further investigated. This challenge was identified as a top priority to address at a prioritizing workshop held by the *Mind the Gap* project, largely due to the historic and ongoing colonial and discriminatory practices in healthcare that Indigenous people on hemodialysis experience. Acknowledging that Indigenous people are overrepresented in the hemodialysis population in Manitoba, it is important to work in partnership with Indigenous people, healthcare

providers, and researchers to explore how this and other challenges and solutions to mental health are interpreted from an Indigenous lens.

Conclusion

The mental health of adult Manitobans receiving hemodialysis is impacted by kidney disease and receiving hemodialysis. Overall, we identified and ranked 24 challenges to mental health and determined the top 10 priority challenges, with "loss of control", "difficulty coping", and "depression" as the top 3 priorities. We observed no effect of demographic characteristics on the frequency of mental health challenges identified. We also identified counselling, health system improvements, and increased availability and access to mental health resources as potential mental health support strategies. However, we observed notable differences in priority challenges and potential mental health support strategies identified by people receiving hemodialysis and caregivers from those identified by healthcare providers. Our findings will help inform subsequent phases of the *Mind the Gap* project, developing and implementing a mental health support strategy in select hemodialysis centers in Manitoba to address some of the priority challenges to mental health identified.

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Chapter 9 Appendix

Appendix Table 1. Relative Risk of Adult Manitobans Receiving Facility-based Hemodialysis for the Challenge to Mental Health "Loss of Control" by Demographic Characteristics

Category	Odds Ratio	Confidence Interval	*p*-value
Gender			
Men	Reference	-	
Women	1.58	(0.69, 3.66)	0.3
Ethnicity			
Racialized White	Reference	-	
Racialized non-White	1.23	(0.51, 3.04)	0.6
Age			
Less than 50 years old	Reference	-	
50-64 years old	1.27	(0.41, 4)	0.7
65+ years old	0.62	(0.21, 1.88)	0.4
Dialysis Vintage			
Less than 1 year	Reference	-	
1-5 years	0.59	(0.16, 2.14)	0.4
More than 5 years	0.47	(0.12, 1.74)	0.3
Relocation for Dialysis			
No	Reference	-	
Yes	0.82	(0.22, 2.71)	0.8

Note: Odds ratios were determined using Firth logistic regression

Appendix Table 2. Relative Risk of Adult Manitobans Receiving Facility-based Hemodialysis for the Challenge to Mental Health "Lack of Acceptance" by Demographic Characteristics

Category	Odds Ratio	Confidence Interval	*p*-value
Gender			
Men	Reference	-	
Women	1.08	(0.39, 2.98)	0.9
Ethnicity			
Racialized White	Reference	-	
Racialized non-White	1.95	(0.65, 6.91)	0.2
Age			
Less than 50 years old	Reference	-	
50-64 years old	1.05	(0.28, 4.27)	0.9
65+ years old	0.61	(0.16, 2.49)	0.5
Dialysis Vintage			
Less than 1 year	(EXCLUDED) (Note: Only 1 outcome)	-	
1-5 years	Reference	-	
More than 5 years	0.77	(0.24, 2.31)	0.6
Relocation for Dialysis			
No	Reference	-	
Yes	0.49	(0.05, 2.28)	0.4

Note: Odds ratios were determined using Firth logistic regression

Appendix Table 3. Quantitative Analysis of the Top 10 Challenges to Mental Health Stratified by Demographic Characteristics of Adult Manitobans Receiving Hemodialysis

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
	gender	Man vs Woman	18 vs 18	35 vs 22	Chi-Square	0.4
	ethnicity	Racialized non-White vs Racialized White	24 vs 11	35 vs 20	Chi-Square	0.8
Loss of control	age	Less than 50 years old vs 50-64 years old vs 65+ years old	8 vs 15 vs 13	11 vs 16 vs 29	Chi-Square	0.3
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	6 vs 18 vs 13	5 vs 26 vs 24	Fisher's Exact Test	0.5
	relocation	Yes vs No	4 vs 32	8 vs 50	Fisher's Exact Test	0.8
	gender	Man vs Woman	12 vs 10	41 vs 30	Chi-Square	1
	ethnicity	Racialized non-White vs Racialized White	16 vs 7	43 vs 24	Chi-Square	0.8
Difficulty coping	age	Less than 50 years old vs 50-64 years old vs 65+ years old	5 vs 11 vs 7	14 vs 20 vs 35	Fisher's Exact Test	0.2
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	0 vs 13 vs 10	11 vs 31 vs 27	Fisher's Exact Test	0.1
	relocation	Yes vs No	1 vs 23	11 vs 59	Fisher's Exact Test	0.3

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Depression	gender	Man vs Woman	7 vs 6	46 vs 34	Chi-Square	1
	ethnicity	Racialized non-White vs Racialized White	9 vs 5	50 vs 26	Fisher's Exact Test	1
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	4 vs 5 vs 6	15 vs 26 vs 36	Fisher's Exact Test	0.8
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	3 vs 9 vs 3	8 vs 35 vs 34	Fisher's Exact Test	0.2
	relocation	Yes vs No	1 vs 13	11 vs 69	Fisher's Exact Test	0.7
Loneliness/Isolation	gender	Man vs Woman	15 vs 11	38 vs 29	Chi-Square	1
	ethnicity	Racialized non-White vs Racialized White	15 vs 9	44 vs 22	Chi-Square	0.9
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	7 vs 11 vs 8	12 vs 20 vs 34	Chi-Square	0.2
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	4 vs 15 vs 7	7 vs 29 vs 30	Fisher's Exact Test	0.2
	relocation	Yes vs No	5 vs 20	7 vs 62	Fisher's Exact Test	0.3
	gender	Man vs Woman	16 vs 8	37 vs 32	Chi-Square	0.4

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Grief/Dealing with loss	ethnicity	Racialized non-White vs Racialized White	17 vs 6	42 vs 25	Chi-Square	0.5
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	6 vs 12 vs 7	13 vs 19 vs 35	Chi-Square	0.1
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	2 vs 11 vs 12	9 vs 33 vs 25	Fisher's Exact Test	0.6
	relocation	Yes vs No	4 vs 21	8 vs 61	Fisher's Exact Test	0.7
Anxiety	gender	Man vs Woman	5 vs 8	48 vs 32	Chi-Square	0.2
	ethnicity	Racialized non-White vs Racialized White	8 vs 3	51 vs 28	Fisher's Exact Test	0.7
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	4 vs 2 vs 7	15 vs 29 vs 35	Fisher's Exact Test	0.3
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	1 vs 6 vs 6	10 vs 38 vs 31	Fisher's Exact Test	0.9
	relocation	Yes vs No	1 vs 12	11 vs 70	Fisher's Exact Test	1
Worry/Stress	gender	Man vs Woman	15 vs 9	38 vs 31	Chi-Square	0.7

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
	ethnicity	Racialized non-White vs Racialized White	18 vs 4	41 vs 27	Chi-Square	0.1
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	5 vs 8 vs 11	14 vs 23 vs 31	Fisher's Exact Test	1
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	1 vs 15 vs 8	10 vs 29 vs 29	Fisher's Exact Test	0.2
	relocation	Yes vs No	3 vs 21	9 vs 61	Fisher's Exact Test	1
Dialysis-related symptoms	gender	Man vs Woman	12 vs 10	41 vs 30	Chi-Square	1
	ethnicity	Racialized non-White vs Racialized White	15 vs 6	44 vs 25	Chi-Square	0.7
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	5 vs 8 vs 9	14 vs 23 vs 33	Fisher's Exact Test	0.9
	dialysis vintage	**Less than 1 year vs 1-5 years vs More than 5 years**	**5 vs 13 vs 4**	**6 vs 31 vs 33**	**Fisher's Exact Test**	**0.02**
	relocation	Yes vs No	3 vs 19	9 vs 63	Fisher's Exact Test	1
	gender	Man vs Woman	10 vs 8	43 vs 32	Chi-Square	1

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Acceptance/Adjustment to situation	ethnicity	Racialized non-White vs Racialized White	14 vs 4	45 vs 27	Chi-Square	0.3
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	4 vs 7 vs 6	15 vs 24 vs 36	Fisher's Exact Test	0.7
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	1 vs 9 vs 6	10 vs 35 vs 31	Fisher's Exact Test	0.8
	relocation	Yes vs No	1 vs 17	11 vs 65	Fisher's Exact Test	0.5
Lack of confidence/trust in healthcare providers/health care system	gender	Man vs Woman	5 vs 10	48 vs 30	Chi-Square	0.1
	ethnicity	Racialized non-White vs Racialized White	7 vs 6	52 vs 25	Fisher's Exact Test	0.4
	age	Less than 50 years old vs 50-64 years old vs 65+ years old	1 vs 7 vs 7	18 vs 24 vs 35	Fisher's Exact Test	0.3
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	1 vs 8 vs 6	10 vs 36 vs 31	Fisher's Exact Test	0.9
	relocation	Yes vs No	2 vs 12	10 vs 70	Fisher's Exact Test	1

Appendix Table 4. Sub-analysis of Survey Responses for the Challenge to Mental Health "Dialysis-related Symptoms" by Dialysis vintage of People Receiving hemodialysis, with Bonferroni Correction

Challenge	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value	Adjusted p-value
Dialysis-related symptoms	Dialysis vintage	Less than 1 year vs 1-5 years	5 vs 13	6 vs 31	Fisher Exact Test	0.4734	1
		Less than 1 year vs More than 5 years	5 vs 4	6 vs 33	Fisher Exact Test	0.0205	0.1
		1-5 years vs More than 5 years	13 vs 4	31 vs 33	Chi-square Test	0.0737	0.2

Appendix Table 5. Quantitative Comparison of the Preferred Settings and Methods of Adult Manitobans Receiving Hemodialysis for Receiving Mental Health Support, Stratified by Demographic Characteristics

Survey Question	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Q10.) If there was a mental health care provider available, would you prefer to be seen (check all that apply to you):	gender	Man vs Woman	17 vs 17	36 vs 23	Chi-Square	0.4
	ethnicity	Racialized non-White vs Racialized White	23 vs 13	36 vs 18	Chi-Square	1
	age	50-64 years old vs 65+ years old vs Less than 50 years old	16 vs 15 vs 5	15 vs 27 vs 14	Chi-Square	0.2
In-person at your dialysis station	dialysis vintage	1-5 years vs Less than 1 year vs More than 5 years	18 vs 1 vs 16	26 vs 10 vs 21	Fisher	0.1
	relocation	No vs Yes	34 vs 2	48 vs 10	Fisher	0.1
In-person in a private clinic room outside of dialysis	gender	Man vs Woman	23 vs 13	30 vs 27	Chi-Square	0.4
	ethnicity	Racialized non-White vs Racialized White	21 vs 15	38 vs 16	Chi-Square	0.3
	age	50-64 years old vs 65+ years old vs Less than 50 years old	9 vs 16 vs 10	22 vs 26 vs 9	Chi-Square	0.2
	dialysis vintage	1-5 years vs Less than 1 year vs More than 5 years	14 vs 5 vs 17	30 vs 6 vs 20	Fisher	0.4

Survey Question	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
	relocation	No vs Yes	29 vs 6	53 vs 6	Fisher	0.4
Virtually or online	gender	Man vs Woman	7 vs 3	46 vs 37	Fisher	0.5
	ethnicity	Racialized non-White vs Racialized White	6 vs 4	53 vs 27	Fisher	0.7
	age	50-64 years old vs 65+ years old vs Less than 50 years old	5 vs 2 vs 3	26 vs 40 vs 16	Fisher	0.2
	dialysis vintage	1-5 years vs Less than 1 year vs More than 5 years	7 vs 2 vs 1	37 vs 9 vs 36	Fisher	0.1
	relocation	No vs Yes	9 vs 1	73 vs 11	Fisher	1
By Telephone	gender	Man vs Woman	10 vs 9	43 vs 31	Chi-Square	0.9
	ethnicity	Racialized non-White vs Racialized White	15 vs 2	44 vs 29	Chi-Square	0.08
	age	50-64 years old vs 65+ years old vs Less than 50 years old	6 vs 5 vs 7	25 vs 37 vs 12	Fisher	0.1
	dialysis vintage	1-5 years vs Less than 1 year vs More than 5 years	12 vs 3 vs 4	32 vs 8 vs 33	Fisher	0.1
	relocation	No vs Yes	16 vs 3	66 vs 9	Fisher	0.7

Appendix Table 6. Comparison of Suggested Mental Health Support Strategies Stratified by Demographic Characteristics of Patients and Healthcare Provider Groups

Patient and Caregiver Survey

Mental Health Support Strategy	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Counselling	gender	Man vs Woman	25 vs 21	28 vs 19	Chi-Square Test	0.8
Peer support	gender	Man vs Woman	10 vs 8	43 vs 32	Chi-Square Test	1
Counselling	ethnicity	Racialized non-White vs Racialized White	31 vs 14	28 vs 17	Chi-Square Test	0.7
Peer support	ethnicity	Racialized non-White vs Racialized White	11 vs 7	48 vs 24	Chi-Square Test	0.9
Counselling	age	65+ years old vs Less than 50 years old vs 50-64 years old	18 vs 10 vs 19	24 vs 9 vs 12	Chi-Square Test	0.3
Peer support	age	65+ years old vs Less than 50 years old vs 50-64 years old	8 vs 6 vs 5	34 vs 13 vs 26	Chi-Square Test	0.4
Counselling	dialysis vintage	1-5 years vs More than 5 years vs Less than 1 year	25 vs 14 vs 7	19 vs 23 vs 4	Fisher's Exact Test	0.2

Mental Health Support Strategy	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Peer support	dialysis vintage	1-5 years vs More than 5 years vs Less than 1 year	11 vs 4 vs 4	33 vs 33 vs 7	Fisher's Exact Test	0.1
Counselling	relocation	No vs Yes	39 vs 7	43 vs 5	Chi-Square Test	0.7
Peer support	relocation	No vs Yes	16 vs 2	66 vs 10	Fisher's Exact Test	1
Increased access to/availability of mental health resources	gender	Man vs Woman	10 vs 7	43 vs 33	Chi-Square Test	1
	ethnicity	Racialized non-White vs Racialized White	10 vs 8	49 vs 23	Chi-Square Test	0.5
	age	18-34 vs 35-49 vs 65+ years old	0 vs 0 vs 10	0 vs 0 vs 32	Fisher's Exact Test	1
	dialysis vintage	Less than 1 year vs 1-5 years vs More than 5 years	2 vs 11 vs 5	9 vs 33 vs 32	Fisher's Exact Test	0.5
	Relocation	Yes vs No	2 vs 16	10 vs 66	Fisher's Exact Test	1

Healthcare Provider Survey

Mental Health Support Strategy	Demographic characteristics	Groups compared	No. of 'Yes' by group	No. of 'No' by group	Test used	p-value
Healthcare System Improvements	role	Allied Health Providers vs Nephrologists and Nurses	5 vs 4	8 vs 10	Fisher's Exact Test	0.7
	gender	Man vs Woman	0 vs 9	3 vs 16	Fisher's Exact Test	0.5
	ethnicity	Racialized non-White vs Racialized White	1 vs 8	6 vs 10	Fisher's Exact Test	0.4
	age	50+ years old vs Younger than 50 years old	3 vs 6	6 vs 14	Fisher's Exact Test	1
Increased access to/availability of mental health resources	role	Allied Health Providers vs Nephrologists and Nurses	10 vs 7	1 vs 5	Fisher's Exact Test	0.2
	gender	Man vs Woman	1 vs 16	1 vs 5	Fisher's Exact Test	0.5
	ethnicity	Racialized non-White vs Racialized White	13 vs 4	3 vs 3	Fisher's Exact Test	0.3
	age	50+ years old vs Younger than 50 years old	4 vs 13	3 vs 3	Fisher's Exact Test	0.3